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Communication partner training to support persons in a minimally conscious state: Identifying and adapting an intervention programme

by

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A thesis submitted in partial fulfilment of the requirements for the degree

Philosophiae Doctor in
Augmentative and Alternative Communication

in the Centre for Augmentative and Alternative Communication

FACULTY OF HUMANITIES

UNIVERSITY OF PRETORIA

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25 November 2022

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The author, whose name appears on the title page of this thesis, has obtained, for the research described in this work, the applicable research ethics approval (HUM029/0720).

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Acknowledgements

I would like to thank the following individuals who have supported me throughout this journey:

- Prof Juan Bornman, my main supervisor, a true visionary and pioneer in the field. It was a privilege to receive your guidance and support throughout this journey. You have made my PhD experience tremendously positive and I thank you from the bottom of my heart for being such an awesome person and wonderful leader.
- Dr Ensa Johnson, my co-supervisor, I would not have been able to complete this journey without you. You have provided the best advice, prayers and support, especially when the PhD journey got tough. I will forever be thankful to you for nurturing my passion for learning and for putting me on this road of becoming a better person and researcher.
- My family (mom, dad, and brother) thank you for listening to me talk about research all the time (even though you had no idea what I was talking about). You have supported me and taught me to rely fully on the Lord and persist with consistency to finish the race.
- Janine Ellis for providing excellent language editing services for all my publications as well as my thesis.
- My work colleagues especially Dr Esther Wallis, Hildegard van Vreden, Beverley du Plessis, Gail Nicholson and our principal Dr De Jager. Thank you for allowing me time off to attend courses and always supporting me to develop as a therapist and person. I would also like to extend my appreciation for always being willing to answer my questions and allowing me to learn.
- To my friends (especially Seijal and Shayma) for always understanding when I can't attend special events and providing snacks and coffee.
- My PhD peers for providing though-provoking questions during onlines that allowed me to streamline my study.
- I would also like to thank my Lord and Saviour, Jesus Christ for allowing me to experience this PhD journey and for making this possible. I have truly learnt to value Micah 6:8, which states: "He has told you, O man, what is good. What does the LORD require of you except to be just, to love [to diligently practice] kindness (compassion), and to walk humbly with your God [setting aside any overblown sense of importance or self-righteousness]?"

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- Lastly, I would like to thank the University of Pretoria who provided financial support through a UP Postgraduate bursary. Additionally, I would like to thank Dr Ensa Johnson for her financial assistance during this study, via the SASUF grant.

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Abstract

Persons in a minimally conscious state (MCS+) often have fluctuating levels of alertness as well as varying self- and environmental awareness. They inconsistently follow concrete-one-step instructions, show a fluctuating understanding of yes/no questions, demonstrate the functional use of objects in an incongruent manner, use vocalisations inconsistently, and present with capricious intentional communication. Due to the dissonance of these behaviours, it is difficult for communication partners to observe early neuro-behavioural signs indicating signs of alertness and awareness as well as later unaided communication attempts. Although, communication partners indicate a willingness to interact with these persons, they may not have sufficient knowledge to identify the communication functions of unaided communication behaviours displayed by the person. Additionally, communication partners might not know which unaided communication behaviours to observe as these behaviours are subtle and consequently easily overlooked or misinterpreted by them. To support communication partners of persons in an MCS+, communication partner training is suggested as one possible intervention. Communication partner training typically focuses on equipping partners to observe, assess, and interpret unaided communication behaviours while also training them to provide appropriate responses. Furthermore, such an intervention may support partners to utilise their own communication strategies to facilitate communication with persons in an MCS+. The aim of this study is to identify and adapt an evidence-based intervention in the form of a communication partner training programme to facilitate interaction between communication partners and persons in an MCS+. This is achieved by empowering communication partners to observe, assess, interpret, and respond to the communication behaviours displayed by these individuals. A qualitative exploratory collective case study design with three sequential phases, each comprising distinct steps, is used to address this aim. From the findings of the study, the Connect^{+} was developed for communication partners of persons in an MCS+ based on E^{3}BP principles. The clinical utility of this programme was also determined.

Keywords: communication; communication partners; communication partner training; Connect^{+}; E^{3}BP principles; person in an MCS+; unaided communication behaviours.

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CHAPTER 1
PROBLEM STATEMENT AND RATIONALE

1.1. Introduction

This chapter introduces the study by describing the problem statement and rationale that led to this research. Additionally, the most frequently used terms are defined in terms of their application to the study. This is followed by a list of the abbreviations and acronyms as well as a brief layout of the six chapters included in this study.

1.2. Problem statement and rationale

Disorders of consciousness (DOC) can be defined as a diagnostic state that includes a decline in psychological functioning, altered consciousness as well as reduced alertness and awareness, due to an acquired condition (Puggina et al., 2012). In adults, DOC can be due to multiple causes. For example, cerebrovascular accidents, traumatic brain injury, and diffuse brain dysfunction (e.g., due to substance misuse, metabolic disorders, or severe hypoglycaemia) can result in a sudden onset of DOC, whereas advanced stages of dementia and other neurodegenerative disorders (e.g., neuromuscular atrophy) can cause DOC with a gradual onset (Cooksley et al., 2018; Roberts & Greenwood, 2019; Royal College of Physicians, 2013). DOC are classified along a continuum with the comatose state on the one end, progressing to unresponsive wakefulness syndrome also described as the vegetative state, then to the minimally conscious state (MCS), and finally to emergence from a comatose state which also marks the other end (Pundole & Crawford, 2018). The MCS has a further dichotomous classification: MCS− (i.e., individuals who present with low level behavioural responses) and MCS+ (i.e., individuals who present with steady behavioural responses) (Overbeek et al., 2018; Pistarini & Maggioni, 2018). This study will focus specifically on persons in an MCS+.

In recent years, a decline in the mortality rate of persons in an MCS has been noted, owing to medical advances that have increased life expectancy between two to 25 years (Gonzalez-Lara et al., 2021; Noohi et al., 2016). Persons in an MCS+ are typically admitted to a hospital's critical care unit for management of physiological instability and are later discharged upon becoming medically stable (Zylberman et al., 2016). Whilst lifesaving innovations are saluted, the new challenges brought about by these clinical advances cannot be

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escaped. The resulting challenges specifically affect the communication partners of persons in an MCS+ as the person requires sustained medical care after discharge.

Due to the sustained medical challenges of these persons, they have difficulty communicating their wants and needs through verbal interaction. Communication partners may experience challenges in communicating with the person in an MCS+ as partners find it difficult to establish signs indicating the person's wakefulness and awareness. This may result in partners having difficulty differentiating whether the person is an active agent or whether the person is completely unresponsive, due to the range of subtle and inconsistent behavioural responses (Edgar et al., 2015). Furthermore, communication partners may also observe limited (or no) behavioural responses (due to the subtility and inconsistency) when they initiate interaction with the person in an MCS+. This impacts on person-partner communication as the partner communicates with the person less frequently and may not initiate interaction with the person. Additionally, this results in a strenuous person-partner relationship and decrease the partner's ability to find meaning in caring (Day & Anderson, 2011; Overall & McNulty, 2017).

Communication partners of persons in an MCS+ focus only on the conventional method of communication, namely verbal responses, as the widespread perception typically exists that verbal communication is the only means to emotionally connect with others. However, persons in an MCS+ have limited verbal responses due to their complex medical challenges. Limited verbal responses may result in behavioural responses of persons in an MCS+ being ignored, misinterpretated or judged as incomprehensible (Ellis & Astell, 2017) as partners may not have sufficient knowledge of these behavioural communication responses of persons in a MCS+. This results in partners perceiving persons in an MCS+ to have limited (or no) behavioural responses (Edgar et al., 2015; Ellis & Astell, 2017). Communication partners may therefore find it challenging to adapt to the notion of observing all behavioural responses of persons in an MCS+ by shifting their focus from only attending to conventional verbal responses to accepting all forms of interaction. In some cases, communication partners may also not receive any support and/or training from healthcare practitioners (HCPs) regarding how to observe and interpret behavioural signs of awareness. As a result, communication partners are unaware of how to optimise and capitalise the use of behavioural signs of communication to facilitate functional interaction.

Communication partners should therefore be made aware of the possibilities of recognising and using augmentative and alternative forms of communication (AAC) to

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facilitate and foster interaction. For example, a variety of unaided communication such as eye movement, vocalisations, gestures, and facial expressions may be used to provide opportunities to communicate for persons in an MCS+ who are not able to use verbal commuication (i.e., speech) (Rasmus et al., 2019). Additionally, focusing on unaided communication may also be beneficial as two thirds of emotional content in communication is not expressed via speech (Bird & Parente, 2014; Rasmus et al., 2019). Communication partners spend extended time caring for persons in an MCS+ and may have ample opportunity to facilitate interaction with them, these communication partners require training to identify, interpret and understand the function of subtle unaided communication behavioural attempts such as persons in an MCS+ closing their eyes to indicate 'stop'. Communication partners also require training to optimise their own means of communication to interact with the person in an MCS+. These partners feel unsure whether they understand the persons communication behaviours and interpret the communication function accurately, which may impact on their communication support and care. When communication partners are able to identify and interpret the persons communication attempts accurately it may increase person-partner communication and also reduce their anxiety and caring burden. Therefore, a communication partner training (CPT) programme is suggested as an intervention to empower communication partners to provide communication support and to care for a person in an MCS+. Training communication partners may increase the ability of the person in an MCS+ to exert autonomy by providing their preferences (e.g., yes/no answers via eye blinking) during clinical decision-making. Additionally, targeting these communication partners may have ethical implications as it expresses value for the person's humanity and respects the dignity of persons in an MCS+. Supporting persons in an MCS+ and their communication partners also aligns with the white paper on the rights of persons with disabilities which aim to strengthen the representative voice of persons with a disability (South African Government, 2016). As these persons have limited chances to exert their autonomy through verbal interaction, communication partners can be trained to strengthen the person's voice. A diagnosis of MCS+ may greatly impact on family functioning, financial expectations and require long-term involvement from communication partners. Communication partner training may be beneficial as equipping partners with the necessary knowledge and skills may improve participation of the person (O'Rourke et al., 2018). Partners also interact regularly with these persons which may cause intervention to generalise to the home context (Behn et al., 2021).

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This study aims to identify and adapt an intervention in the form of a CPT programme to facilitate interaction between communication partners and persons in an MCS+ based on E^3BP principles. These E^3BP principles include research evidence (E^1), practice evidence (E^2) and perspectives of informed stakeholders (E^3) (Ruggero et al., 2020). This is done by empowering communication partners to observe, assess, interpret, and respond to the communication behaviours displayed by these individuals.

1.3. Terminology

The following terms (presented in alphabetical order) are frequently used throughout this study and therefore explained and operationally defined as used in the study.

Augmentative and Alternative Communication: This form of communication aims to establish functional communication when verbal interaction is insufficient to communicate daily needs and wants (Beukelman & Light, 2020). It includes both aided and unaided communication systems (Lloyd & Fuller, 1986). Aided communication refers to technology and non-technology based systems (Beukelman & Light, 2020).

Clinical utility: Clinical utility refers to the relevance and usefulness of a specific intervention centred around a specific patient with a specific condition/disorder (Lesko et al., 2010). In this study, the focus is on the training off communication partners of persons in an MCS+ to positively impact on person-partner communication. Following an umbrella review of relevant CPT programmes that could potentially be adapted to be useful for persons in an MCS+, the TBI Connect programme was selected (see Chapter 4 for a comprehensive discussion). Hence, the current study focuses on the clinical utility of the Connect + (i.e., adapted TBI Connect) programme for communication partners of persons in an MCS+.

Communication competence: Communication competence is defined as the level to which a partner's communication is perceived as effective, while applying sufficient motivation, knowledge and skills. This competence also includes reflecting on ones expectations of a communication partner and judging through observation whether one's own communication responses were accurate. (Spitzberg, 2013).

Communication partners: Communication partners of persons in an MCS+ typically represent a small, yet diverse pool of people who interact with them frequently (often daily). These communication partners can be defined as individuals with affective-bonds and who fulfil a caring role which encompass multidimensional responsibilities. These responsibilities

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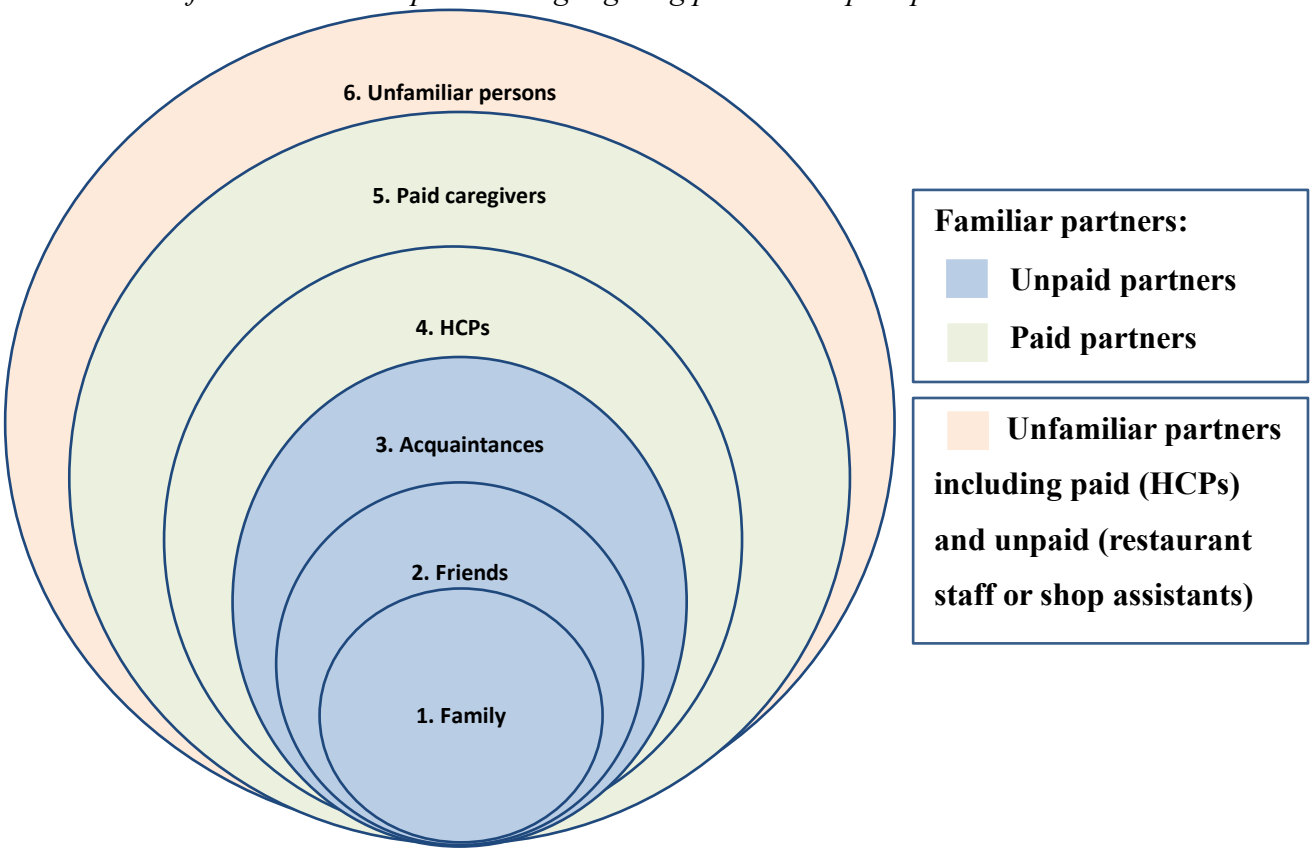
can be related to communication (e.g., positioning the person for optimal communication) and care (e.g., frequently turning the person to prevent bedsores, feeding, bathing, and suctioning).

Sarah Blackstone (1999) first categorised communication partners in terms of familiarity by placing them in one of five circles as shown in Figure 1.1. This idea was further expanded and applied to the current study by broadly grouping communication partners into two categories: unpaid communication partners such as friends, family members, and acquaintances such as neighbours (Giovanetti et al., 2012) and paid communication partners which include HCPs who can assist in supporting the communication of persons in an MCS+ (Behn et al., 2021; Chang et al., 2018; Eriksson, Hartelius, et al., 2016).

Figure 1.1

Circles of communication partners highlighting paid and unpaid partners



Communication partners from the first to third circle as well as the fifth circle, comprise the unpaid partners. The first (family) circle provides the most support for the person in an MCS+ as they tend to care for the person on a daily basis, especially if the person is cared for in the home context. The second (friends) and third circles (acquaintances) of communication partners become restricted for persons in an MCS+, as the number of interactions gradually reduce over time (Sattin et al., 2022). Literature has reported that the partners in these two

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circles frequently no longer know how to communicate with the person or what conversation topics to discuss when the person is in an MCS+ (Chinner et al., 2021). Communication partners from the fourth and fifth circle, comprise the paid partners who typically include HCPs such as medical doctors, nurses, speech-language therapists (SLTs), occupational therapists (OTs), physiotherapists (PTs), and social workers (SWs). In cases where persons in an MCS+ are cared for in a care facility, the paid caregivers would be the most prominent communication partners, although paid partners might also be involved when a person is accommodated in the home context. As stated in the fifth circle, paid partners comprise trained or untrained caregivers who are employed by the family to care for the person in an MCS+.

The sixth circle (unfamiliar partners) is typically unrepresented, or very restricted in terms of interaction with persons in an MCS+ as their complex medical challenges require stationing in one environment. The person also has an existing team of HCPs managing their care and often rarely interact with unfamiliar HCPs. Additionally, as these persons in an MCS+ are stationed in one environment, they have limited contact with unfamiliar partners such as shop assistants or restaurant staff and have restricted access to a variety of communication environments and partners.

Therefore, this study will focus mainly on unpaid partners from the first circle, however, also on paid partners from the fourth and fifth circles, as they are typically responsible for the majority of caring tasks and intervention with the person in an MCS+. As the communication skills of these partners can either inhibit or facilitate the interaction of person in an MCS+, it is important to understand who these partners are, and to identify them as early as possible, to equip and empower them for their role as communication partner. These communication partners should thus be targeted to receive CPT as they can potentially contribute the most to facilitate communication with persons in an MCS+.

Communication Partner Training (CPT): CPT is defined as a type of intervention that targets communication partners in the immediate environment of the client, in this case the person in an MCS+ (Simmons-Mackie et al., 2010). Therefore, communication partners can potentially contribute most to the communication improvement of the person in an MCS+. Research evidence shows that this type of training has positive outcomes if both partners in the communication dyad are targeted (namely the client and partner) (Simmons-Mackie et al., 2010). However, in this study only the communication partners of the person in an MCS+ are targeted to afford them with communication opportunities and to perform their activities of

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daily living. The communication partners should be targeted to facilitate interaction with the person by observing all unaided communication behaviours displayed by the person. In this study, CPT aims to support partner communication with the person in an MCS+ to ensure that the person's humanity and dignity is respected. Additionally, the CPT may assist in facilitating communication with the person in an MCS+ to have benefits beyond communication such as reducing the care demands on the partner.

Disorders of consciousness (DOC): DOC refer to reduced psychological functioning, consciousness and alertness and awareness (Puggina et al., 2012). This diagnostic state occurs along a continuum ranging from coma on the one side, progressing to an unresponsive wakefulness state or vegetative state, thereafter to the MCS (Including both MCS- and MCS+) and finally, emergence to full consciousness on the other side. Patients typically progress from coma to returning arousal and spontaneous involuntary movements within days to weeks after initial injury (Lancioni et al., 2011). Across the globe, the Glasgow Coma Scale or Coma Recovery Scale-Revised are routinely used for the differential diagnosis of DOC. Progression on these scales are tracked by using behavioural signs of wakefulness and awareness to confirm the diagnosis (Seel et al., 2010). If a score of between zero and eight is obtained on the Glasgow Coma Scale a severe brain injury or DOC is indicated.

However, a small percentage of persons who present with DOC do not recover consciousness within this period of spontaneous recovery, which is typically considered to be three months for patients with non-traumatic incidents and 12 months or less for patients with traumatic incidents. In such cases, a patient is considered as presenting with a persistent or permanent disorder of consciousness (Formisano et al., 2013; Jox et al., 2012; Kronbichler et al., 2015; Laureys & Schiff, 2012; Schiff & Fins, 2016). In the current study, the focus is placed on persons in an MCS, and specifically those in the MCS+ as defined later in this chapter as a separate construct.

Evidence-based practice (E^3BP): Evidence-based practice determines the approach taken towards clinical decision-making (Schlosser & Raghavendra, 2004). According to Baker and McLeod (2011); Hegarty et al. (2018); and Ruggero et al. (2020), clinical decision-making should follow an E^3BP approach, emphasising three equally important sources, namely research evidence, practice evidence and preferences of a fully informed patient/family. Research evidence (E^1) is defined as the highest level of available evidence with the application of systematic research as being the most preferred option (Baker & McLeod, 2011; Hegarty et

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al., 2018; Ruggero et al., 2020). Practice evidence (E^2) refers to evidence obtained from clinical practice with application to real-life settings (Baker & McLeod, 2011; Hegarty et al., 2018; Ruggero et al., 2020). Preferences of a fully informed patient/family (E^3) refers to the development of clinicians' shared understanding of the patient's beliefs and preferences to select appropriate goals, targets and interventions to which patients will comply (Baker & McLeod, 2011; Hegarty et al., 2018; Ruggero et al., 2020). In the current study, clinical decision-making is related to determining the level of consciousness in a person with DOC and employs different E^3BP in the different phases of the research design.

Healthcare practitioners/clinicians (HCP): HCPs maintain human health by applying principles and procedures of evidence-based medicine, rehabilitation, and caring (Weng et al., 2013). In this study, HCPs typically refer to those performing clinical duties such as nurses, SWs, OTs, PTs and SLTs. These HCPs are routinely part of the multidisciplinary team that provide care for persons in an MCS+. It is therefore of cardinal importance to include the perspectives of these practitioners when providing holistic care based on the principles of E^3BP, for persons in an MCS+. SLTs are defined in this study as clinicians who specialise in neurorehabilitation of persons in an MCS+. These clinicians provide assessment and intervention for swallowing, communication, cognitive-communication, voice and other disorders in the MCS+ (American Speech-Language-Hearing Association [ASHA], 2016).

Minimally conscious state (MCS): The MCS is the final state on the continuum of DOC before the person emerges to full wakefulness and awareness. It has a dichotomous classification: MCS– (i.e., persons who present with low level behavioural responses) with a later progression to MCS+ (i.e., persons who present with steady behavioural responses) (Pistarini & Maggioni, 2018; Overbeek et al., 2018). The focus of this study is on the MCS+ as these individuals present with neuro-behavioural signs of wakefulness and awareness such as eye blinking to indicate yes/no responses albeit inconsistent.

Multimodal communication: Multimodal communication is based on human nature which combines both speech and non-speech modes to communicate (Alant et al., 2006). As such, it thus includes both aided AAC and unaided AAC. Aided AAC includes low-mid-high technology communication supports. Unaided communication uses the body to communicate and includes eye, head and body movements, manual signs and natural gestures, vocalisations, body language, prosody, and facial expressions (Sigafoos & Drasgow, 2001). In this study, the focus will be on unaided communication, specifically non-speech modes, including a variety

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of multimodal communication strategies that can be used by communication partners of persons in an MCS+ to facilitate communication with them.

Unresponsive wakefulness syndrome/vegetative state: The unresponsive wakefulness syndrome also known as the vegetative state occurs on the continuum between coma on the one side and full emergence to consciousness on the other side. Persons who emerged from a coma following an acquired neurological condition, into an unresponsive state of wakefulness, are diagnosed as being in a vegetative state or as having unresponsive wakefulness syndrome (Bruno et al., 2012; Giacino et al., 2009; Lulé et al., 2013). Individuals in a vegetative state are thus seen as being wedged between individuals in a coma and individuals in an MCS+ (who are the focus of this study).

Verbal communication: Verbal communication is defined as speech production including sounds from language (Finke et al., 2008). Language contains three specific aspects namely language form (syntax, morphology), content (semantics) and use (pragmatics) (Owens, 2012).

1.4. Abbreviations and acronyms

The following abbreviations are included in the various chapters of this study:

AAC: Augmentative and alternative communication
ASHA: American Speech-Language-Hearing Association
CP: Communication partner (Only in Appendices)
CPT: Communication partner training
CVA : Cerebrovascular accident
DOC : Disorders of consciousness
E^{3}BP : Evidence-based practice comprising three sources
HCP : Healthcare practitioner
HPCSA: Health Professions Council of South Africa
MCS : Minimally conscious state (+/−)
OT : Occupational therapists
PhD : Doctor of Philosophy
POPI : Protection of Personal Information Act
PT : Physiotherapists
SLT : Speech-language therapists
SW : Social workers

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TBI : Traumatic brain injury

1.5. Outline of the chapters

Chapter 1 provides the problem statement and rationale for the study. Additionally, a clarification of the frequently used terminology, abbreviations and acronyms, and outline of the six chapters is provided.

Chapter 2 employs the model of communication competence to describe communication challenges experienced by communication partners of persons in an MCS+. Five factors were identified as influencing communication competence of communication partners, namely motivation, knowledge, skills, context of communication, and judgement to provide appropriate responsive behaviours. These five factors included a discussion of the communication partners' communication challenges, the impact on interpersonal communication, and communication competence of the communication partner. This chapter concludes with a discussion of the observation approach and application of the behaviour-response theory to facilitate interaction between the person and partner. Additionally, the benefits of using an observation approach to guide CPT was also discussed.

Chapter 3 describes the qualitative exploratory collective case study design with three sequential phases, each comprising distinct steps. The main aim of the study is then addressed, followed by the sub-aims as well as the ethical considerations. This chapter also discusses the research design, ethical principles followed in this study, and trustworthiness. Thereafter the remaining chapter focuses on Phase 1 (Exploratory Phase) which includes three different steps. Step 1.1. consists of a scoping review of the unaided communication behaviours displayed by persons in an MCS+ as well as the communication functions that are addressed through these behaviours. Synchronous online interviews were conducted with communication partners to complete Steps 1.2 and 1.3.

Chapter 4 describes Phase 2 (Intervention Identification and Adaptation) which entailed two steps. Step 2.1.1 includes an umbrella review aimed at identifying an evidence-based intervention (CPT programme) as well as the adult learning principles and trainee engagement addressed by the training programme. Step 2.1.2 then includes a discussion of the theory for CPT as well as the content, layout, and design/format of the programme. This chapter also includes Step 2.2.1, specifically the Intervention Mapping approach that was employed to adapt the identified CPT programme. Step 2.2.2 included synchronous online interviews with

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clinicians with a special interest in neurorehabilitation and focused on discussing the adaptations required for the identified CPT programme to ensure that it is applicable to the target population. Chapter 4 concludes with a discussion of the identified adaptations.

Chapter 5 describes Phase 3 (Clinical Utility of Intervention), which is the final phase of the methodology. It begins with a discussion on clinical utility of the adapted CPT referred to as the Connect^{+}, and thereafter employs a pilot study of the proposed nominal group technique to identify SLTs perspectives on the adaptations of the training programme and its clinical utility in practice.

Chapter 6 concludes this study and includes a summary of the findings, a critical evaluation of the strengths and limitations of the study, the relevance and implications for clinical practice, and recommendations for further research.

1.6. Summary

This chapter commenced with an introduction to the study by describing the problem statement and rationale. Next the most frequently used terminology in the study was defined as it is operationalised in this study, followed by a description of the abbreviations and acronyms. This chapter concluded with the outline of the six chapters.

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CHAPTER 2
LITERATURE REVIEW

2.1. Introduction

This chapter commences with an overview on the landscape of DOC and specifically explores the role of the communication partners who care for persons in an MCS+. Additionally, the model of communication competence is discussed and applied to communication partners of person's in an MCS+. From this model, five factors are identified that influence the communication competence of communication partners, namely motivation, knowledge, skills, the communication context and their judgement to provide appropriate responsive behaviours. In the discussion of these five factors, the focus is placed on the communication partners' communication during interaction and care of persons in an MCS+, the communication partner's role in interpersonal communication and the communication competence of the communication partner. Finally, as part of applying appropriate judgement, an observation approach is suggested. The observation approach and application of the behaviour-response theory are discussed to motivate the use of CPT to support communication competence of partners caring for persons in an MCS+. The chapter concludes by alluding to the benefits of using an observation approach to guide the training of communication partners.

2.2. Exploring the DOC landscape

Consciousness is viewed as the capacity of a person to integrate information and is dependent on the brain's ability to support complex activity patterns distributed among interacting brain regions (Abbate et al., 2014; Casali et al., 2013; King et al., 2013). DOC can be the consequence of a multitude of conditions, usually of sudden onset such as cerebrovascular accident (CVA), traumatic brain injury (TBI), diffuse brain dysfunction (for example as a result of substance misuse), metabolic disorders, severe hypoglycaemia, advanced stages of dementia as well as other neurodegenerative disorders (Cooksley et al., 2018; Wilson et al., 2016). Edlow et al. (2021) suggest that the most common cause of DOC is cardiac arrest, TBI, intracerebral haemorrhage and CVA. However, in some cases a gradual onset is possible for example with neurodegenerative diseases such as dementia. There is a relationship between the severity of these conditions and the level of the DOC. As alluded to earlier, DOC exist on a continuum and affect adults with sudden or gradual onset non-traumatic conditions or traumatic brain conditions (Pundole & Crawford, 2018). The continuum of DOCs includes coma, vegetative state or unresponsive wakefulness syndrome and the MCS. Patients who

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emerged from a coma following a brain injury, into a state of wakefulness, however, are unresponsive are diagnosed as being in a vegetative state or as having unresponsive wakefulness syndrome (Bruno et al., 2012; Giacino et al., 2009; Lulé et al., 2013). As highlighted in the terminology, persons in an MCS can be divided into two distinct groups; MCS- (i.e., individuals who present with behavioural responses on a lower level of brain functioning) and MCS+ (i.e., individuals who present with steady behavioural responses) (Overbeek et al., 2018; Pistarini & Maggioni, 2018). In the MCS- the person presents with visual tracking, localisation of noxious stimuli and behavioural responses such as smiling or crying to emotional stimuli, whereas in the MCS+ the person is able to follow commands and may present with non-functional communication and/or with intelligible vocalisations (Aubinet et al., 2022; Bruno et al., 2011). Persons in the MCS+ also show inconsistent, yet observable neuro-behavioural responses and present with a higher probability for others to observe behavioural responses (Sautet et al., 2022).

In the MCS+ emerging communication behaviour is often the first sign of self- and environmental awareness and is therefore one of the core categories in identifying the level of consciousness during behavioural assessment. Behavioural assessment is considered the gold standard for assessment of DOCs (Bodart et al., 2013; Casarotto et al., 2016; Morozova et al., 2018; Sattin et al., 2014; Xie et al., 2017). These behavioural scales focus on attention, eye opening (spontaneous or to stimuli), localisation to sound, command following, answering yes/no and simple questions, reflexive behaviour to noxious stimuli or a motor response. For the communication section behavioural scales focus on functional and non-functional communication, however, they do not specify criteria to be met in each section and a high emphasis is placed on verbal responses such as vocalisations, nonsense words, and intelligible verbal utterances. Although, these scales include sections on communication they do not focus on communication per se, which may make assessment scales susceptible to misdiagnosis (Cruse et al., 2011; Estraneo, et al., 2015; Gosseries, et al., 2014; Sattin et al., 2014; Sattin, et al., 2017; Schnakers et al., 2009). These scales do not include a continuum of unaided communication behaviours and the various communication functions that can be accessed through these behaviours (Pundole & Crawford, 2018). Differential diagnoses of levels of consciousness can also be complicated due to the patient's presentation of significant cognitive, sensory, motor- and speech impairments (apraxia/aphasia) that prohibit the patient from responding to environmental stimuli (Gosseries, et al., 2014; Sattin et al., 2014; Schnakers & Majerus, 2012). Due to the persons challenges, they may be at risk for misdiagnosis of either

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the unresponsive wakefulness state or MCS+. The frequent misdiagnosis between these states of consciousness has been discussed in various studies (Chatelle et al., 2016; Giacino et al., 2009; Seel et al., 2010). Aubinet et al. (2022); and Pundole and Crawford (2018) suggest that the evaluation of communication during behaviour assessment should be more extensive focusing on residual language functioning of the person in an MCS+. The assessment of receptive and expressive language should therefore include a broader range of communication such as unaided communication (e.g., facial expressions, eye movement and vocalisations) with verbal communication when assessing language comprehension. Exploring literature on the behavioural assessment of persons in an MCS+ is beneficial as it provides an emphasis on the importance of unaided communication especially for the differential diagnosis between the unresponsive wakefulness syndrome and minimally conscious state.

Pundole and Crawford (2018) suggest that a communication model be used by the HCP during assessment which include short instructions with familiar words and incorporate gestures that can be repeated. Assessment could also incorporate giving a choice of items, picture or sound matching, use of non-linguistic taks, familiar stimuli and stimuli that elicits a contextually relevant emotional response (Othman & El-hady, 2015; Pundole & Crawford, 2018; Roberts & Greenwood, 2019). To increase accurate diagnosis of the MCS+, assessment could facilitate responses by using a combination of unaided and aided communication such as referential object sharing, referential gaze, appropriate facial expressions, recognising their name, making unintelligbile sounds during interaction and attempting to gesture or point (Pundole & Crawford, 2018). Examples of non-linguistic tasks include observing signs to indicate appreciation of music and environmental navigation (Fedorenko & Varley, 2016; Pundole & Crawford, 2018; Sattin et al., 2014; Schnakers & Majerus, 2012). Considerations for communication during behaviour assessment are particularly important for low-middle income contexts such as South Africa. Within the South African context, limited published research is available on communication in DOC as well as assessment for differential diagnoses between the MCS and the unresponsive wakefulness syndrome.

In high income contexts, the same difficulties during differential diagnoses have also been reported by scholars (Edlow et al., 2017; Thibaut, Bodien, et al., 2019; Tomaiuolo et al., 2016). These high income contexts have supportive technology that assist them with the differential diagnoses between the MCS and unresponsive wakefulness syndrome such as functional magnetic resonance imaging, electroencephalograms, brain computer interfaces and microswitch adapted technology (Chabuda et al., 2019; Chatelle et al., 2012; Chatelle et al.,

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2018; Comte et al., 2015; Evanson et al., 2016; Harrison & Connolly, 2013; Lancioni et al., 2021; Lugo et al., 2014; Lulé et al., 2013; Ortner et al., 2017). Options such as these are not available in low-to-middle income contexts such as South Africa, which complicates the successful assessment and early intervention for the DOC population. For this resource limited context, HCPs should, therefore, be aware of the unaided communication behaviours including the appropriate verbal communication that they should employ when assessing and treating persons in an MCS+ (Sautet et al., 2022). Not only HCPs but all communication partners, whether paid or unpaid, should be made aware of these strategies as they are the individuals who support the person in an MCS+ the most.

2.3. Communication partners of persons in an MCS+

As a rule of thumb, MCS+ not only impacts the person but also the communication partners who could be either unpaid communication partners (e.g., family members such as life partners, parents, or children) who fulfil this role in a voluntary capacity or in some cases, they might be paid caregivers (e.g., paid carers or healthcare aides). The care of the person typically befalls the unpaid communication partners suddenly (although at times it can be gradual), leaving them feeling ill-equipped and unprepared for their new role (Alghnam et al., 2017; Magnani et al., 2020). Communication partners of persons in an MCS+ are mostly unpaid partners such as family members (life partners, parents, or children) (Bijnsdorp et al., 2021; Chinner et al., 2021; Corallo et al., 2018; Covelli et al., 2016; Pagani et al., 2014). This population is the target stakeholder group for this study, although it would be applicable to all communication partners.

As alluded to earlier in the terminology section, persons in an MCS+ have different circles of communication partners (Blackstone, 1999). The circles of potential unpaid communication partners may also include siblings, extended family members such as grandparents, nieces and in-laws, friends as well as paid caregivers including nurses or nursing aides with some training as well as aides and carers with minimal training (Chinner et al., 2021). Most of the time the person is cared for by persons who have received little to no training regarding their roles as communication partners, irrespective of whether they are paid or unpaid (Covelli et al., 2016; Liang et al., 2017; Lindquist et al., 2011; Van Campen et al., 2013). Both the paid and unpaid carers spend large amounts of time with the person in an MCS+ state ranging from more than 1 hour per day to almost 24 hours a day (Chinner et al., 2021; Sattin et al., 2022). Due to the communication partners spending most of their time with the person

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in an MCS+, they become socially isolated with loss of friendships and only having the person in an MCS+ as communication partner.

The various communication partners of the person in an MCS+ all find themselves in a similar position: where they suddenly have to face a unique and unfamiliar situation brought about by the care demands of a person with severe and complex medical needs. This care mostly takes place at home, however, in some cases care can be provided at a care facility (Sattin et al., 2022; Soeterik et al., 2017). In both Asian and European contexts, a large number of persons receive care at home (Hoffman & Wallace, 2019; Liang et al., 2017; Lin et al., 2012). In the South African context, care often relies on the socio-economic status of the family, since most South Africans fall within the low-to-middle income category, persons in an MCS+ also receive care at home by unpaid carers, or by a paid carer receiving minimal wages.

At times, the duty for ensuring that the person in an MCS+ receives social visitors or that their absence in other relationships are compensated for, also falls on the unpaid partner, reducing the time that they have for themselves (Chinner et al., 2021; Gonzalez-Lara et al., 2021). The unpaid carer has to schedule times for social visitors where the person is more alert or has to keep the person's friends informed regarding their progress. Initially, when the person is discharged home, social visitors, friends and other family members visit the person but may have differing reactions to the person's level of functioning and communication due to their diagnosis and may spend less time with the person in an MCS+. The person's level of functioning and communication therefore impacts on the socialisation of the unpaid partner as well, and further isolates the communication partner leading to deterioration in personal relationships and relationship quality (Chinner et al., 2021; Gonzalez-Lara et al., 2021). Additionally, Gonzalez-Lara et al. (2021) mention that communication partners have a loss of their previous social status and identity at work and home. These partners also spend less time socialising with their previous social groups due to their multidimensional responsibilities of caring for the person in an MCS+ that leave them with little time for themselves.

Paid trained partners such as nurses and nursing aides and untrained paid partners such as community helpers or family members of persons in an MCS+ may experience the same difficulties as unpaid partners due to them forming close relationships with the person and the family (Barnhart et al., 2014). These paid communication partners often form friendship relationships with the person and family and are viewed by the family as 'one of them' (Barnhart et al., 2014).

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Both paid and unpaid communication partners experience communication difficulties when caring for persons in an MCS+ (Giovannetti et al., 2015; Liang et al., 2017). Communication difficulties are often exacerbated by the care responsibilities that the partner experiences (Savundranayagam et al., 2005; Watson et al., 2012). Additionally, communication breakdowns can be caused by the inconsistent neuro-behavioural responses of the person in an MCS+ (Rasmus et al., 2019; Sautet et al., 2022). These neuro-behavioural complexities impact person-partner communication by increasing ineffective communication and hence communication breakdowns which subsequently decrease the quality of interaction and relationships (Savundranayagam et al., 2005). The communication competence of the partner can result in ineffective person-partner communication (MacDonald, 2017; Spitzberg, 2013). In this chapter the theoretical model of communication competence is used to describe the communication competence needed by the communication partner (Spitzberg, 2013).

2.4. Theoretical model of communication competence

Various intervention models are proposed for the treatment of communication challenges of adults with a variety of acquired neurological conditions with varying levels of severity. Many of these intervention models focus on the role of the communication partners due to the transactional nature of communication. However, limited models are available that focus on the management of persons with DOC by supporting their communication partners. The research evidence addressing person-partner communication challenges in persons in an MCS+ is scant. To provide a unified perspective on the various challenges experienced by the person in an MCS+, their communication partners and challenges that affect their communication competence, a comprehensive and integrated care model is required. Due to inconsistent behavioural responses from the person in an MCS+ the transactional nature of communication may be affected. Person-partner communication may become unidirectional instead of bidirectional. Therefore, a communication model is required to identify which factors of the partner may contribute to poor communication and to support the partner to accommodate for the persons communication challenges. This may increase the transactional nature of communication and the continuity of speaker and listener changes.

To this end, Spitzberg (2013) proposed a theoretical model of communication competence. Communication competence is defined as the level to which a partner's communication is perceived as effective, while applying sufficient motivation, knowledge and skills. This competence also includes reflecting on ones expectations of communication partner

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and judging through observation whether one's own communication responses were accurate. (Spitzberg, 2013). This definition of communication competence proves beneficial especially for partners of persons in an MCS+, as this allows partners to apply appropriate motivation, knowledge, skills, judgement during communication and reflect on their expectations of a communication within a specific context. This concept of communication competence is important as regardless, of whether the speaker intends to send a message, the listener interprets and assigns meaning to the speaker's communication behaviour. Therefore, all the speaker's observable behaviour is interpreted and meaning is assigned to it (Spitzberg, 2013). The speaker can therefore judge whether their communication was effective by using an observation approach. This is of specific relevance to the communication partners of persons in an MCS+ as they often misinterpret or overlook the person's attempts to communicate due to limited knowledge regarding which verbal and nonverbal behaviours they should observe and pay attention to (Rasmus et al., 2019).

Communication is vital for effective relationships and for improved quality of life. If interpersonal communication improves, positive effects can be observed in both the person and in the communication partner (Savundranayagam et al., 2005; Spitzberg, 2013). The model of communication competence attempts to provide a unified, integrated perspective of communication competence. This perspective is achieved by evaluating communication competence as separate from communication quality as the latter is viewed as a subjective function of the communication partner's motivation, knowledge and skills in context (Spitzberg, 2013).

In any context, judgements on the appropriateness and effectiveness of communication are affected by five interchanging communication partner factors. Whether a partner is judged as competent is based on their motivation to achieve the communication goal, their knowledge of appropriate and effective communication behaviour and their ability to respond with appropriate communication behaviour (Spitzberg, 2013). Additionally, the communication behaviour of the partner may be facilitated or constrained by the context in which communication takes place as well as the communication partner's skills (O'Rourke et al., 2018; Spitzberg, 2013). Figure 2.1 illustrates these factors as applied to persons in an MCS+.

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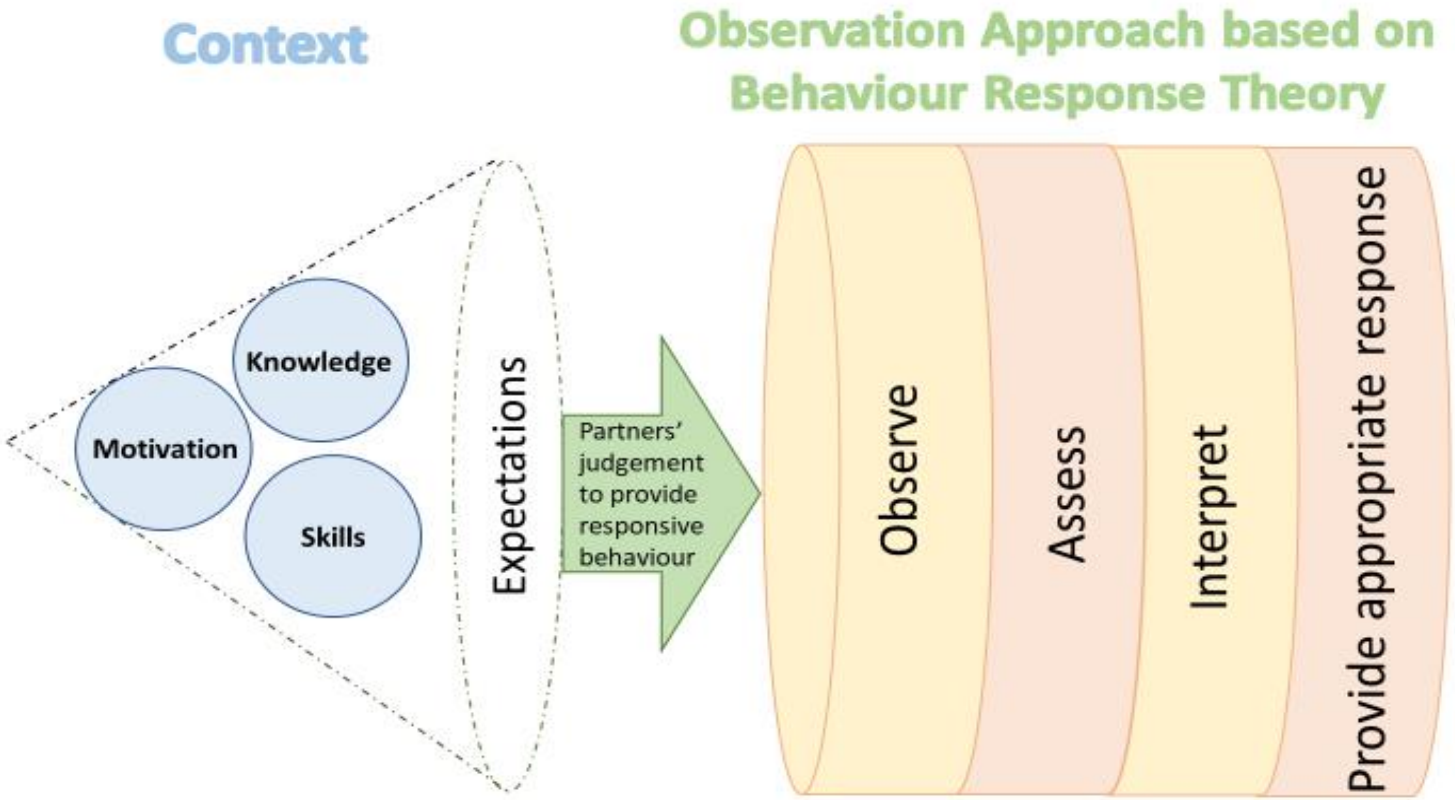
Figure 2.1

Model of communication competence for communication partners of persons in an MCS+



Source: *conceptualised from Spitzberg (2013)*

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2.5. Model of communication competence as applied to communication partners of persons in an MCS+

Both Light and McNaughton (2014); and MacDonald (2017) include a definition of communication competence that focuses on the person with an acquired neurological conditions. Light and McNaughton (2014) suggest that communication competence is a dynamic interpersonal process that incorporates appropriate knowledge, skills, and judgement to achieve functional communication. Additionally, these authors utilised the person's language skills and communication skills to facilitate participation in social contexts, to access support (from communication device or person) and to reduce participation barriers for communication (Light & McNaughton, 2014; MacDonald, 2017). This focus provides a deeper understanding of communication competence for an individual with an acquired neurological condition, however, may not be within reach for persons in an MCS+ as it focuses on individuals that have regained some form of verbal communication (Darrigrand et al., 2011; MacDonald, 2017; Mohatt et al., 2021). However, for persons in an MCS+, verbal communication is challenging since they are highly dependent on communication partners to fulfil their daily activities (Rasmus et al., 2019; Sautet et al., 2022). It is therefore suggested that the definition of communication competence be expanded to also target the communication partner in cases of persons in an MCS+, since this may facilitate communication competence. Spitzberg's (2013) model targets the communication partners as suggested in figure 2.1. To this end, Spitzberg (2013) defined communication competence as a subjective function of the communication partners motivation, knowledge, judgement and skills in context. Even though, the communication partner of persons in an MCS+ are the focus of this study, it is also beneficial to consider aspects that may impact the competence of the person in an MCS+. As communication is bidirectional and the person in an MCS+ may be the only communication partner of the carer. Person-partner communication may become unidirectional as the person may appear to not respond to the attempts of the partner to communicate (Ellis & Astell, 2017). To this end, Kiessling and Fabry (2021) reiterate that communication competence is the ability to achieve communication goals through the application of all forms of unaided communication including speech in an organised and goal-orientated manner. Therefore, by applying Kiesling and Fabry (2021) and Spitzberg's (2013) definition five specific factors believed to influence communication competence, namely motivation, knowledge, skills, context, and judgement are discussed and applied to the target population. in detail. Due to difficulty establishing executive functions such as motivation, knowledge and judgement in persons in an MCS+, only skills

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were discussed (Penn et al., 2017). Supporting the communication competence of the partner may indirectly assist the competence of the person and therefore Spitzberg's model is applied to the communication partner.

2.5.1. Motivation

Communicators are regarded as being competent when they are sufficiently motivated and not apprehensive to approach interaction (Spitzberg, 2013). Communication partners' motivation to interact with persons in an MCS+ is influenced by their care responsibilities. Communication challenges and care responsibilities can affect the willingness of the communication partner to approach communication with a person in an MCS+ which may cause them to appear disengaged during interaction (Sattin et al., 2022).

The motivation of the communication partner relates to the reasons why they communicate with the person and provide care (Quinn et al., 2010). These reasons may be impacted by a sense of personal or work-related duty and responsibility as well as by emotional aspects (e.g., affection or guilt) and commitment toward the person (Quinn et al., 2010; Romaniello et al., 2016). Additionally, the communication partner's ability to find meaning in communication and caring also impacts their perceived well-being and motivation (Quinn et al., 2010; Van Campen et al., 2013). If the communication partner perceives the communication and caring responsibilities as too high compared to the benefit thereof, they may often become demotivated and disengaged when caring for the person in an MCS+ (Giovannetti et al., 2015). The partner may perceive the communication responsibility when interacting with the person as high due to the person's medical complexities, characteristic of the person's condition, that impact their experience when communicating with the person (Rasmus et al., 2019; Roberts & Greenwood, 2019; Sautet et al., 2022). This may result in communication partners experiencing difficulty differentiating the persons' actual needs as opposed to the needs of the person reported by HCP (Pagani et al., 2014). Additionally, the person appears absent during interaction which further decreases the communication partners' motivation to continue communicating with the person (Cruzado & De la Morena, 2013). This greatly impacts interpersonal communication between the partner and person as the communication partner tends to present with decreased initiation of interaction and can become apprehensive toward communication due to limited observed reciprocal responses from the person in an MCS+.

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2.5.2. Knowledge

Communicators are regarded as being competent when they display appropriate knowledge of the language (both receptive and expressive), communication modes, and functions (Spitzberg, 2013). Communication partners' interaction with persons in an MCS+ is influenced by the partner's knowledge of the person's condition and the impact of this condition on the person's functioning with regard to cognitive, physical/sensory, emotional/psychosocial characteristics, and communication skills (Behn et al., 2021; O'Rourke et al., 2018). A poor understanding of the person's condition can increase the partner's communication difficulties and add to their care responsibilities (Cruzado & De la Morena, 2013; Moretta et al., 2017). Additionally, communication partners are often unprepared to care for the person and have limited knowledge regarding their communication and care responsibilities for the different skills the person in an MCS+ has (Chinner et al., 2021; Cruzado & De la Morena, 2013).

2.5.3. Skills

Communicators are regarded as being competent when they apply effective skills to become successful communication partners (Spitzberg, 2013). Communication partners can only apply effective skills when they understand both their own communication skills as well as that of the person with MCS+. The skills of both members of the communication dyad is important as meaning is co-constructed through communication (Vettorel, 2019). These communication skills (affected by the partner's cognition, physical, and emotional characteristics) are influenced by the care responsibilities of the communication partner and can result in increased communication challenges with the person in an MCS+ (Savundranayagam et al., 2005). The following section includes a discussion of first the person's skills and thereafter the communication partner's skills for each characteristic.

2.5.3.1. Personal skills of the person in an MCS+ prior to the condition

Personal skills or characteristics of the person prior to the MCS+ condition such as background, age, gender, race, ethnicity, socio-economic status, culture, religion, and nationality are important considerations for interpersonal communication (Ciccia & Threats, 2015; Cunningham et al., 2017; Kostanjsek et al., 2011; O'Halloran et al., 2008; Threats 2007). These characteristics affect communication with communication partners as it dictates communication style, role, and language used during interaction. Additionally, these personal characteristics are also determined by personality. The latter is referred to as unique traits

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within an individual, for example, coping style and assertiveness that could influence a person's ability to communicate their needs to their communication partner (Threats, 2007). Person's in an MCS+ may present with pre-existing psychological conditions such as mood disorders (e.g., depression, obsessive-compulsive disorder, and anxiety) which may affect their progress and recovery (Ciurli et al., 2011). They may also experience significant personality changes due to the severity of their disorders which will impact their relationship with their communication partners (Diaz et al., 2014). Such personality changes and negative behavioural patterns may decrease communication, add to communication partners' care responsibility, and lead to additional psychological problems for both the person and the partner (Diaz et al., 2014; Haberstroh et al., 2011). Additionally, the person's behaviour may result in communication partners communicating less with the person (Watson et al., 2012).

The person's condition may also include damage directly related to the area of injury, yet can affect other structural systems as well such as the nervous-, sensory – (i.e., visual and auditory), cardiovascular -, respiratory -, and digestive systems as well as the skin (McCormak & Worrall, 2008). The impact of MCS+ on the structural systems in turn impact on cognitive, emotional, social, sensory, motor, speech, voice, respiration, and language skills, resulting in speech-language impairments (Aubinet et al., 2022; Roberts & Greenwood, 2019). This may cause these affected structural systems to prevent the person from responding to environmental stimuli which negatively impact person-partner interaction (Gosseries et al., 2014; McCormak & Worrall, 2008; Sattin et al., 2014; Schnakers & Majerus, 2012).

2.5.3.2. Personal skills of communication partner

The care responsibilities of the communication partner may influence their expressiveness (use of unaided communication including speech), attentiveness (attention, concern and interest in others), composure (avoiding anxiety and displaying confidence, controlled communication responses, respectfully asserting opinions, and agendas), and coordination (creating opportunities for communication and overcoming communication breakdowns). Providing support through CPT may assist the communication partners to improve their confidence during interaction and use facilitative behaviours to assist the person to communicate (O'Rourke et al., 2018).

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2.5.3.3. Cognitive skills of the person in an MCS+

MCS+ influences a whole range of cognitive functions such as the person's observable consciousness, awareness and alertness, memory, cognitive processing, planning, attention and concentration, and the acquisition of new information (Ackley & Brown, 2020; Grauwmeijer et al., 2018; Martens et al., 2019; Noé et al., 2021; Rabinowitz & Levin, 2014; Torrisi et al., 2018; Varley et al., 2020; Wilson et al., 2016). Impaired cognition also influences the neuro-behavioural recovery as well as self-awareness of a person in an MCS+ (Martens et al., 2019; Noé et al., 2021; Sugimura et al., 2020).

It is imperative for communication partners to identify the neuro-behavioural signs of recovery as early as possible because persons in an MCS+ show the best improvement within the first year after onset, in sudden onset cases. Another reason why communication partners should identify neuro-behavioural signs of consciousness and cognition as early as possible, is because the recognition of emotional functioning is an indicator of quality of life in persons in an MCS+ (Rabinowitz & Levin, 2014; Sattin et al., 2019; Stenberg et al., 2015). These cognitive processes all influence the person's communication as communication and cognition are interdependent constructs. Cognition should also be considered as it affects the person's ability to process social interaction and inhibit unwanted behaviours (MacDonald, 2017). Cognition of the person in an MCS+ can greatly impact the communication partner's perceived communication with the person as these persons may respond inconsistently to social interaction attempts of partners and may present with challenging behaviour (Aubinet et al., 2022). These aspects may have a negative influence on the partner and may subsequently reduce communication attempts by the communication partner.

2.5.3.4. Cognitive skills of the communication partner

Interpersonal communication between the communication partner and person in an MCS+ may be impacted by the effect of the care responsibility on the partner's cognition and communication. Unpaid communication partners who care for persons in an MCS+ may experience their care responsibilities as increasing and this can negatively impact their executive functioning by hampering tasks that require cognitive skills such as attention, verbal fluency, and visuospatial memory (Chinner et al., 2021). Additionally, unpaid communication partners' coordination of their different care responsibilities may be impacted which results in them creating less opportunities for communication with the person and applying less cognitive skills to overcome communication breakdowns, reducing their own communication

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competence (Spitzberg, 2013). Paid, untrained communication partners may also have limited health literacy skills or limited knowledge on the person's condition, which limits their ability to provide effective communication support for the person in an MCS+ (Eliacin et al., 2022). These effects may also influence partners' resourcefulness (problem solving) during communication breakdowns and their ability to positively view interaction with the person in their care (Bekhet, 2013). One strategy that has been shown to be effective in addressing this issue, is providing support to the communication partner through CPT to improve their resourcefulness during interaction (O'Rourke et al., 2018).

2.5.3.5. Emotional and psychosocial skills of the person in an MCS+

The emotional skills of the person represent the dynamic and complex relationship among emotional, physical, cognitive, and communication factors that determine the person's communication competence for full life participation (MacDonald, 2017). Due to the severity of the structural impairments, the emotional functioning of persons in an MCS+ is affected, including emotional aspects of decision-making, motivation, and impulsivity (Rabinowitz & Levin, 2014; Silver & Nedelec, 2020; Stenberg et al., 2015). Other emotional components include frustration, anxiety, depression, inappropriate affective responses (e.g., increased aggression), disinterest or dislike in others, and unhappiness (Failla et al., 2016; Grauwmeijer et al., 2018; Kumar et al., 2018; McDonald, 2013; Silver & Nedelec, 2020; Stenberg et al., 2015). Affected emotional components may influence these person's voluntary eye opening to indicate their emergence to consciousness in the MCS+ (Rabinowitz & Levin, 2014; Van Ommen et al., 2018).

When communication partners observe voluntary eye movements in persons in an MCS+, it allows the partner to provide familiar, emotionally laden stimuli ensuring that the person is supported to present a positive neuro-behavioural response (Sautet et al., 2022). Additionally, when partners provide these stimuli to facilitate neuro-behavioural responses, it may increase positive communication-specific coping skills, ease any immediate distress and decrease the occurrences of communication breakdowns for both the person and partner (MacDonald, 2017).

2.5.3.6. Emotional and psychosocial skills of the communication partner

Unpaid communication partners often have no choice but to assume this sudden role as caregiver due to their relationship prior to the onset of the person's condition (e.g., parent or

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spouse), however, also due to the unwillingness of others to take on the care responsibility. These new demands result in the partner becoming unavailable or incapacitated themselves (Gonzalez-Lara et al., 2021; Magnani et al., 2020). Both paid and unpaid communication partners may experience psychological distress which includes depression and anxiety due to their high care responsibilities (Chinner et al., 2021; Gonzalez-Lara et al., 2021; Liang et al., 2017; Magnani et al., 2020; Moretta et al., 2014). Other emotional and psychological symptoms could also include post-traumatic stress disorders, psychosomatic symptoms such as guilt and hopelessness (Chinner et al., 2021; Gonzalez-Lara et al., 2021; Magnani et al., 2020). Magnani et al. (2020) also suggest that the care responsibilities of the partner can lead to feelings of anger due to amplification of situational and emotional constraints. In contrast, Soeterik et al. (2017) describe reactions such as sadness, pain, loneliness, loss, and grief commonly seen in partners of persons in an MCS+. This may be the result of the communication partners' emotional state that echoes the medical state of the person, particularly in unpaid partners (Chinner et al., 2021). Due to the medical state of the person, the partner may receive limited feedback from the person as the partners may not know how to observe communication behaviours, increasing their feelings of loneliness and grief (Covelli et al., 2014). Additionally, the emotional or psychosocial skills of the partner may impact their composure to avoid anxious behaviour and display confidence during communication (Spitzberg, 2013). The emotional and psychosocial skills of the partner can be supported during CPT to promote successful communication between them and the person in an MCS+. To support partners, CPT may also allow the partner to access a range of communication modes and functions to facilitate interaction with the person in an MCS+ (Eriksson, Hartelius et al., 2016).

2.5.3.7. Sensory skills of the person in an MCS+

Sensory dysfunction occurs within the sensory-perceptual domain of the person in an MCS+ and can result in them having limited neuro-behavioural responses to environmental stimuli and self-awareness (Alwis et al., 2013; Bareham et al., 2019; Martens et al., 2019, 2020; Padilla & Domina, 2016).

Vision is a sensory function that is particularly affected in persons with MCS+, mostly due to unilateral neglect (Wannez, Hoyoux, et al., 2017). Unilateral neglect may lead to agnosia (i.e., the inability to recognise faces, objects, places, and voices), and light sensitivity. It may also impact sleep (Barman et al., 2016; Elliott et al., 2018). Sleep disorders are common in

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persons in an MCS+ and could negatively influence their cognitive-communication functions (MacDonald, 2017).

Since eye movement (especially visual tracking) is often one of the first signs showing that a person in an MCS+ is emerging to consciousness, it is important to identify residual visual functioning (Bareham et al., 2019; Barman et al., 2016; Kwiatkowska et al., 2019; Martens et al., 2019). Peterson et al. (2019) suggest that some communication partners perceived persons in an MCS+ to have visual skills and that these persons were able to observe their environment. This knowledge may be beneficial for all communication partners as it may motivate and encourage them to initiate communication with the person in the MCS+ by presenting various familiar visual stimuli to facilitate awareness in these persons (Sautet et al., 2022).

Hearing or sound perception often remains preserved when the person is in a comatose state (Aubinet et al., 2022). As such, it is a valuable sensory component to identify in persons with MCS+ (Blundon et al., 2020; Kandeepan et al., 2020; Sattin et al., 2022). It is imperative to identify the hearing function of a person in an MCS+ as it also influences the person's auditory perception and can further indicate noise sensitivity (Blundon et al., 2020; Elliott et al., 2018; Kandeepan et al., 2020). Additionally, sound perception and hearing may also affect person-partner interaction and the person's ability to respond to the communication partner. Communication partners should therefore continue verbal interaction with the person as their hearing skills may be intact and auditory stimulation may assist in stimulating awareness and wakefulness (Peterson et al., 2019; Zhu et al., 2019).

Apart from vision and hearing, it is also vital to identify sensory functions such as olfaction, tactile, vestibular, gustatory, and proprioception in persons in MCS+ to develop a sensory stimulation programme (Sautet et al., 2022). Considering sensory functions is integral for communication as sensory stimulation facilitates wakefulness and awareness in persons with an MCS+ and may increase their responsiveness during interaction (Sautet et al., 2022). By targeting these sensory functions, the neuro-behavioural responses of persons in an MCS+ may be improved – especially in persons who appear to be noncommunicative (Pape et al., 2015). If sensory stimulation such as familiar environmental stimulation is not provided, recovery can be delayed and a decline of the reticular activation system threshold can occur (Padilla & Domina, 2016; Singh et al., 2019). Communication partners are perfectly situated to provide sensory stimulation for a person in an MCS+ as they spend the most time with the

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person and know them best (Sattin et al., 2019; Sautet et al., 2022). Providing this form of stimulation may decrease communication partners' perceived care responsibilities as they may feel less helpless. Furthermore, providing familiar stimulation may also facilitate interaction between the person and partner and may reduce communication breakdowns. Communication partners therefore require support to optimise familiar emotionally laden sensory stimulation to provide the best opportunity for the person to respond to partner's attempts to initiate interaction (Sautet et al., 2022). This could be effectively done using CPT.

2.5.3.8. Physical-motor skills of the person in an MCS+

The lack of physical skills influences the communication performance of the person in an MCS+. Motor impairments comprise both fine and gross motor movement. Therefore, the identification of both fine and gross motor impairments in persons in MCS+ is important as it may prevent these persons from responding to environmental stimuli and it could also affect their communication and speech production. The latter is negatively influenced by oral-motor dysfunction (body function impairments) due to structural impairments (Barman et al., 2016; Jani & Gore, 2014; Mandaville et al., 2014).

Motor impairments may influence interpersonal communication negatively as communication partners may expect the person in an MCS+ to respond verbally to the partner's communication attempts (Ellis & Astell, 2017). However, even though the person's motor-speech production may be impaired, they may present with other motor responses such as eye movement, facial expressions, gestures such as finger tapping and body movement which form part of unaided communication behaviours (Rasmus et al., 2019; Sautet et al., 2022). Fine motor skills related to communication that may be unaffected include finger-tapping, grip strength, and object manipulation (Alwis et al., 2013; Carron et al., 2016; Edlow et al., 2017).

2.5.3.9. Physical-motor skills of the communication partner

Communication competence of the partner can be influenced by the impact of their care responsibility on their physical skills. According to Bekhet (2013); and Chinner et al. (2021), unpaid communication partners of persons in an MCS+ often experience decreased health related quality of life due to their care responsibility. The physical health of partners are generally negatively affected as they may experience physical and psychosomatic symptoms (Magnani et al., 2020). These can include insomnia, sleep disturbances, fatigue, digestive problems, headaches, eczema, and general physical stress symptoms (Chinner et al., 2021;

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Sacco et al., 2018). Additionally, physically caring for the person in an MCS+ may also result in backache and arm/knee conditions (increased pain in arms or legs due to physical labour). (Chinner et al., 2021). These physical effects of the care responsibility may influence person-partner communication as the partner may be too fatigued to initiate or create opportunities for interaction and they may be less attentive to observe the person's communication behaviours (Spitzberg, 2013). Unpaid communication partners therefore require support to optimise the communication opportunities during interaction with persons in an MCS+ (Simmons-Mackie, 2018). Research suggests that CPT utilises opportunities for communication during activities of daily living (Simmons-Mackie et al., 2010).

2.5.3.10. Communication skills of the person in an MCS+

The MCS+ condition can greatly affect the person's communication, including receptive and expressive language skills (Barman et al., 2016; Ciccia & Threats, 2015; Marini et al., 2011). Communication partners have difficulty in determining the receptive language skills of the person in an MCS+ due to their inconsistent neuro-behavioural responses to indicate understanding. For example, they might be able to follow instructions and understand simple yes/no questions but have limited communication modes to indicate this (Chatelle et al., 2020; Formisano et al., 2019; Kotchoubey et al., 2013; Martens et al., 2020; Rasmus et al., 2019; Roberts & Greenwood, 2019).

Even though communication partners may have difficulty differentiating between intentional versus unintentional behavioural responses, the person in an MCS+ has intact lexical-semantic functioning (Nigri et al., 2017). This type of information facilitates a strong and significant activation of Broca's area and of Wernicke's area as well as weaker activation of the premotor cortex and thalamus (Aubinet et al., 2020; Chatelle et al., 2020; Formisano et al., 2019; Kotchoubey et al., 2013; Nigri et al., 2017; Rohaut et al., 2015). It can therefore be assumed that persons in an MCS+ may not necessarily have difficulties with language content (lexical-semantic processing) but with language form (i.e., syntax, morphology, and phonology), and with language use (i.e., pragmatic) (Kwiatkowska et al., 2019; Owens, 2012; Paul & Norbury, 2012). Difficulties with language form may result in reduced capacity to comprehend speech acts due to challenges in identifying the intended meaning of the communication partners' messages (Bosco et al., 2015; Marini et al., 2011). Language use may also be affected as the person may present with decreased pragmatic skills such as requesting and providing adequate information during person-partner interaction (Bosco et al., 2015).

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The person in an MCS+ may be able to understand language content, yet, may present with difficulties related to their condition when providing consistent neuro-behavioural and verbal responses to partner's attempts to communicate (Kotchoubey et al., 2013). Rather than respond with verbal utterances, these persons may use other subtle unaided communication behaviours in response to environmental changes (Rasmus et al., 2019; Sautet et al., 2022). Unaided communication behaviours occurs on a continuum ranging from unintentional to intentional (Kuyler et al., 2022b). These unaided communication behaviours also allow the person to access a range of communication functions such as requesting, asking questions and indicating their preferences (Kuyler et al., 2022b). Unaided communication may provide insights into the emotional state of the person in an MCS+ (Sattin et al., 2022).

Communication partners' knowledge and awareness of the unaided communication displayed by persons in an MCS+ should therefore be increased and partners should observe, interpret, and support these behaviours in an attempt to facilitate interaction with the person in an MCS+. Knowledge of the person's condition and communication may improve communication and decrease care responsibility (Cruzado & De La Morena, 2013). This may be achieved through the partner's observation of the persons intentional responses to their communication attempts (Rasmus et al., 2019). Improved knowledge of the person's condition and communication skills may also allow the communication partner to have a greater understanding of the person's difficulties and allow them to make informed decisions regarding the care of the person (Smart & Giacino, 2015).

2.5.3.11. Communication skills of the communication partner

The communication competence of the partner can be impacted by the partners communication skills and their care responsibilities. Initially, unpaid and paid untrained communication partners describe a need to be in close physical proximity to the person with an MCS+ to sustain an emotional connection with them (Chinner et al., 2021). However, over time the unpaid communication partner may start to view the person differently or as a child-like figure, and subsequently his/her needs for physical closeness may reduce (Chinner et al., 2021). Communication partners may thus experience a reduced need for physical closeness as they receive limited feedback from the person regarding their preferences and needs (Gonzalez-Lara et al., 2021). Unpaid communication partners may also begin to view themselves and the person in their care as a single unit within a nonreciprocal relationship (Chinner et al., 2021; Gonzalez-Lara et al., 2021). This perception of a single unit is further exacerbated by the fact

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that the person lacks consciousness, however, is alive (Chinner et al., 2021; Gonzalez-Lara et al., 2021; Soeterik et al., 2017).

Furthermore, if the person in the MCS+ does not respond to the unpaid communication partner, the partner could avoid engagement in interaction but then their avoidance may increase their emotional distress, thereby feeding into a vicious circle (Chinner et al., 2021; Cruzado & De la Morena, 2013). Communication partners experience increased psychological distress if they are not able to communicate effectively with the person in an MCS+ (Chinner et al., 2021). Typically, these communication challenges also cause the partner to experience an increased loss of who the person was before the injury (Chinner et al., 2021; Magnani et al., 2020). This may result in communication partners continuing to avoid interaction and then feeling guilty for not spending more time with the person (Chinner et al., 2021). This warrants the need for support through CPT, which may teach the communication partner skills and improve their awareness of unaided communication behaviours. CPT may also assist communication partners to identify these behaviours and this may allow them to attain smaller goals (increasing their motivation and reducing their stress) (Wiseman-Hakes et al., 2020).

Sattin et al. (2022) suggest that persons in an MCS+ often have higher scores in motor and auditory areas when behavioural assessment is conducted. This suggests that the brain is able to interpret auditory stimuli at a complex level and that lexical-semantic processing can occur in isolation from the rest of the mental activity and without awareness (Formisano et al., 2019; Kotchoubey et al., 2013; Nigri et al., 2017). Therefore, communication partners should scaffold their own communication by verbally presenting short, simple sentences to the person which the person can understand (Kotchoubey et al., 2013; Nigri et al., 2017; Rohaut et al., 2015).

It is suggested that the communication partner use multimodal communication to communicate with the person in an MCS+ (Purdy & Can Dyke, 2011). Communication partner's use of multimodal communication may create the opportunities for the person in an MCS+ to respond to the partners attempts to interact (Sautet et al., 2022). Multimodal communication can be further enhanced through the use of familiar stimuli that is emotional, so that the person recognises it and it facilitates an emotional response from the person (Purdy & Van Dyke, 2011; Sautet et al., 2022). Familiar multimodal communication may include using the person's name, presenting familiar objects and shared communication about biographical experiences (Magliacano et al., 2019). Communication partners often share biographical

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experiences with the person in an MCS+ and therefore have ample knowledge of the familiar objects and familiar stimuli that the person responds best to (Sattin et al., 2022). Through CPT, communication partners can be taught to optimally utilise their shared biographical knowledge and multimodal communication to provide the person in an MCS+ the best opportunity to respond (Purdy & Van Dyke, 2011).

2.5.4. Context

The context wherein communication takes place could further have an impact on the knowledge of the communication partner (MacDonald, 2017). The context includes the cultural, chronological, relational, situational, and functional factors that impact communication (Spitzberg, 2013). In the original model of communication competence, Spitzberg (2013) suggests that the context is an extension of knowledge. However, for communication partners of persons in an MCS+ the context is an overarching factor that largely impacts all areas of communication. Hence, the context is treated differently in the new proposed model. The context relates to the environment wherein person-partner communication occurs and can be impacted by the care responsibilities of the communication partner (Lancioni et al., 2021).

2.5.4.1. Cultural factors

The cultural context refers to the rites, rules, rituals, beliefs, and values of the partner and the person in an MCS+. The cultural context of communication partners may influence person-partner communication between themselves and the person in an MCS+. Paid communication partners are employed to care for these individuals, yet they do not necessarily share the same cultural background as the person (Lin et al., 2012). Cultural factors determine how engaged or disengaged a communication partner is in the person's care and communication (Spann et al., 2020). Additionally, the cultural context influences the partners' subjective perspective of what constitutes a consistent unaided communication behaviour indicating environmental awareness (Sattin et al., 2022). Both Sattin et al. (2022); and Moretta et al. (2017) suggest that unpaid communication partners of persons in an MCS+ view the person's unaided communication behaviours more positively than HCPs. Frequent communication partners perceive unaided communication with intent as they have the same background as the person. Communication partners responsiveness to the person may therefore be improved, which increases interpersonal communication between the person and partner (Sautet et al., 2022).

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2.5.4.2. Chronological factors

The communication partner often attempts to communicate with the person in an environment characterised by multiple competing priorities. Over and above facilitating communication with the person, both paid and unpaid communication partners have to provide basic care tasks such as feeding and bathing the person, cleaning the excretion of the patient, and administering medication (Liang et al., 2017).

Additionally, communication partners have to consider different medical considerations at different stages of care which can disrupt the partners' daily life (Chinner et al., 2021; Eliacin et al., 2022; Gonzalez-Lara et al., 2021). Communication partners tend to prioritise person-related activities, leaving the partner with limited time for their own basic needs of self-care and nutrition in line of accommodating their new caring roles (Chinner et al., 2021).

Unpaid communication partners may lack opportunities for indoor and outdoor leisure activities, low engagement in previous hobbies and changes in their physical activity over time (Chinner et al., 2021). These chronological time demands may often lead to reduced opportunities for communication with the person in an MCS+ and increase the communication partners' care responsibilities (Savundranayagam et al., 2005). However, Chinner et al. (2021) suggest that six to 12 months after the injury, unpaid communication partners have created more sustainable life routines. This is usually when unpaid partners (e.g., family) tend to employ paid partners with whom they can build a trusting and long-term relationship. Both paid and unpaid communication partners can schedule time to interact with the person during their daily routines. Furthermore, if a fixed time is scheduled to communicate with the person, the partner may increase their duration of interaction. Increased duration of interaction allows for communication partner opportunities to observe all communication behaviours of the person and provide appropriate responsive behaviours by means of multimodal communication (Purdy & Van Dyke, 2011).

2.5.4.3. Relational factors

The communication competence of communication partners is influenced by relational factors. For unpaid communication partners of persons in an MCS+, HCPs may become a barrier. Limited support from HCPs and clashing ideas of best interests of the person in an MCS+ also increase care responsibilities and minimises communication within the multidisciplinary team (Chinner et al., 2021; Peterson et al., 2019). Additionally, unpaid

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communication partners report that they have lack of access to medical teams, adequate care resources and support services (Gonzalez-Lara et al., 2021; Tramonti et al., 2019).

The role of caring for the person in an MCS+ occurs suddenly, leaving the unpaid communication partner unprepared for their new role. This new role may require them to leave their jobs, their interests, and have limited interaction with friends and relatives to care for the person in an MCS+ (Hoffman & Wallace, 2019; Noohi et al., 2016). As a result, unpaid communication partners have reduced opportunities to participate in social and workplace events which may increase feelings of social isolation and negative psychological states (Giovannetti et al., 2013). Limited feedback from the person in an MCS+ may also increase their feelings of isolation (Gona et al., 2014). According to Gonzalez-Lara et al. (2021), communication partners indicate a preference to remain part of social and community networks as these networks assist them to meet their needs and to cope with their care demands. Additionally, Noohi et al. (2016) suggest that social support can include relatives, friends, colleagues, professional groups, or people from the broader communities. CPT can also provide social support as the unpaid communication partner may have access to individuals who are in similar life situations and may provide them with communication skills to facilitate interaction with the person (Behn et al., 2021).

Paid communication partners become part of the family when caring for the person and provide emotional support to the whole family (Liang et al., 2017; Reckrey et al., 2021). This may limit the amount of time they have with their own families, increase work pressure, and reduce their access to social support (Liang et al., 2017). Providing a means of social support for these paid communication partners may increase their subjective feelings of belonging, acceptance, recognition, and assistance in the required situation (Giovannetti et al., 2015; Noohi et al., 2016). CPT can provide a means of social support (Buckley, 2017). If the paid communication partners receive support, they may feel more motivated to initiate interaction with the person in an MCS+ and appear intentional with their own interaction but also more responsive to unaided communication behaviours of the person.

2.5.4.4. Situational factors

The situational contextual factors refer to the physical environment of the communication partner that may impacts on interpersonal communication (Spitzberg, 2013). The physical environment of both the communication partner and person in an MCS+ can be impacted by the care responsibility and ultimately influences person-partner communication.

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According to Chinner et al. (2021), taking care of a person in an MCS+ may impact the employability and productivity for communication (attempting and continuing communication with the person) in both paid and unpaid communication partners of persons in an MCS+. Unpaid communication partners may be the sole provider for the family and could also have other family members apart from the person in an MCS+ (Gonzalez-Lara et al., 2021). Some unpaid communication partners must temporarily or permanently resign from their jobs to provide care for the person while others remain permanently employed but have reduced functioning due to the stress of their care responsibilities and poor person-partner interaction (Chinner et al., 2021). Furthermore, the person in an MCS+ may have been the breadwinner in the family and now the unpaid communication partner has this added responsibility (Chinner et al., 2021).

Financial constraints may be problematic as caring for the person may increase indirect and direct costs for the family (Giovannetti et al., 2015). Upon discharge, architectural adaptations to personal homes are required such as ramps and broader door frames, to equip the home with aids necessary for hygiene, mobility, and sustenance (Zylberman et al., 2016). Additionally, depending on the severity of the person's medical complexities, they often require extended rehabilitation services from multiple HCPs that could increase financial responsibilities (Eliacin et al., 2022). Furthermore, the financial circumstances of the unpaid communication partners affect the attraction and retention of paid communication partners (Hoffman & Wallace, 2019).

Paid untrained communication partners may also experience financial constraints as due to limited qualifications, their wages may be low (Hoffman & Wallace, 2019). Financial constraints may increase stress for both paid and unpaid communication partners which may decrease the duration of interpersonal communication between the person and communication partner. Additionally, increased stress may lead to less responsive behaviours from communication partners to unaided communication behaviours of persons in an MCS+, as partners become preoccupied and absent-minded during interaction.

2.5.4.5. Functional factors

Unpaid communication partners of persons in an MCS+ often experience great distress which leaves them unable to concentrate on anything other than their loss and this affects their coping strategies (De la Morena & Cruzado, 2013). Distress may further affect communication partners' ability to learn new skills, use problem-focused coping strategies and to manage

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information (De la Morena & Cruzado, 2013). Often unpaid communication partners are expected to manage their own lives with additional appointments and responsibilities when caring for the person in an MCS+. For example, the partner often becomes the care coordinator of the person in an MCS+ having to coordinate multiple services, specialised transport, and remuneration of trained communication partners (such as PTs, OTs, SWs, SLTs) (Chinner et al., 2021; Gonzalez-Lara et al., 2021). This can negatively affect the wellbeing of the communication partners and increased partner stress which reduces duration of interaction with persons in an MCS+ (Gonzalez-Lara et al., 2021). Furthermore, other daily responsibilities of the unpaid communication partner such as parenting or managing household chores that were often shared with the person in an MCS+ now also becomes the partner's responsibility (Chinner et al., 2021).

Due to paid communication partners having to support unpaid communication partners, they may experience compassion fatigue (Lin et al., 2012). Therefore, both the paid and unpaid communication partners require support to promote communication within the multidisciplinary team and with the person in an MCS+ as well as to reduce their care responsibilities. This support can be provided through CPT that can teach communication partners to optimise the time they have for interaction to support unaided communication behaviours of persons in an MCS+.

2.5.5. Judgement as applied in an observation approach

Communicators are regarded as being competent when demonstrating responsive behaviours to others' communication attempts by integrating knowledge, skills, and motivation in a context (Spitzberg, 2013). For communication partners to apply appropriate responsive behaviours they require sufficient judgement to apply an observation approach. An observation approach allows them to judge when and what to observe and how to assess, interpret, and respond appropriately to the person's communication behaviours. This observation approach is based on behaviour-response theory which is the foundation for CPT (Behn et al., 2021). CPT teaches communication partners to utilise multimodal communication (combination of aided and unaided communication) (behaviour-response theory) and to apply appropriate judgement when utilising these strategies to facilitate rather than impede communication (O'Rourke et al., 2018).

Finally, communication partners should review their expectations of persons in an MCS+ to not only require a verbal response but rather any communication behaviour, including

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unaided forms of communication such as body movements, which they can observe as a response to the partners attempts to initiate interaction with the person. These factors should all be continuously monitored by observing any communication behaviour and to then respond accordingly. Next, the communication partner evaluates whether their responsive behaviour was accurate, appropriate, and effective. Figure 2.1 illustrates the suggested model of communication competence for partners of persons in an MCS+.

2.5.6. CPT for communication partners of persons in an MCS+

This section includes a short description of CPT with a more detailed description of CPT in Chapter 4. CPT is a method that is used to reduce participation barriers for both the paediatric and adult populations but for the purposes of this study a specific focus is placed on CPT for persons with acquired neurological conditions (Chang et al., 2018; Cruice et al., 2018; Eriksson, Forsgren et al., 2016; Kagan et al., 2018; Mann et al., 2015). The aim of CPT is to facilitate an opportunity for the person to express themselves, to improve their language, communication participation and well-being (Ahlsén & Saldert, 2018; Chang et al., 2018; Finch et al., 2017; Jensen et al., 2015; Simmons-Mackie et al., 2010). Another goal of CPT is to acknowledge and accommodate communication with techniques and tools which are recognizable to the person with an acquired condition (Jensen et al., 2015; Mann et al., 2015).

Utilising a CPT programme to support unaided communication behaviours of persons in an MCS+ may be beneficial as it enhances awareness of various factors that may affect interpersonal communication (Ahlsén & Saldert, 2018; Cameron et al., 2018; O'Halloran et al., 2012). These factors specifically include addressing contextual or environmental factors (goals, roles, physical, and psychological components influencing communication) that can cause barriers to communication in natural settings (Ahlsén & Saldert, 2018; Behn et al., 2021; Eriksson, Forsgren et al., 2016). This approach assists in analysing communication interaction patterns including turn management, eliciting feedback (e.g., words or sounds such as hmm or yes, head movements, shoulder shrugs and facial expressions which indicate a response to the partners contributions) as well as the production and comprehension of communicative contributions (e.g., speech, gestures, drawing, writing and other AAC) (Ahlsén & Saldert, 2018; Eriksson, Hartelius et al., 2016). Although the diagnosis of a person's condition affects the individual in different ways, the communication partner strategies used are often the same irrespective of the persons diagnosis (Eriksson, Forsgren et al., 2016). If these strategies are used in natural settings during activities of daily living favourable conditions are created for

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communication and the use of these strategies assist in identifying barriers and areas of support required for these persons (Eriksson, Forsgren et al., 2016). Additionally, CPT can be used to empower communication partners by improving their knowledge and skills during communication with these persons (Finch et al., 2017; Jensen et al., 2015). Participant's behavioural skills, motivation, self-efficacy, social support, evaluation, and social engagement are often also better (O'Rourke et al., 2018). If communication partners are untrained they experience more difficulties when exposed to their partners acquired neurological conditions (Kagan et al., 2018; Kent-Walsh & McNaughton, 2005).

Persons in an MCS+ are fully dependent on the communication partner to perform activities of daily living and communication. To support the communication competence of the communication partner and subsequently reduce the care responsibility, they may benefit from CPT programmes (Simmons-Mackie et al., 2010). CPT may support interpersonal interaction between the person and partner and potentially improve the psychological state and quality of life of both. The training of communication partners may assist to sensitise them to acknowledge the unaided communication behaviours displayed by persons in an MCS+. Additionally, CPT can assist the communication partners to provide appropriate responsive behaviour through multimodal communication, thereby creating a supportive communication environment (Bruno et al., 2011; Haberstroh et al., 2011; Henriques et al., 2016; Kondziella et al., 2020). CPT can also be beneficial for communications partners as it increases responsive behaviour by focusing on an observation approach within a specific context (Finch et al., 2017; Kent-Walsh & McNaughton, 2005).

When communication partners are trained to use an observation approach, they are trained to observe the unaided communication behaviour displayed by persons in an MCS+ which in turn could facilitate communication opportunities. To facilitate communication opportunities, the communication partner may use responsive behaviour such as verbal instructions, physical guidance (e.g., pointing), and demonstrations (Libby et al., 2008). As explained earlier, an observation approach is based on the behaviour-response theory. The behaviour response theory is based on the cue-response theory conceptualised by Olson and Ortega-Pérez (2019) (Figure 2.2). This theory suggests that the person with an acquired neurological condition experiences challenges in various areas (e.g., speech production, motor and sensory abilities) but may display a cue or behaviour (agitation) to communicate. The communication partner observes this cue or behaviour, assesses and interprets the cue or behaviour and interprets the cue to provide an appropriate response or intervention (Olson &

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Ortega-Peréz, 2019). As the behaviour-response theory depends highly on the observation of the of cues or behaviours displayed by the person, this theory provides the basis of the observation approach. Although, some components were mentioned in Figure 2.1, Figure 2.2 expands on the observation approach mentioned in the first figure. By basing an observation approach on behaviour-response theory, the communication partner can firstly be taught to observe all communication behaviours of the person (how any emotional, physical or physiological behaviours present). Subsequently, the communication partner can be taught to assess and interpret the behaviour and finally, to follow with the appropriate responsive behaviour as intervention to mediate the need (Olson & Ortega-Perez, 2019). Application of the observation approach can teach the communication partner new skills as well as problem-focused strategies to facilitate communication (Horton & Pound, 2018). This suggests that the partner cannot only be taught to observe all communication behaviour (including unaided forms of communication) of persons in an MCS+ but also to provide appropriate responsive behaviour through multimodal communication. This may enhance the partners ability to monitor the accuracy, appropriateness and effectiveness of their own behaviour and to potentially facilitate reciprocal, flexible co-productive interaction that promotes long-term commitment and continuity (Horton & Pound, 2018).

CPT may also teach partners to manage information and advocate for both their own needs and those of the person in an MCS+'s (Horton & Pound, 2018). The training of communication partners may provide valuable support to improve the competence of communication partners by increasing their knowledge on observation approaches. This led to the formulation of the main aim of this study which is to identify and adapt an intervention in the form of a communication partner training programme to facilitate interaction between communication partners and persons in an MCS+ based on E^3BP principles. It is proposed that this can be done by identifying a programme that may empower communication partners to observe, assess, interpret, and respond to the communication behaviours displayed by these individuals.

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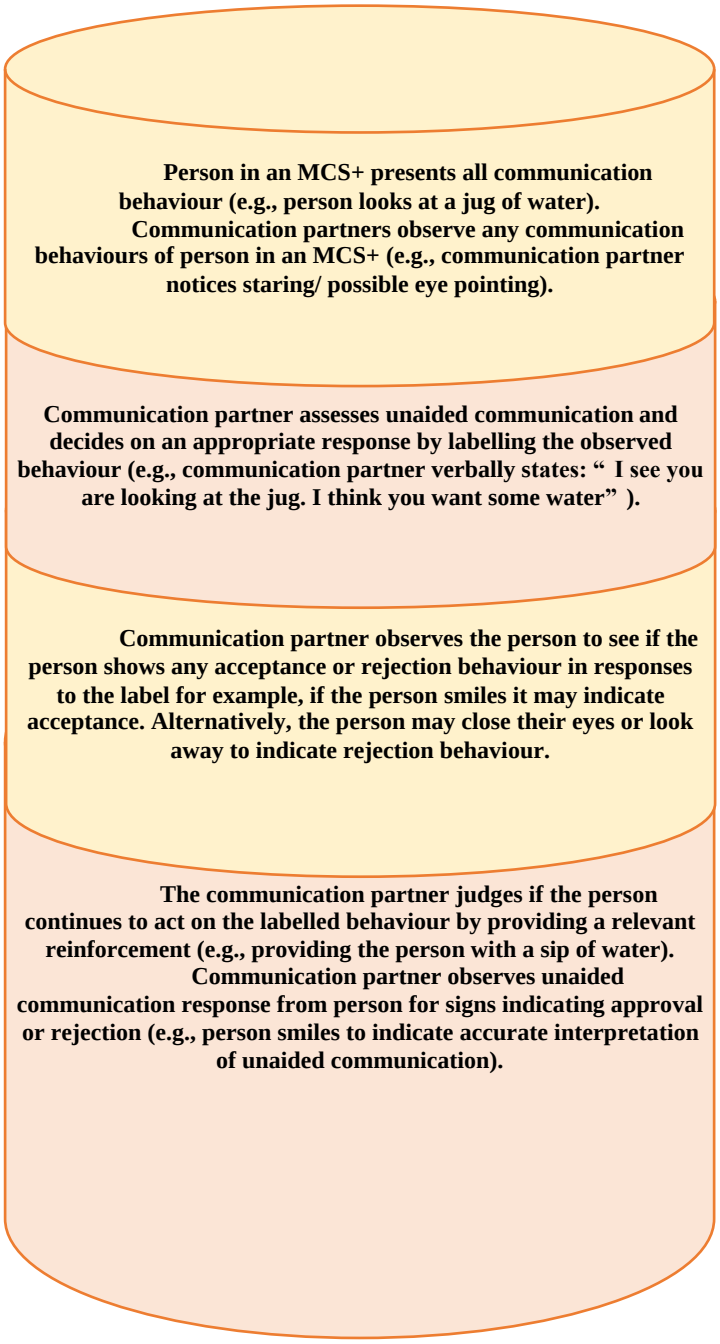
Figure 2.2

Observation approach based on behaviour-response theory



Source*: adapted from Olson and Ortega-Perez (2019)*

From Figure 2.2, it is clear that the communication partners of persons in a MCS+ may identify the person's unique communication behaviours through observation. Unpaid communication partners familiar with the person may be able to describe unique communication behaviours that the person typically displays. This may form part of a gesture

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dictionary which unpaid partners can provide to paid partners caring for the person in an MCS+. The gesture dictionary may provide paid communication partners with contextual assistance to help them to identify, assess, and intepret the persons communication mode accurately and to provide an appropriate responsive behaviour (Ogletree & Pierce, 2010).

2.6. Conclusion

This chapter started by discussing DOC and then explored who the communication partners of persons in an MCS+ typically are. Next, the model of communication competence was discussed and applied to communication partners of persons in an MCS+. Five factors (i.e., motivation, knowledge, skills, context, and judgement) were identified as influencing communication competence of communication partners. These five factors included a discussion of the communication partners care responsibilities, the impact on interpersonal communication and communication competence of the communication partner. A discussion of the observation approach based on the behaviour-response theory followed to facilitate interaction between the person and partner. The chapter concludes by discussing the benefits of using an observation approach to guide CPT. The next chapter (Chapter 3) will focus on the research methodology proposed for this qualitative case study design with three sequential phases each comprising distinct steps.

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CHAPTER 3: PHASE 1- EXPLORATORY PHASE

Methodology, Results, and Discussion

3.1. Introduction

This chapter outlines the methodology adopted for this study and commences with a description of the aims of the study as well as the qualitative exploratory collective case study design with three sequential phases each comprising distinct steps. It highlights the advantages and strengths of the design, however, also cautions about the potential weaknesses. Identifying the advantages and disadvantages of the design assisted in steering the development of the process in the most effective manner but being aware of potential pitfalls upfront. Thereafter, the ethical considerations as well as the techniques employed to improve the trustworthiness of all three the sequential phases are discussed.

The second part of the chapter focuses specifically on Phase 1 and describes the unaided communication behaviours of persons in an MCS+, as well as the multimodal communication strategies used by communication partners of persons in an MCS+. Additionally, this chapter includes the communication partners' support needs based on their communication experiences with persons in an MCS+.

Thereafter, chapter 4 will focus on Phase 2, the Intervention Identification and Adaptation phase and Chapter 5 will focus on Phase 3, the Clinical Utility of the proposed intervention programme respectively. Chapters 3, 4 and 5 should thus be read in conjunction with each other.

3.2. Research aims

A main aim and sub-aims were formulated to address the problem statement described in Chapter 1.

3.2.1. Main aim of the study

The main aim of this study is to identify and adapt an evidence-based intervention in the form of a communication partner training programme to facilitate interaction between communication partners and persons in an MCS+. In identifying the programme preference was given to a programme that may empower communication partners to observe, assess, interpret and respond to the communication behaviours displayed by these individuals.

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3.2.2. Sub-aims of the study

To address the main aim of the study and ensure alignment with the design, the following three sub-aims were formulated, each addressing and forming the main aim of a specific phase of the proposed three-phase qualitative case study design:

i) To explore the evidence on communication behaviours displayed by persons in an MCS+ (unaided communication) as well as the multimodal communication strategies utilised by communication partners (Phase 1);

ii) To identify a CPT programme based on E^{3}BP principles and to adapt this programme based on the recommendations by clinicians with a special interest in neurorehabilitation (Phase 2);

iii) To explore SLTs perspectives on the clinical utility of the adapted intervention and to incorporate these perspectives into the proposed intervention (Phase 3).

3.3. Research design

The present study utilises a qualitative exploratory collective case study design with three sequential phases each comprising distinct steps to address the aims of the study (Carolan et al., 2015; Crowe et al., 2011). Phase 1 is the Exploratory Phase and is followed by Intervention Identification and Adaptation (Phase 2) and finally the Clinical Utility of Intervention (Phase 3), which culminates in a new proposed intervention, as shown in Figure 3.1. Phase 1 (Chapter 3) is indicated in a block as it is the focus of this chapter.

Qualitative research focuses on constructing social reality through subjective meaning comprising the building of knowledge (Hesse-Biber & Burke Johnson, 2015). This approach regards the participant as the expert and aims to understand human behaviour based on lived experience (Hesse-Biber & Burke Johnson, 2015; McMillan & Schumacher, 2014). Naturalistic settings are often used to understand the process of subjective reality by allowing the researcher to utilise broader sources of information (Creswell & Creswell, 2018; McMillan & Schumacher, 2014). By utilising this design, the research was grounded on theoretical underpinnings constructed from participants' subjective meaning to build knowledge which resulted in the identification and adaptation of a relevant and sensitive intervention (i.e., CPT programme) (Creswell & Creswell, 2018; Hesse-Biber & Johnson, 2015). In this study a case was defined as a unit of analysis (Carolan et al., 2015). For example, an interview with a specific participant with constitute a case. Collective case study designs explore the shared meaning and common characteristics of multiple cases (units that can be analysed) (Baxter &

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Jack, 2008; Carolan et al., 2015). For example, the collective case study design explored the shared meaning or similarities between multiple participants that were interviewed to address a specific aim in the research. In this study, three main phases were identified each targeting a specific sub-aim of the study (Phase 1-Exploratory Phase; Phase 2-Intervention Identification and Adaption and Phase 3-Clinical Utility of Intervention).

A constructivist paradigm was used to approach the case (Carolan et al., 2015; Prasad Bhatta, 2018). This approach relates to the fundamental recognition that human interpretation is the reference point for application in real world contexts (Thorne, 2014). The paradigm consists of two distinctive features namely meaning and interpretation (Putman & Banghart, 2017). Meaning refers to how individuals make sense of their experiences or understand their daily lives, while interpretation refers to the process of making meaning or forming inferences about their experiences (Putman & Banghart, 2017). The theoretical position then becomes intellectual standpoints based on an individual's perspective and claims that truth is simply an idea in itself (Thorne, 2014). Philosophically, it describes a case as a form of reality apart from human perception but recognizes that human perceptions are shaped by our historical and cultural positionings upon it (Thorne, 2014). Thus, applied constructivist work suggest that the polarities of subjective and objective truth are not disproportionate or mutually exclusive, and strands of both realism/positivism and idealism/relativism can potentially inform knowledge development (Putman & Banghart, 2017; Thorne, 2014). Thorne (2014) suggests that research does not occur in a vacuum and that although identifying a problem in research is beneficial, one also wants to provide a possible solution for the problem in this case a CPT programme. In the constructivist approach the understanding of meaning and processes from multiple perspectives are obtained as information related to the case (E^3BP intervention in the form of a CPT programme for persons in an MCS+ and their communication partner) (Crowe et al., 2011).

In the present study, multiple perspectives (literature, communication partners, clinicians and SLTs) were included in the three phases and multiple data sources (scoping review, umbrella review, face-to-face interviews, synchronous online interviews and a nominal group technique) assisted in adding new information to the case and subsequently the research field (Creswell & Creswell, 2018; Crowe et al., 2011). Multiple data sources in case study designs can assist in aiding understanding and explaining the links resulting from new initiatives (Crowe et al., 2011). However, for a clear understanding of the links between the multiple data sources, the researcher plays an integral role in case study designs and the

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researchers positioning toward the cases should be considered. Pitard (2017) suggests that researcher positioning relates to the researchers view of themselves and their research and their understanding of self when creating knowledge. Reich (2021) reiterates this statement by suggesting that the researchers own embodiment and social location be considered when designing and conducting research. Therefore, instead of viewing researcher reflexivity as a transgression when engaging with the field, one could view this process as advantageous and important (Reich, 2021). The researcher's positionality includes self-reflecting on the ethics of care. The ethics of care include being mindful of non-maleficence and respect for informants (Reich, 2021). In an interpretivist or constructivist approach the researcher is guided by perspectives of the participants while acknowledging the influence of their own background and experiences (Kamal, 2019). The researcher took a person-centred approach toward the research which viewed the communication partner as the most important when planning and implementing communication support (McNaughton et al., 2019). This approach assists the study to be based on the needs of communication partners caring for persons in an MCS+ and allows them to express their unique perspectives regarding their experiences (Alvariza et al., 2018). Moreover, the researcher utilised active self-reflection during the research process to reduce possible biases which can influence the quality of the study (Creswell, 2018). This self-reflection process was based on the researcher's therapeutic experience working with persons with complex communication needs and their families which allowed the researcher to be sensitive during the interview processes to the needs of the communication partners. Additionally, the researcher is a qualified speech-language pathologist and has a master's degree in AAC which has provided the researcher with the appropriate academic background to conduct the interview process appropriately ensuring that all participants benefit equally from the study. The researcher did not have direct personal relationships with the participants in this study. However, a small number of participants were identified from the researcher's network. These individuals had no personal relationship with the researcher but were met through continuing professional development activities and therefore no bias was imparted or any conflict of interest occurred. This process of self-reflection assisted the researcher to avoid ethical pitfalls during the research process (Reich, 2021). Ethics of care also include the researcher's ability to choose which personal information to share with participants to make the researcher more trustworthy and establish closeness with participants (Reich, 2021). Due to the researcher's therapeutic background, experience and skills interviewing participants the participants felt comfortable to share their experiences in a safe environment.

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A disadvantage of this design could be the duration of data collection as there are multiple phases with a variety of data collection methods. Furthermore, this design expects a significant amount of skill from the researcher in terms of the subject knowledge and knowledge on different types of data collection methods, making it a demanding design (Creswell & Creswell, 2018). Another disadvantage of qualitative research is that generalisability of findings to other contexts may be limited. However, this study crystalised multiple data sources as well as multiple perspectives which increased the reach and representativeness of findings (Berg, 2007).

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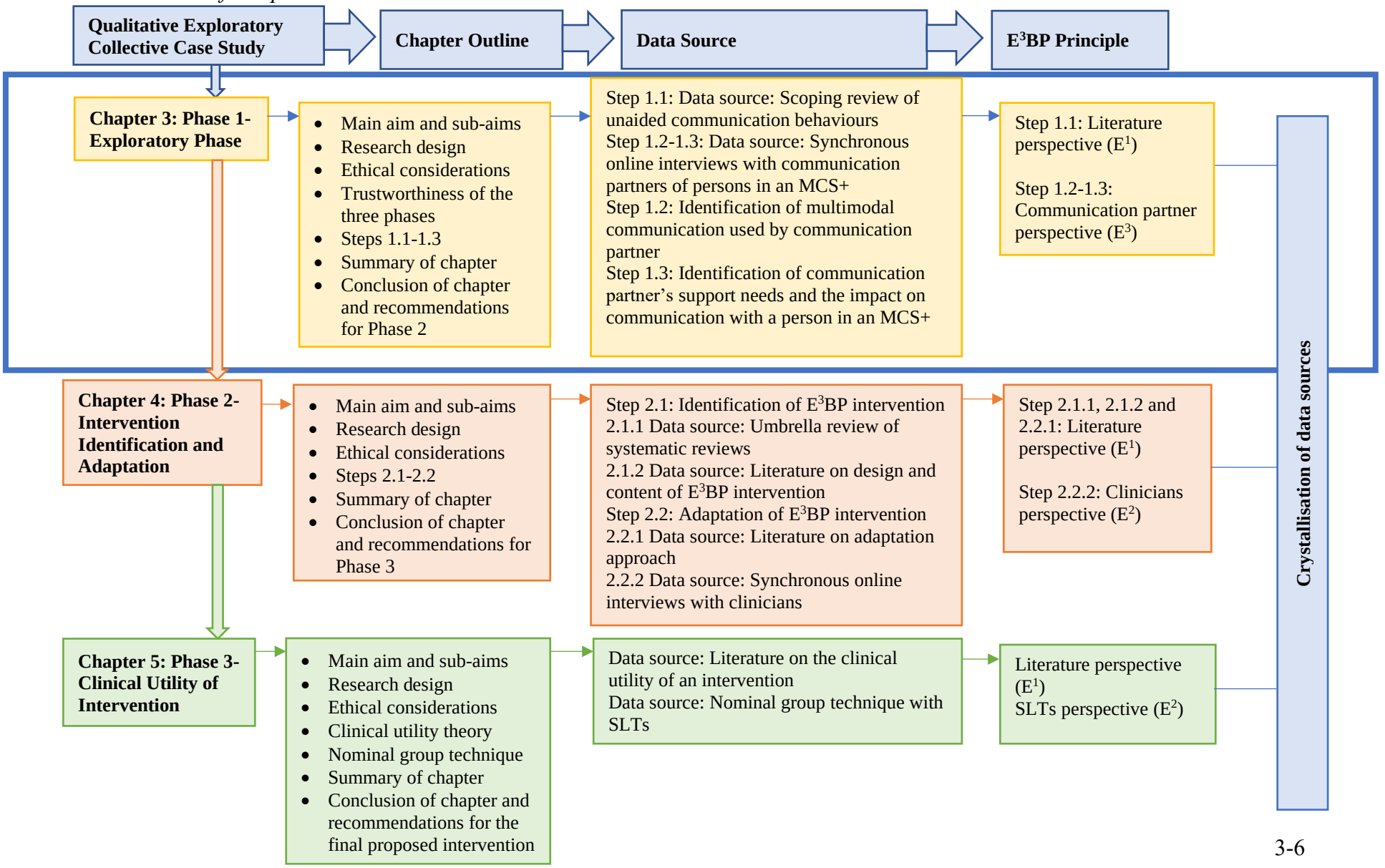
Figure 3.1

Outline of Chapter 3



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3.4. Ethical considerations

The researcher is tasked during a study to ensure that research procedures are ethical and include informed consent, privacy and confidentiality of personal information, not inflicting harm (non-maleficence and beneficence) (Berg, 2007; McMillan & Schumacher, 2010). Although the same broad principles applied throughout the present study, the following aspects were specifically considered in Phase 1.

3.4.1. Principle of informed consent

Prior to data collection, ethics approval was obtained from the Research Ethics Committee of the Faculty of Humanities at the University of Pretoria (Appendix A). This process included obtaining permission from the practice manager who acted as a gatekeeper in recruiting participants (Appendix B). Additionally, written informed consent was obtained from all participants before conducting the interviews (Appendix C1-C3). This letter of informed consent assisted in providing participants with opportunities for autonomy (Hofmann, 2009). The process of informed consent consisted of the provision of information regarding the aim and rationale of the phase, what was expected of participants as well as the relevance of participants' contributions in the research. To ensure that participants understood the information, jargon and technical/medical vocabulary was restricted and avoided when possible, attempting to present information on a level that participants would understand (Creswell et al., 2011).

3.4.2. Principle of voluntary participation and withdrawal

The participants recruited for this phase understood that the findings of this phase could contribute to their personal growth and would assist other participants in similar situations (Berg, 2007; Creswell et al., 2011). The participants did not receive incentives or any other financial gains from participating in this phase. All participants could withdraw their participation at any time without providing a reason or encountering negative consequences (Creswell et al., 2011).

3.4.3. Principle of privacy (confidentiality)

To maintain the privacy of participants, information was de-identified by allocating participant numbers to all participants (Levine, 1979; Rothstein et al., 2020). The confidentiality of information will be maintained during storage of data for a period of 15 years on an online platform designed by the University of Pretoria as per the institution's

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specifications. During the informed consent procedures participants also agreed to the re-using of data for alternative scientific purposes (e.g., conference presentations, teaching, and journal publications) in addition to the present study.

3.4.4. Principle of beneficence

An interview script (Step 1.2) and research protocol were constructed to ensure that all participants benefitted equally from participation in the research thus increasing beneficence. These procedures also ensured that no information was withheld from participants (Hofmann, 2009). Following their participation, communication partners stated that their participation assisted in reducing their communication burden as they had the opportunity to reflect on their practice. It is therefore expected that the findings of the research would yield similar benefits for other communication partners in similar situations (Berg, 2007).

3.4.5. Principle of non-maleficence

No harm was caused to any participant during the execution of the research (Newman & Kaloupek, 2009). Even though the population of communication partners of persons in an MCS+ are vulnerable, emphasis was placed on not conveying emotionally laden information (Berg, 2007). During the interviews some communication partners did become distressed, but the cognitive interview allowed them to debrief (DeMuro et al., 2012). Additionally, the member checking process allowed communication partners to reflect on information they provided (Birt et al., 2016; Harper & Cole, 2012). Some commented that they found it helpful and rewarding.

3.5. Trustworthiness

To maintain the trustworthiness of the findings of the present study, the following four principles were adhered to namely credibility, dependability, confirmability, and transferability (Elo et al., 2014). Table 3.1 includes a description of the trustworthiness principles included in all three phases and will therefore not be repeated in the subsequent chapters (Chapter 4 and 5). The reporting of trustworthiness is important to ensure confidence in the findings.

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Table 3.1

Trustworthiness of data across all three phases

Definition	Applicability to the Study
Credibility	
Accurate identification and description of participants as well as data analysis (Elo et al., 2014).	**Phase 1** The research question is clearly written with specific aims for Phase 1 (Baxter & Jack, 2008). Multiple data sources and perspectives were used to obtain information and was guided by theoretical frameworks which increased credibility (Rudolph, 2021). Additionally, the researcher and her supervisors (who acted as independent researchers) sought consensus during data analysis (Nowell et al., 2017). **Phase 2** Member checking was used to the ensure that participant perspectives were portrayed accurately in the data. This was accomplished by asking participants to review the interview transcripts after the interviews and return these transcripts (Anney, 2014). Additionally, crystallisation was also used to ensure credibility of the findings (this included integration of data from Phase 1 and Phase 2). **Phase 3** During the nominal group technique consensus was required between participating members (Romagnoli et al., 2014). Additionally, member checking was conducted after the nominal group technique to improve the credibility of the data (Korstjens & Moser, 2018).
Dependability	
Data stability or consistency over time and different conditions (Elo et al., 2014).	**Phase 1** During the scoping review specific keywords and terms were used. Additionally, various electronic platforms were searched that included access to multiple electronic databases (Aromataris & Riitano, 2014). Librarians assisted in streamlining this process and several trial searches were conducted prior to the process of data searches. The search terms used were based on the theoretical classification by Lloyd and Fuller (1986) on linguistic and non-linguistic communication and included dates from 1986 to 2021. **Phase 2** The data from the synchronous online semi-structured interviews was analysed by means of qualitative content analysis. To ensure dependability of the results the researcher and her two supervisors analysed the data and agreement was required between them (Cutcliffe & McKenna, 1999). **Phase 3** During Phase 3 an external audit was conducted by the researcher and her two supervisors on the data collection procedures, data and data management (Korstjens & Moser, 2018). This assisted in improving the dependability of the phase and increased the transparency of research procedures.
Confirmability	
Data objectivity (Elo et al., 2014).	**Phase 1** Member checking was used to reduce researcher bias and increase researcher reflexivity (Baxter & Jack, 2008). This assisted in increasing confirmability of findings (Harper & Cole, 2012). During the data collection procedures researcher reflexivity was also promoted through field notes and record-keeping (Anney, 2014). **Phase 2** Researcher reflexivity assisted in enhancing confirmability of data (Anney, 2014). This was achieved through field notes and peer debriefing with fellow PhD students, the researcher's colleagues and supervisors. **Phase 3** To address this aspect the focus was placed on researcher reflexivity. Researcher bias was reduced by means of weekly supervisory meetings (Forero et al., 2018).

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Definition	Applicability to the Study
Transferability	
Potential for extrapolation to other settings is identified (Elo et al., 2014)	**Phase 1** Transferability was enhanced through purposive sampling (Anney, 2014). This allowed the researcher to identify participants based on specific selection criteria (Campbell et al., 2020). These participants were communication partners caring for persons in an MCS+. **Phase 2** Purposive sampling was used to assist in recruiting and sampling participants knowledgeable in neurorehabilitation (Anney, 2014). The participants for this phase consisted of clinicians with a special interest in neurorehabilitation. **Phase 3** Purposive sampling and data saturation was used during this phase to improve transferability (Forero et al., 2018). Theoretical saturation was achieved by means of weekly meetings where progress of coding and identification of variations in each of the key concepts were reported and discussed (Forero et al., 2018; Nowell et al., 2017).

3.6. Phase 1: Exploratory Phase

As highlighted in Figure 3.1, the focus of this chapter is on Phase 1 and hence addresses the first two sub-aims of the study. This phase included two separate data sources, each with a unique methodology. The first two data sources have both been published (Kuyler et al., 2022a; Kuyler et al., 2022b), while the third manuscript is currently under review. After describing the aims of Phase 1 the two manuscripts are described separately, each ending with a conclusion. Finally, this chapter concludes by highlighting the implications of this phase for the next phase.

3.6.1. Main aim of Phase 1

The main aim of Phase 1 is to explore the evidence on communication behaviours displayed by persons in an MCS+ as well as the multimodal communication strategies utilised by communication partners.

3.6.2. Sub-aims of Phase 1

In order to address the main aim for Phase 1, the following three sub-aims were formulated:

i) To explore the evidence on communication behaviours displayed by persons in an MCS+ as described in the extant published literature (Step 1.1);

ii) To describe the multimodal communication strategies used by communication partners of persons in an MCS+ (Step 1.2);

iii) To identify the support needs of communication partners caring for persons with MCS+ by means of synchronous online semi-structured interviews (Step 1.3).

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3.7. Research design of Phase 1

A qualitative research design is employed in Phase 1, which assists in defining the population of interest, namely the communication partners of persons in an MCS+ (Hesse-Biber & Burke Johnson, 2015). To bolster this in-depth understanding of persons in an MCS+' communication behaviours as well as communication functions addressed by these behaviours, a scoping review was conducted. Thereafter, to gain an in-depth understanding of the lived experienced of communication partners of persons in an MCS+, synchronous online semi-structured interviews were conducted. These types of interviews allow for rich narrative descriptions and improve sensitivity to the context while also being flexible to the participant (e.g., in terms of response pace) (Creswell & Creswell, 2018; Josselson, 2013; McMillan & Schumacher, 2014; Silverman, 2013). It also allows the data to be collected in a natural setting which increases communication partners' comfort to relay their unique personal perspectives (Carlander et al., 2011; McMillan & Schumacher, 2014). One possible disadvantage of this method is that not all participants are equally articulate when sharing experiences but with probing questions this can be addressed (McMillan & Schumacher, 2014).

3.8. Scoping review (Step 1.1)

Even though various conditions may result in persons being in an MCS+ as explained in chapter 2, this scoping review only focused on CVA as it provided a more homogenous population and stronger premise for the review. If a broader perspective was used to achieve the same aim the findings may be more scattered which may lead to less cohesive data. The following information was adapted from an excerpt of the published journal article "Unaided communication behaviours of persons displayed by adults with cerebrovascular accidents (CVA) and little or no functional speech: A scoping review" (Kuyler et al., 2022b). Permission was obtained from the publisher to include this paper as part of my PhD study (Appendix D). Please see Appendix E for the published article.

3.8.1. Aim

The aim of the scoping review was to identify the range of different unaided communication behaviours used by adults with CVA and little or no functional speech, as well as the function of these behaviours. This knowledge can be used when communication partners are trained to be sensitive and to observe subtle unaided forms of communication used by this often-neglected group of individuals.

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3.8.2. Rationale

Unaided communication behaviours displayed by adults with CVA are typically subtle, and therefore communication partners need to know which unaided strategies are used as communication attempts, as well as what their function is (in other words, what the person aims to achieve with the communication) (Fleischer et al., 2009). Unfortunately, in cases where the communication partners are untrained or not familiar with the affected person, these subtle communication attempts can easily be ignored, misinterpreted, or judged as incomprehensible (Ellis & Astell 2017, Radtke et al., 2011). Therefore, if communication partners are trained to identify these behaviours it may improve overall person-partner communication and decrease negative behaviours of communication partners (O'Rourke et al., 2018).

3.8.3. Method

This section includes a summary of the method followed to complete the scoping review. To address the aim of the scoping review and identify relevant literature the following relevant interfaces such as Ebscohost, Scopus, Proquest and Cochrane were used, through which databases such as Medline, CINAHL, Pubmed, Psycharticles, Academic Search Complete, Health Source: Nursing/Academic Edition, Taylor and Francis, and Psychinfo were searched individually by using the identified keywords (Khalil et al., 2016) (Appendix E). Keywords included general AAC nomenclature obtained from the AAC profile code set (Rowland et al., 2011) and the AAC symbol taxonomy classification (Lloyd & Fuller 1986). The searches were guided by the following selection criteria: Only studies published in English were included, the population of the studies had to focus on human participants who are 18 years and older (adults), the publication date of studies ranged from 1986 to 2020, various types of publications (i.e., grey literature) with different methodologies (quantitative, qualitative and mixed methods) were included.

During the initial interface and database search, 732 studies and 10 additional searches were identified as shown in the PRISMA diagram (Appendix E) (Blanco et al. 2019). After the removal of duplicates, 531 studies remained from which 438 studies were excluded on title level. These studies were excluded as they did not focus on the topic of the review and resulted in 93 studies being reviewed on abstract level. After reviewing these studies, a total number of 18 studies were included for full-text screening. More information on the inclusion and exclusion can be obtained in the published manuscript. Three authors performed the screening of the studies during the various stages of the review to ensure procedural consistency and to

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improve inter-rater agreement (Graham et al., 2012). A data extraction tool was developed to assist the authors in compiling consistent and independent data reports. The data from the 18 articles were extracted independently by the different authors and when consensus was reached, transferred to an Excel spreadsheet.

3.8.4. Findings

Thematic analysis was used to analyse the data, as this process allows for the systematic and insightful identification and organisation of data into themes to address the aim of the research (Nowell et al., 2017). A summary of the demographic characteristics of the various studies are included in Appendix E. The following findings were obtained based on the thematic analysis:

3.8.4.1. Population: Communication partners

In 61% (n=11) of the 18 studies included in this review, communication partners were often HCPs who researched the target population. These HCPs included SLTs, OTs, PTs, nurses, psychologists, or medical specialists who conducted the data collection procedures. Trained communication partners who acted as communication partners were included in three studies (e.g., nurses, SLTs, students and others) and only four studies focused on untrained communication partners (e.g., family members, friends, or life partners).

3.8.4.2. Unaided communication behaviours

An illustration of unaided communication behaviours displayed by adults with CVA and little or no functional speech ranging on a continuum from non-linguistic to linguistic, is demonstrated in Figure 3.2. To guide further analysis of these identified unaided communication behaviours, the seven levels of communication depicted in the Communication Matrix of Rowland (2011) were used as reference. Table 3.2 describes the various types of unaided communication behaviours as well as the meaning of these behaviours. Most of the unaided communication behaviours identified consisted of gestures (n=15) and included facial expressions (n=7), reflexive behaviours (n=4), eye movement (n=4) and vocalisations (n=4).

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Figure 3.2

Continuum of unaided communication behaviours

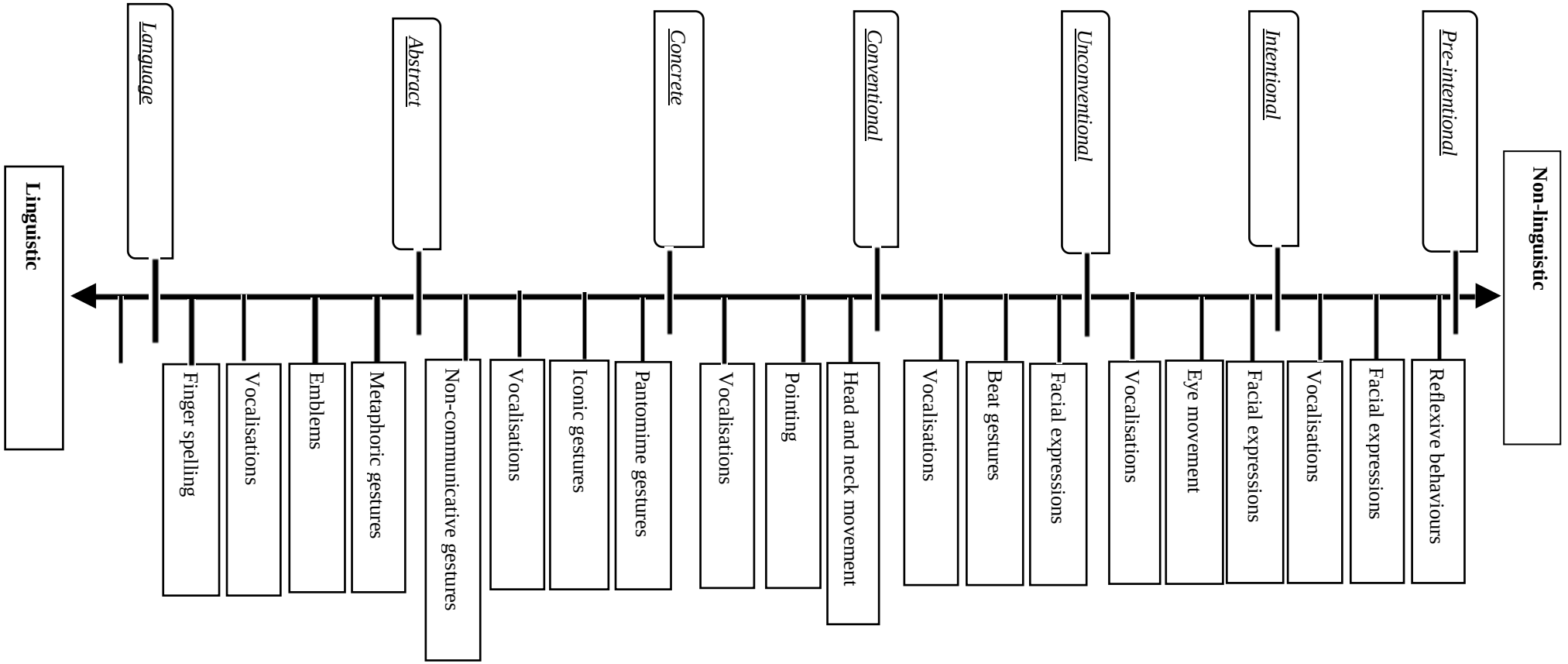

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Table 3.2

Types of unaided communication behaviours

Type of Unaided Communication Behaviour	Meaning	Characteristics or Examples	Studies
Non-linguistic unaided communication			
Eye movements	Using eye movement to communicate.	Eye blinking; eye gaze; prolonged eye closure; referential gaze to person's face, object or elsewhere; weeping eyes; closing eyes tightly; opening/slight opening of eyes; visual pursuit; gaze withdrawn; gaze returned	4, 10, 14, 16
Facial expressions	Using the face to communicate/ to indicate a thought or an emotion.	*Positive* – smile; blowing a kiss; winking; lip puckering *Neutral* – eyebrow raise, posed or spontaneous; licking lips; scratching chin; scratching nose; relaxed face; open mouth; chewing; finger in mouth; chewing thumb *Negative* – crying; frowning; levator contraction or cheek tightening; poking out tongue; not opening mouth for feeding; biting lower lip; clenching teeth; wincing; grimacing	1, 10, 12, 13, 14, 15, 18
Gestures			
Head and neck movement	Moving the head and neck to communicate.	Nodding head; shaking head; lifting head of bed; slow turn; moving head side to side; rubbing head on bed; turning head to one side (left or right)	2, 3, 4, 5, 6, 7, 8, 9, 11, 12, 14, 15, 16, 17, 18
Pantomime gestures (miming)	Actions of a complex concrete, sequential nature that are used to describe a construct and can be interpretated in isolation – substituting verbal utterances. These gestures include body parts that can be used as objects.	Walking that refers to forward movement of hand with alternating extension and flexion of index and middle finger Drawing a vertical rectangle to indicate air or holding an imaginary remote	
Metaphoric gesture	Presenting an image of an abstract concept, such as knowledge or justice.	Two fists bouncing against each other can refer to "clashing arguments" in a heated discussion Tilting the horizontal hand from side to side to indicate equivocation	
Pointing – Deictic	Pointing to self, a location on the body or pointing to a referent in physical environment.	Pointing to referents, to their arm or to something on the table	
Pointing – Referential gesture	Assigning an entity of referents, such as objects, places or characters in the story.	Pointing to distant referents, for instance, to the wall to indicate the neighbours or something outside Pointing to abstract referents, for instance to the sky to refer to "heaven"	
Beat gestures	Movements that do not present a discernible meaning are recognised by prototypical repetitive movements and following speech intonation patterns.	Touching nose during conversation	

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Type of Unaided Communication Behaviour		Meaning	Characteristics or Examples	Studies
Emblem gestures		Hand movements that go simultaneously with the rhythm of speech, used for emphasis and to accentuate syllables or words.	Thumbs-up gesture in the Dutch and English culture Thumb and pointer finger making a circle shape for "OK"	
Non-communicative gestures		These gestures do not indicate communication intent but the motor execution of activities.	Fidgeting: repetitive movements involving self-touch but not grooming of body Grooming: grooming the body and changing the body's position	
Reflexive behaviour		These behaviours are automatic and reflexive motor movements of the body.	Muscle tension or compliance; rising temperature; sweating; heartbeat; heart rate; flexing and deflating muscles; absence of movement; restlessness; flexion;, flushing; tactile and olfactory response; opening mouth;, removes feeding tube; squeezing hand; shrugging shoulders; shaking body; leaning forward; clasping/shaking hands; leaning on partner; feeling collar; slow cautious movement; repetitive movement; attempting to reach pain site; touching pain site; guarding oneself from the communication partner; massaging pain site; pulling tube; defensive grabbing; cooperative movement; attempting to return to supine; clenching fist; slapping nurse's hand away; rubbing knees	9, 10, 12, 13
Vocalisations		These vocalisations are voiced or voiceless utterances that are not considered as words.	Laughing; yawning; clearing throat; heavy breathing; producing high-pitch sound; growling; clicking tongue; sighing; singing; tutting; moaning; intonation (pitch and prosody); coughing; mouthing (voiceless vocalisation)	9, 12, 13, 18
Linguistic unaided communication				
Gestures				
Iconic gestures (symbolic, meaning-laden, speech focused and codified)		These are hand gestures that have semantic content closely related to speech production. The gestures can be used for word retrieval. They are context specific and support speech production. They are combined with natural speech and cannot be interpreted in isolation.	The iconic gesture of pretending to drink is similar to the real activity of drinking Swinging arms back and forth could indicate running Tracing index finger in the frontal space from left to right to indicate running Imitating the action of throwing a ball Pointing index finger upwards and making a circular movement upwards to indicate going up the stairs Moving lips without producing sound and moving hand back and forth in front of mouth to indicate one cannot speak	2, 5, 9, 10, 11, 12, 13, 14, 15
Finger spelling	Time	Spatial indication to denote a time, such as past or future.	Indicating the past (back of the body) or the future (front of the body)	
	Letter	Movements associated with writing letters.	Writing letters in the air or on the desk/thigh with an empty hand or fingers	
	Number	Using one's fingers to display numbers.	Displaying numbers by showing the fingers	

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3.8.4.3. Communication functions

From the 18 studies included in the review, 31 core communication functions were identified that indicated the purpose or intent of the unaided communication behaviours and these are mentioned in Table 3.3. These 31 communication functions were categorised according to the communication function categories of the Communication Matrix (Rowland, 2011). The communication function categories specified by Rowland (2011) are refusal (declining the options), obtaining (acquiring what is desired), social engagement (engaging in social interaction) and information (providing and seeking information) which are linked to the seven levels of communication (Rowland, 2011).

The first communication level refers to pre-intentional communication which included four core communication functions categorised in three communication function categories – specifically social engagement (n=1), obtain (n=1) and refuse (n=1). Secondly, the intentional behaviour communication level included two communication functions classified according to two communication function categories, namely social engagement (n=1) and obtain (n=1). These two communication functions were mentioned in seven studies and were specifically used to convey affect (i.e., emotions). Communication functions in Level 3 (unconventional communication) focused on expressing wants and needs (n=3), using unaided communication for basic or beginning communication support (n=4) and for comprehending messages (n=3).

Level 4 (conventional communication) included six communication functions categorised according to three communication function categories, namely social engagement (n=3), obtain (n=2) and information (n=1). The conventional communication function mentioned in most of the studies was responding (n=10). Communication function categories included in Level 5 (concrete communication) referred to social engagement (n=1), information (n=3) and obtain (n=2). The second last level (Level 6 – abstract communication) included the information (n=2) and social engagement categories (n=1). Lastly, Level 7 (linguistic communication) was the only level that included all four categories of communication functions – social engagement (n=4), information (n=1), refuse (n=1) and obtain (n=1). The communication function mentioned most in Level 7 was narratives (n=7).

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Table 3.3

Communication functions

Communication Level According to Communication Matrix	Communication Function According to Communication Matrix	Nr	Label	Definition	Studies
Level 1: Pre-intentional behaviour	Social	**1**	Searching behaviour	Searching for a person or object in the environment.	15
	Obtain	**2**	Expressing components related to physical functioning	Communication regarding the physical functioning of the person.	10, 15
	Refuse	**3**	Expressing pain/discomfort	Physiological expression of pain.	10, 13, 15
Level 2: Intentional behaviour	Social	**4**	Drawing attention	Focusing the communication partner's attention on a specific object, person or event.	3
	Obtain	**5**	Expressing affect	This refers to the individual's ability to communicate positive or negative emotions and feelings (e.g., happy, sad, anger, fear)	1, 2, 3, 9, 15, 18
Level 3: Unconventional communication	Obtain	**6**	Comprehending messages (basic)	Understanding the intent of a message produced by a communication partner.	11, 12, 14
		7	Choice making	Conveying personal preferences to the communication partner.	5, 11
		8	Expressing wants and needs (basic)	Expressing wants and needs.	4, 12, 15
		9	Basic or beginning communication support	Using unaided communication to represent basic messages.	4, 5, 12, 15
Level 4: Conventional communication	Social	**10**	Greeting	Following social etiquette rules such as saying "hello" or "goodbye".	1, 3, 15
		11	Engagement in interaction	Attending to the communication partner through active listening and body engagement.	1, 5
		12	Turn taking	Reciprocity of turns with communication partners.	1, 10, 16
	Information	**13**	Functional use of objects	Knowing the function of an object e.g., using a comb.	5, 7, 15
	Obtain	**14**	Requesting information by asking questions	Requiring the communication partner to provide more information.	1, 4, 15
		15	Responding (basic)	This refers to a voluntary response to a communication partner's initiation to communicate.	1, 2, 3, 4, 5, 8, 10, 12, 14, 15
Level 5:	Social	**16**	Imitation	Imitating an action, object or person.	5, 11

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Communication Level According to Communication Matrix	Communication Function According to Communication Matrix	Nr	Label	Definition	Studies
Concrete communication	Information	**17**	Naming	Labelling an object, person or event in the person's environment.	7, 16
		18	Commenting	Providing comments during the conversation.	1
		19	Answering questions	Responding to the communication partner's questions (yes/no or general).	1, 2, 3
	Obtain	**20**	Requesting a turn	When the person with a CVA initiates the interaction or requests to take part in the conversation.	16
		21	Requesting participation	When the person with a CVA is requesting reciprocal interaction from a communication partner.	3, 15, 16
Level 6: Abstract communication	Information	**22**	Providing clarification	Elaborating or providing more information based on the communication partner's request.	1, 4
		23	Describing	Describing an object, event or person to the communication partner.	5
	Social	**24**	Modelling	Demonstrating what is required of the communication partner.	3, 5
Level 7: Linguistic	Information	**25**	Narrative	Telling a story.	1, 2, 3, 6, 11, 14, 17
	Refuse	**26**	Arguing	Debating the point of view of the person with a CVA.	1
	Social	**27**	Leading the conversation	Leading the conversation by discussing topics related to the concerns or interests of the person with a CVA.	3, 16
		28	Observing social etiquette	Using words that are socially appropriate or inappropriate.	1
		29	Termination	When the person with a CVA withdraws from the conversation.	16
		30	Interrupting	The person with a CVA interrupts the conversation to provide their point of view.	1
	Obtain	**31**	Conversational pause	The speaker takes a rest, hesitates, or temporarily stops.	16

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3.8.5. Discussion

From the review it became apparent that limited studies focused on the untrained communication partners of persons with CVA and little or no functional speech (e.g., family members, life partners or friends). This is concerning as Aloweni et al. (2019) mention that the number of life partners that act as primary communication partners are increasing and they typically spend more than 52 hours a week on their caregiving responsibilities. Life partners often take on the primary caregiving role more than other types of untrained communication partners such as domestic workers and trained communication partners (e.g., HCPs such as nurses or care aids) (Aloweni et al., 2019). The caregiving responsibilities of untrained communication partners frequently increase upon discharge of the person resulting in caregiving becoming burdensome due to various financial, psychosocial and personal difficulties (Zylberman et al., 2016). Due to the increasing number of responsibilities related to care it is therefore understandable that subtle communication attempts of persons with CVA are misinterpreted or overlooked (Ellis & Astell, 2017).

If communication partners overlook or misinterpret persons with CVAs' subtle communication such as unaided communication behaviours this often leads to ineffective person-partner communication. Conway and Chenery (2016) as well as Egan et al. (2010) mention that ineffective person-partner communication is one of the major stressors for communication partners as they may want to communicate with the person with a CVA but do not know how to address their unique needs. These communication partners also expect the persons with CVAs' functional verbal communication to return within the first seven weeks after the incident (Martens et al., 2020). However, due to the severity of the persons' injuries these communication difficulties may persist (Baylor et al., 2018). When communication challenges persist, both the communication partner and a person with a CVA experience various communication breakdowns that may result in both partners having difficulty to mutually engage in communication.

To remediate communication breakdowns and reduce the misinterpretation or overlooking of subtle communication attempts, both the communication partner and person require skills, knowledge and judgement to communicate within a restrictive environment (Beukelman & Mirenda, 2013; Light & McNaughton, 2014; Midtlin et al., 2015). Training communication partners to identify these subtle communication attempts should not focus on only the well-known unaided communication behaviours such as eye movements (Fager et al.,

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2012), facial expressions (Blonder et al., 1993) and gestures (for instance sign language), but also less common unaided communication behaviours identified through the scoping review such as reflexive behaviour. Increasing communication partner knowledge on both well-known and unknown unaided communication behaviours is important as these behaviours occur on a continuum. This continuum addresses unaided communication behaviours that occur at various stages of recovery after the incident (such as eye movement indicating waking up from a coma) and persons with CVA often still access a range of unaided communication behaviours even after verbal expression is regained (Bareham et al., 2019; Rasmus et al., 2019).

Furthermore, not only is it important to train communication partners on identifying unaided communication behaviours displayed by persons with CVA but also on the intent and motivation of the behaviour. This intent and motivation of unaided communication behaviour include accessing a range of communication functions and partners should be alerted to this. Unaided communication is often ambiguous and complex as behaviour is not randomly occurring and is always purposeful (Holt et al., 2012, Lin et al., 2010, Rasmus et al., 2019). The interpretation of these behaviours is therefore also complex and cannot rely solely on the personal perspective, knowledge and beliefs of communication partners but requires attention, motivation and time to occur accurately and effortlessly (Lin et al., 2010). Training communication partners of persons with CVA is therefore of cardinal importance as it may influence partner expectations and thoughts and may also bring about positive partner behaviour modification (Holt et al., 2012).

Training communication partners on unaided communication behaviours and the communication functions addressed by these behaviours may improve partner knowledge of communication strategies which in turn facilitates building of mutual trust and the creation of reciprocal understanding during person-partner communication (Watson et al., 2012). This may benefit both the person with a CVA as well as the communication partner as both partners may experience enhanced perceptions of personhood and quality of life (Watson et al., 2012). Furthermore, persons with CVA may experience greater success during interaction with a trained partner, which may lead to increased communication autonomy, engagement and quality of interaction. This may ultimately also have a positive impact on the quality of life of both partners. This concludes the excerpt of the published article entitled “Unaided communication behaviours displayed by adults with CVA and little or no functional speech – A scoping review (Kuyler et al., 2022b).

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3.8.6. Conclusion of Step 1.1

This scoping review emphasised the importance of the identification of unaided communication behaviours displayed by persons with CVAs as well as the communication functions addressed by these behaviours. The initial search of literature during the scoping review, revealed limited published data on communication in disorders of consciousness focusing on behaviour responses. The scoping review included a broader review of the aetiologies of disorders of consciousness such as TBI, CVA and neurodegenerative diseases such as Alzheimer's disease (Royal College of Physicians, 2013). However, most literature during this initial search included a specific focus on unaided communication behaviour in persons with CVA. This resulted in the selection of persons with a CVA for the scoping review.

Since unaided communication behaviours displayed by persons in an MCS+, irrespective of their specific diagnosis, are typically subtle and therefore easily overlooked or misinterpreted, training of communication partners can be seen as an appropriate strategy to improve the quality of interaction in the person-partner dyad and ultimately the quality of life of persons in an MCS+. This review also showed that unaided communication strategies were used to target a wide range of communication functions – from indicating an initial awareness and alertness to being an active participant in communication. For interactions to be effective or successful, both paid and unpaid communication partners should be empowered to actively participate in interaction. The training of partners should empower them to observe, interpret and reinforce all communication behaviours (including unaided communication) to elicit a range of communication functions. The range of unaided communication behaviours includes physiologic responses on the one end of the spectrum and progresses to the acquisition of more complex communication with linguistic attributes such as manual gestures (e.g., sign language).

Step 1.1 in Phase 1 of this study aimed to identify the unaided communication behaviours that would be possible for persons in an MCS+, by focusing on persons with CVA, as well as communication functions addressed by these behaviours from literature published between 1986 to 2020. This knowledge will be used to inform the identification and adaptation of the CPT programme for communication partners of persons in an MCS+. Knowledge of these identified unaided communication behaviours used by persons in an MCS+ could provide communication partners with new information and suggest alternative possibilities for facilitating communication with persons in an MCS+. Furthermore, it may reduce negative

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communication partner behaviours that prevent effective person-partner communication. Identifying these specific unaided communication behaviours will thus assist in early communication intervention for persons in an MCS+ and their communication partners. As Step 1.1 focused on the communication behaviours of persons in an MCS+, the next step will attempt to explore the communication strategies and support needs of communication partners who care for persons in an MCS+.

3.9. Synchronous online interviews with communication partners (Step 1.2-1.3)

The data source for this section comprises synchronous online semi-structured interviews with communication partners of persons in an MCS+. The findings were separated into two steps, due to their respective focus. Step 1.2 focused on the multimodal communication strategies utilised by communication partners of persons in an MCS+ while Step 1.3 focused on the support needs of communication partners who care for persons in an MCS+. Although, the participant sample, participant demographics and data collection procedures for Step 1.2 and Step 1.3 are thus the same, their aims and findings differ substantially.

Step 1.2: Identification of multimodal communication used by communication partner

The following information was adapted from an excerpt of the published manuscript entitled "Multimodal communication displayed by familiar communication partners to build communication capacity in persons in an MCS+" (Kuyler et al., 2022a). Appendix F includes the copyright agreement with the editor of the journal. Provisional approval to use this manuscript in the study was obtained through the copyright agreement. Please see Appendix G for the published manuscript.

3.9.1. Aim

The aim of the synchronous online semi-structured interviews with communication partners of persons with MCS+ was to obtain information on the multimodal communication strategies that they currently use when communicating with persons in an MCS+, their perspectives of unaided communication behaviour displayed by persons with MCS+ and the communication partners' perceived communication functions of persons with MCS+. This information will enable data crystallisation by integrating data from the two different steps (i.e., the scoping review and synchronous online semi-structured interviews) conducted in Phase 1 to inform the adaptation of the CPT programme.

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3.9.2. Rationale

Persons in an MCS+ experience fluctuating levels of alertness and awareness which impact their person-partner communication (Zhang et al., 2020). Fluctuating levels of alertness and awareness may entail intentional sustained eye contact and behavioural reflexes during periods of wakefulness but increase difficulty for communication partners to establish functional communication (Gui et al., 2020). This may be as communication partners have limited knowledge of behavioural reflexes and often misunderstand these persons' intent to communicate (Ellis & Astell, 2017). Communication partners also misinterpret or miss these behaviours due to their lack of skills during identification of behavioural responses (Day & Anderson, 2011; Overall & McNulty, 2017). Social stimulation and companionship may alleviate this difficulty for communication partners as it may create opportunities for communication during activities of daily living (Andréasson et al., 2018; Ellis & Astell, 2017). Therefore, if communication partners are sensitised and trained to identify and elicit cues to reinforce interaction, a supportive environment can be created (Bruno et al., 2011; Henriques et al., 2016; Kondziella et al., 2020; Thibaut, Schiff, et al., 2019). Creating a supportive environment is important as communication partners can use natural language stimulation which the person in an MCS+ is familiar with (Gui et al., 2020; Lancioni et al., 2017). The aim of the synchronous online semi-structured interviews was to utilise communication partner self-reports to identify the familiar and natural language stimulation that communication partners of persons in an MCS+ use. These interviews are of cardinal importance for the adaptation of the CPT programme (in Phase 2) as essential information from the communication partners' perspectives will be included for optimal engagement of the person in an MCS+ and effective reinforcement of unaided communication strategies.

3.9.3. Method

A qualitative design was used employing in-depth, semi-structured interviews to address the aims of Phase 1. This design allowed flexibility for participants to portray their perspectives on aspects which they value (Creswell & Creswell, 2018). Conducting these type of interviews results in participants feeling that their voices were heard, which increased their sense of empowerment as the participants were regarded as the experts (Creswell & Creswell, 2018). The Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist was used to guide the reporting of the manuscript methodology (Tong et al., 2007).

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3.9.4. Participants

3.9.4.1. Recruitment and selection

Prior to the commencement of data collection, ethics approval was obtained from the research ethics committee of the Faculty of Humanities at the University of Pretoria (Appendix A). Thereafter, the practice manager of the private practice where participants were recruited, was contacted by the researcher, telephonically to request participation in the phase (Appendix B). Written permission was obtained from the practice manager, who also identified a nurse who recruited participants for the phase, based on the specific selection criteria. This nurse also informed potential participants of the nature of the research and obtained consent to provide the researcher with their contact details (Appendix C1–C3). Once written consent was gained, a time and date convenient to the participants was selected to conduct the interview (Janghorban et al., 2014).

3.9.4.2. Sampling

Purposive sampling was used to recruit participants from a private practice in Gauteng, South Africa where persons in an MCS+ with diverse acquired neurological conditions are treated. These conditions included a diagnosis of Dementia, severe TBI or severe CVA. Specific selection criteria were used to identify potential participants (Creswell & Creswell, 2018). All communication partners had to: (1) be/have been actively involved in the care of the person who is/was minimally conscious for at least two months; (2) be older than 18 years themselves; (3) (have) fulfil(led) their caring role for at least two consecutive hours a day; and (4) be literate and proficient in English. Furthermore, a criterion was set that the person with the acquired neurological condition should have been in an MCS+ for at least two to six months prior to the interview. Communication partners of both living and deceased persons who are or were minimally conscious were included in this manuscript. This allowed the participants to self-reflect on the process, accessing their extensive knowledge and skills as well as give valuable advice to other communication partners in similar situations, while not having the time pressure of still actively participating in caregiving activities. Table 3.4 includes the participant demographic information. Please note participants are numbered according to the step. (e.g., P1.2.1)

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Table 3.4

Demographic information of participants (N=7)

Communication partner								Person in an MCS+			
Participant Nr	**Age in Years**	**Sex**	**Relationship to Person**	**Home Language**	**Additional Language**	**Qualification**	**Duration of Care (hours per day) Received**	**Age in Years**	**Sex**	**Reason for MCS+**	**Duration of MCS+**
P1.2.1	63	F	Wife	E	A	Diploma	2	66	M	Abscesses on the brain	7,7 years
P1.2.2*	40	F	Daughter	E	A	Master's degree	2	69	F	CVA	2 years
P1.2.3	62	F	Mother	E	A	Diploma	24	31	M	TBI	5 years
P1.2.4*	54	F	Daughter	A	E	Diploma	2	80	M	Alzheimer's Disease	6 months
P1.2.5*	57	F	Daughter	E	A	Diploma	2	76	F	Alzheimer's Disease	4,5 years
P1.2.6*	54	F	Daughter	A	E	Diploma	2	83	M	Alzheimer's Disease	71 days
P1.2.7	45	F	Wife	A	E	Bachelor's Degree	24	41	M	TBI	1 year

Note Abbreviations. F=Female; E=English; A=Afrikaans; TBI=Traumatic Brain Injury; CVA=Cerebrovascular Accident. *Indicates that person who was minimally conscious was deceased

3.9.5. Materials

3.9.5.1. Letter of informed consent and biographical questionnaire

A biographical questionnaire (Appendix C3) was developed to obtain descriptive information from the participants. The descriptive information includes participant demographics such as ethnicity, gender, age, marital status, home language, qualification, years of service or title. Information regarding the incident, medication, discharge date, therapy and duration of the person with MCS+ was also obtained. This information assisted in determining whether participants met the selection criteria for the phase (Sargeant, 2012). Table 3.5 includes the theoretical justification for the questions in the biographical questionnaire.

Additionally, a permission letter was given to the practice manager, stating the aim, rationale and expectations of the practice (Appendix B). Each participant received a letter of informed consent stating the aim, rationale, individual expectations as well as ethical considerations (Appendix C1-C2).

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Table 3.5

Theoretical justification of biographical questionnaire for communication partners

Communication Partner Information		Person in an MCS+ due to a CVA	
Background information	**Theoretical justification of questions**	**Background information**	**Theoretical justification of questions**
How old are you?	Adults are classified as persons who are 18 years and older (Carlander et al., 2011). This study will focus on adult communication partners of persons within an MCS+.	**How old is he/she?**	Acquired neurological conditions such as TBI, CVA or neurodegenerative disorders often effect the adult population (18 years and older) (Beukelman & Light, 2020).
What is your gender?	Communication partners are often spouses or relatives of person with CVA (Aloweni et al., 2019). Spouses (e.g., wife or husband) or relatives (e.g., daughter, son or cousin) consist of different genders (Carlander et al., 2011). Xiong et al. (2020) mention that there are sex and gender differences in the perceived burden of care of communication partners.	**What is his/her gender?**	CVA effect both genders. Different variables unique to each gender effect therapeutic outcomes (Munivenkatappa et al., 2016).
What is your first language? What other languages do you speak?	The South African context consists of multiple languages but English proficiency is required of participants as this will be the medium of communication (Masuku et al., 2018).	**What is his/her first language?**	The person needs to understand either English or the first language of the communication partner as the communication partners may provide naturalistic and familiar language stimulation in their first language as the person may attend better (Gui et al., 2020; Ijalba, 2015).
What is your highest education level?	The interviewee's will expected to make an informed decision whether to indicate participation in this study for which they require the capacity to perform decision-making (Masuku et al., 2018; Salmons, 2015).	**What is the person's highest level of qualification?**	It is important to know the literacy level of the person as it will determine the type of symbol used in intervention. Persons in an MCS+ often retain their reading comprehension skills (Kwiatkowska et al., 2019).
What is your employment status? What is your occupation?	Due to caregiving responsibilities communication partners are often only able to work part time or are full time communication partners of persons in an MCS+ (Aloweni et al., 2019; Carlander et al., 2011). This question focuses on whether they are unemployed, employed part-time/full-time. The communication partners should state their occupation as some individuals do not work in the area in which they obtained a qualification.	**What was their occupation?**	After the incident persons with CVA are unable to return to work due to the severity of their injuries. This could place a socioeconomic burden on communication partners (Glader et al., 2017). However, this information may aid in determining a sense of personhood for the person in an MCS+.
How do you know the person in an MCS+?	Communication partners of persons with CVA are often spouses or relatives but can include trained carers such as HCPs as well	**Incident information**	

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Communication Partner Information		Person in an MCS+ due to a CVA	
	(Aloweni et al., 2019; Andréasson et al., 2018; Carlander et al., 2011).	**What happened to the person or what caused the incident?**	MCS+ can have multiple causes such as CVA, TBI, diffuse brain dysfunction due to drugs, metabolic disorders, severe hypoglycaemia and advanced stages of dementia and other neurodegenerative disorders (Cooksley et al., 2018; Wilson et al., 2016). However, the focus of this study will be on persons who experienced a TBI.
How many hours a day do you take care of the person? **How long have you been caring for the person in an MCS+?**	Communication partners often spend more than 52 hours a week on caregiving responsibilities (Aloweni et al., 2019). The duration of caregiving can range from short periods to over 40 years (Anhange et al., 2016).	**When did this happen? How long was the person in the hospital? When was the person discharged?**	Information regarding the duration of the impairment as well as whether the condition is transient, chronic or stable is important as it will in identifying the severity of the injury (Seel et al., 2013).
Are you the only person providing care for the person in an MCS+? **If no, who else takes care of the person in an MCS+?**	If communication partners need to financially support the family, other untrained communication partners (e.g., domestic worker or relative) or trained communication partners (e.g., HCP) take on some of the caregiving responsibilities (Berglund et al., 2015).	**When was the person diagnosed as being in an MCS+?** **How long has the person been in an MCS+?**	Differential diagnoses between the MCS+ and unresponsive wakefulness syndrome forms part of the selection criteria for this study. Knowledge of the duration of the MCS+ will assist in determining whether person can be classified as having a persistent disorder of consciousness (Schnakers & Majerus, 2012).
Training information		**Therapeutic information** **What type of medication is the person currently taking?**	Medication can affect the level of awareness and alertness of the person in an MCS+ which will influence therapeutic outcomes (Noormandi et al., 2017).
Do you feel that you have received enough information from HCPs to help with caregiving?	Most communication partners do not receive sufficient training to care for person in an MCS+ and if they receive training it is often not sustained as the training is not founded on their needs (Godwin et al., 2013).	**How do you know the person is awake and not sleeping?**	Due to the fluctuating levels of awareness and alertness it is important to identify whether the person in an MCS+ is asleep or awake as this will determine the best time of day for intervention to occur (Wielek et al., 2018).
If no, what information do you need?		**Is the person currently receiving therapy?**	For early intervention to occur person in an MCS+ require therapy (Seel et al., 2013).
Have you received training to care for the person in an MCS+?	Most communication partners of the person in an MCS+ are untrained and therefore require support (Caddell & Clare, 2011).	**What therapy does the person receive?**	Various HCP often give multi-disciplinary therapy to person in an MCS+ (Seel et al., 2013).

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Communication Partner Information		Person in an MCS+ due to a CVA	
If yes, what type of training have you received?		**Does the person receive individual or group therapy?**	The person in an MCS+ often receives individual therapy as these individuals are unique and do not respond differently to the same intervention (Li et al., 2020).
Who provided the training?	Training is often facilitated by HCP (Kuyler et al., 2022a). Facilitators can also include trained communication partners	**State the frequency of therapy that the person receives?**	The person in an MCS+ often receives frequent therapy as it is recommended that behavioural assessment to determine level of consciousness should occur multiple times daily for a period of at least two weeks (Wannez, Heine, et al., 2017).
Did you feel that the training was helpful?	Communication partners often report that they receive limited formal training from HCP to provide care for persons with CVA (Jeyathevan et al., 2020).	**How long has the person been receiving therapy?**	Due to the severity of the motor, cognitive and linguistic challenges of persons in an MCS+ often require long-term care (Seel et al., 2013).
If you need more training or have not received training, what would you like the training to include?	Communication partners report that when they receive training they were not given the opportunity to practically apply these skills and therefore still required support even after training (Jeyathevan et al., 2020).		

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3.9.5.2. Synchronous online script development

An interview script (Table 3.6) was developed based on information obtained from an earlier scoping review that focused on the communication strategies used by persons with CVA with little to no functional speech (Kuyler et al., 2022b). Both open- and closed-ended content-driven questions were used to obtain answers of a factual nature, but also include the participant's opinions, beliefs and judgements (Creswell & Creswell, 2018). Probing techniques as well as recasting questions were used to obtain additional information or to accommodate for the misunderstanding of questions (Josselson, 2013).

Table 3.6

Question selection and rationale for synchronous online interview script development

Nr	Information Type	Description	Theoretical Justification
Introduction (10 minutes)			
1	Personal narrative	As explained in the consent letter, my name is Ariné and I am currently conducting my PhD study, which is focused on training communication partners to identify unaided communication behaviours of a person in an MCS+ and to improve the duration of communication partner conversational turns.	The welcome and introduction are important as this creates the appropriate atmosphere and provides the tone of the discussion (Krueger & Casey, 2002). Appropriate introductions also allow engagement from the participants as it establishes an interviewer-interviewee relationship which is important for the portrayal of personal experiences (Josselson, 2013).
2	Procedural narrative	I will be referring to my notes to make sure that I remember to ask all my participants the same questions!	If the same procedure is followed with the participants, the validity of the data obtained will be increased (Gregory & Radivinksy, 2012).
3	Procedural narrative	The interview might take up to 90 minutes. If you need a break, please tell me as I would like to accommodate you.	Communication partners have many other responsibilities related to their daily routine and may require a break (Giovannetti et al., 2013). Informing communication partner on the duration of the interview also allows them to anticipate their commitments (Salmons, 2015).
4	Procedural narrative	Thank you for your willingness to share your experiences with me. This will help me to adapt a training programme for other communication partners with similar experiences.	By explaining the aim of the study, the researcher will monitor the understanding of the participant and attempt to set the participant at ease throughout the interview (Josselson, 2013).
5	Sequential narrative	I will now ask you some questions regarding your experience communicating with the person in an MCS+. And at the end we will conclude with your reflection on the interview process and then we can also add any other aspects that you might feel are important for me to understand.	Informing communication partners of the procedures may improve the type of information obtained and communication partners may be more at ease to share their lived experiences, as their knowledge and understanding is grounded in their experience (Birt et al., 2016).
6	Procedural narrative	You already completed the informed consent letter, but I want to remind you that I will be audio-recording our interview. Only I will listen to the recording and I will use it to identify aspects that you regarded as important and to provide feedback for you.	Reminding participants of informed consent and audio-recordings allows them to apply autonomy during data and that they have human rights (Salmons, 2015).
7	Procedural narrative	At times I might ask you to elaborate or clarify some information. Are you ready? Let's get started!!	Follow-up questions will be made to fact-check information from the biographical questionnaire and to ensure the researcher obtains additional information not included through communication partner completion of the forms (De Fina & Georgakopoulou, 2015). Verbal probing techniques

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Nr	Information Type	Description	Theoretical Justification
			will be used to obtain the information (Examples of probing techniques are in the question section).
Questions (30-60 minutes)			
8	Open-ended question	Can you tell me more about your experience caring for the person in an MCS+?	The opening question is meant to direct the participants attention and facilitate narration of their experience (Josselson, 2013). Caring for persons in an MCS+ often has a physical (e.g., health), psychological, social and financial impact on the communication partner (Covelli et al., 2016; Magnani et al., 2020; Zylberman et al., 2016). The act of caring for the person in an MCS+ is often a full-time job and the communication partner often has to quit their job or work part-time (Aloweni et al., 2019). Anhange et al. (2016) suggest that communication partner experiences are not only negative as they also experience positive feelings when providing care for persons in an MCS+.
9	Closed-ended question	Did you receive adequate support and information to assist you in adjusting to your new role as communication partner? **Follow-up question:** • Who provided support to you (e.g., a family member or HCP)?	Various reasons can result in communication partners taking on the role of caring such as feeling obligated due to social norms, ties of affection, commitment or altruism (Silva et al., 2013). These communication partners are often unprepared and require support and information to adjust to take on their new identity as carer (Andréasson et al., 2018; Silva et al., 2013).
10	Open-ended question	Please explain whether you think the person in an MCS+ can or cannot communicate? **Follow-up question:** • How do you know the person is or is not communicating with you? • How do you respond to this? • What do you think the person is trying to tell you? • Why do you think it is necessary or unnecessary to communicate with the person in an MCS+? • If you should receive CPT what should the training include?	Verbal responses are the main focus for communication partners as the perception exists that verbal responses are the only way to emotionally connect with people (Ellis & Astell, 2017). They therefore often miss subtle communication attempts of patients. Conway and Chenery (2016) mention that not being able to effectively communicate with persons with CVA is a major stressor for communication partners. Communication partners often require training to improve their knowledge and skills when communicating with persons with CVA (Day & Anderson, 2011; Overall & McNulty, 2017).
11	Closed-ended question	Do you think the person responds to any activity from the environment? **Follow-up question:** • What type of activity does the person respond to best? • How do they respond during this activity? • How do you respond when the persons do this?	Person who are minimally conscious often respond best to environmental stimulation that is familiar (Lancioni, Singh, et al., 2017).
12	Closed-ended question	When is the person the most awake and alert during the day?	Identifying the time of day and position in which the patient is most responsive will assist in promoting patient engagement in intervention and increasing responses (Chatelle et al., 2016; Wannez, Heine, et al., 2017).
13	Open-ended question	In what position do you think is the person the most responsive (e.g., sitting up or lying down?	
Final thoughts and self-reflection (10 minutes)			

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Nr	Information Type	Description	Theoretical Justification
14	Procedural narrative	The interview is ending, please answer some final questions on your experience of this interview (these questions are related to the **PILOT** study)	
15	Open-ended question	Is there anything else that you would like to add?	A cognitive interview will be conducted to conclude the interview to obtain feedback regarding the applicability and relevancy of questions included in the interview, as well as the communication partner's experiences of being interviewed (Lee, 2014).
16	Open-ended questions	How did you experience this interview?	
17	Open-ended question	Please comment on the questions asked (e.g., language and phrasing)?	
18	Open-and closed-ended questions	**Follow-up questions:** • What changes would you recommend regarding the type of questions asked? • What changes would you suggest for the procedures of the interview? • What other changes would you recommend ensuring that other communication partners have a positive experience of being interviewed? • Do you have any additional comments?	
Closing (5 minutes)			
19	Procedural narrative	Thank you for participating in this interview, I appreciate your time and that you shared your experiences so freely with me.	Showing appreciation to the participant signals the closure of the interview and the return to daily activities (Salmons, 2015).
20	Procedural narrative	I will summarise all the information that you so kindly shared with me. Please read through it and see if I accurately captured your answers and comment on whether I accidentally missed something. I will appreciate it is you can send your comments back to me within three days.	This process contributes to member checking and increases the trustworthiness of the results obtained (Birt et al., 2016).

3.9.6. Data collection

Seven semi-structured in-depth interviews were conducted with communication partners of persons in an MCS+ (Creswell & Creswell, 2018). An interview script was used to guide the process. Interviews were specifically selected as opposed to alternative measures such as observations, as literature indicates that communication partners who spend extensive periods of time with persons in an MCS+, can offer in-depth information of their behaviour as opposed to HCP who typically spend shorter periods of time during assessment. Furthermore, clinical data has shown that a greater variety of behaviours are seen in the presence of communication partners (Lancioni et al., 2013). Four interviews were conducted virtually using Google Meet and three were conducted face-to-face. This was done depending on participant preference, as data was collected during different levels of lockdown during the Covid-19

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pandemic. Google Meet was selected as it is a free platform suited to conduct synchronous online semi-structured interviews, allowing the reach of a wider sample not precluded by time, locations and social barriers in a feasible and convenient manner (Kathiravan et al., 2021).

The Google Meet online application allowed for audio recordings; and the face-to-face interviews were also audio recorded. The duration of the semi-structured interviews ranged from 29 to 90 minutes with a mean time of 54 minutes. Although the author confirmed with the participants that they were correctly understood throughout the online interview to ensure that the findings are trustworthy, formal member checking was done with each of the participants once the recorded interviews had been transcribed by the first author (Josselson, 2013). All participants confirmed the correctness of the transcripts.

3.9.7. Data analysis

Upon receiving feedback from the participants, a qualitative content analysis consisting of three phases, namely: immersion; reduction; and interpretation was used to analyse the data (Braun & Clarke, 2020). More information can be obtained in Appendix G regarding the data collection procedures.

3.9.8. Trustworthiness

The trustworthiness of the studies was sought to be enhanced in several ways. Three main components of trustworthiness were addressed namely credibility, transferability and conformability. More information can be obtained in Appendix G regarding the trustworthiness of the findings.

3.9.9. Findings

Findings are set out in three sections according to the sub-aims of the phase:

3.9.9.1. Communication strategies of communication partners

Communication strategies consisted of two main themes namely non-verbal communication and verbal communication which are included in Table 3.7.

Non-verbal communication

Non-verbal communication strategies included modalities such as kinesics, active listening, proxemics, vocalics, haptics, chronemics, and artefacts (Keutchafo et al., 2020). Kinesics included facial expressions ("*We used to smile at my dad" [P1.2.6]*), expressing

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positive affect and using body language to facilitate conversation. Proxemics mentioned by participants included being physically present, the physical presence of other familiar people in the persons care facility as well as positioning both persons in the dyad in such a way that it would facilitate communication (*"We used to organise outings with the family to a tea garden and take him with us" [P1.2.3]).* The specific vocalics mentioned by participants were that upon hearing familiar voices the person would show increased responsiveness or attempt to locate the source of the voice.

Haptics (touch) was used to gain the persons attention (Orientation Touch), to provide comfort (Affectionate Touch) *("I held his hand to comfort him" [P1.2.1])* and using massaging to prevent contractures through stretching. Chronemics were mentioned by all seven of the participants and included showing an active interest or engagement when interacting with the person and acknowledgement of the person's personhood (*"I always engaged with him even though he didn't respond" [P1.2.4]).*

Two types of artefacts, namely physical objects and environmental objects were mentioned by the participants. The physical objects are specific and familiar to the person in an MCS+ and included a communication aid such as a book with photos of family and friends. Six participants reported that familiar environmental objects such as a television increased responsiveness in persons in an MCS+.

Verbal communication

Verbal communication (spoken language) was divided into language form, content and use as per the classification by Owens (2016). The linguistic form used by participants portrayed the first language of the participants, namely Afrikaans (n=3) and English (n=4). All the participants used simple subject-object-verb sentences (e.g., syntax) and simple vocabulary which were scaffolded according to the perceived linguistic and cognitive level of the person in an MCS+. They perceived themselves to anticipate what the person wanted with only 50% accuracy which led to increased frustration for both the person and the participant. Four participants mentioned that even though the person showed minimal responses in conversation, they still attempted to include them in the interaction *("I would always include him in conversations and prepare unfamiliar communication partners on communicating with him" [P1.2.1]).*

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All seven participants assumed certain things they thought the person would want to communicate about. For example, that the person might want to tell them that they are doing okay, that they love them, that they miss their family and that they understood what was being said but that they did not know how to respond.

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Table 3.7

Multimodal communication strategies used by familiar communication partners

Sub-theme	Codes	Examples of Verbatim Quotations from Participants with Participant Numbers
Non-verbal communication		
Kinesics (i.e., body movement)	Facial expressions	We used to smile at my dad. (*My dad couldn't speak but he would try to joke with gestures*) (P1.2.6)
	Body language	Body language is important when you communicate with them (P1.2.7).
Active listening (silences)	Using expectant delay	If you couldn't understand what she said you would observe her to try and understand what she wanted (P1.2.2).
Proxemics (i.e., distance and space)	Presence of familiar persons	We would sit around her bed/wheelchair and talk to her (P1.2.2). If she didn't respond we would talk around her (P1.2.2, P1.2.6). We used to organise family functions at our home to ensure that they interact with the family (P1.2.4, P1.2.5, P1.2.6). The whole family would go and visit him at the care facility (P1.2.7). We used to organise outings with the family to a tea garden and take him with us (P1.2.3).
	Fellow persons in the facility	He would share a room with someone else and they would not talk to each other (P1.2.6). The other people would lay across from my husband and make a lot of noise (P1.2.1). The place where my mom was had a large room with many beds and so the other people at the care facility would often talk to my mom (P1.2.5).
	Positioning	They would often put her in the wheelchair or in an upright position in bed (P1.2.6). This made her respond better during interaction (P1.2.6). I would say that she/he responded better when she/he was upright as was more awake (P1.2.2, P1.2.3, P1.2.4, P1.2.5, P1.2.6, P1.2.7). It didn't really matter in which position we had him he was minimally conscious (P1.2.1).
Vocalics (i.e., prosody)	Familiar voice	He recognised my voice. (*He would move his eyes and his eyes would light up* (P1.2.1)). I could see that he recognised my voice. (*You could see in his eyes that he was happy to see me* (P1.2.3)).
	Singing	My dad would sing to my mom (*She would smile at him*) (P1.2.2). I would sing to him to get his attention (P1.2.1). My daughter used to sing hymns to him and you could see that he relaxed (P1.2.4). I used to sing to my mom as she used to love singing. (*Later on, as the disease progressed it was easy for her as it became automatic and she didn't have to remember the words)* (P1.2.5).
Haptics (i.e., touch)	Orientation to touch Affectionate touch	I kissed him to regain his attention (P1.2.1).… and I pulled his ear to irritate him (P1.2.1). I held his hand to comfort him (P1.2.1). I touched him to let him know I am there (P1.2.1, P1.2.4). I used to hold his hand and then start to talk to him about my day (P1.2.4). I used to touch him to let him know I wanted to communicate with him (P1.2.3). I also touched him to reassure him (P1.2.1).

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Sub-theme	Codes		Examples of Verbatim Quotations from Participants with Participant Numbers
	Massage		I used to massage him from top to toe (P1.2.3). When I used to visit her, I would put cream on her skin while stretching her (P1.2.5). I used to put cream on her hands and she used to smell her hands afterwards (P1.2.5)
Chronemics (i.e., time and communication behaviour)	Active engagement		I always engaged with him even though he didn't respond (P1.2.4). I would hold her/his hand and try to engage with her/him. (*My mom/dad would lay with her/his eyes closed*) (P1.2.1, P1.2.2, P1.2.6). I really wanted to engage with my son and I used to do my own speech therapy (P1.2.3). You have to talk to him even if you just tell them about your day even though they don't respond. (*Months after he finally regained his consciousness, he would mention things that I told him while he was in a minimally conscious state*) (P1.2.7).
	Personhood		I wanted to treat him as a person as he would do this for me if I was in the situation (P1.2.4). I was patient with her (P1.2.2, P1.2.5). I used to let him assist in activities of daily living such as peeling potatoes to help him regain his independence (P1.2.6). It was about my husband and not me and I wanted to do my best for him (P1.2.1, P1.2.3).
	Familiar activities		My mom really enjoyed eating and my dad really just wanted to please her and therefore gave her some treats (P1.2.2). My dad used to love to eat fruit and we always gave him some fruit (P1.2.6). I really wanted to do things for him that he enjoyed (P1.2.3, P1.2.4, P1.2.5).
	Activities of daily living		I used to help feed her, comb her hair and help her to drink tea (P1.2.5). I used to help my dad by washing his feet, cutting his toenails and putting cream on him (P1.2.4, P1.2.6).
	Communication opportunities		You need to create time to communicate with the person because there are various other things that take up your time during daily life (P1.2.7). You need to make time to spend with her (P1.2.2).
Artefacts (i.e., physical and environmental objects)	Physical objects (person specific):	Communication aid Phone (WhatsApp)	I used a book to show photos or a picture of family and friends (P1.2.1, P1.2.2, P1.2.3). I showed him videos and photos of where I went and who I was talking to (P1.2.1) and I played voice messages of friends and his brother (P1.2.3). We would also do video calls on WhatsApp with familiar people such as relatives and friends (P1.2.2).
	Familiar environmental objects that facilitate responsiveness:	Television	There was a television in the room to see if we could get a response from my son. (He used to hate the television and got such a fright because of the light) (P1.2.3). My husband was in a minimally conscious state and I used to put the television on as he used to love watching sports (e.g., rugby, cricket and Formula 1 racing) and I thought he would enjoy it (P1.2.1). My mom used to put on the television for my dad as it calmed him down. It was also something that he used to do with my mom while he was able to walk (P1.2.4).

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Sub-theme	Codes		Examples of Verbatim Quotations from Participants with Participant Numbers
			They would put the TV on to provide environmental stimulation to the patients. (Nobody would be watching as everyone would just stare at each other) (P1.2.5, P1.2.6). My mom wasn't interested in watching television she preferred interaction with people (P1.2.2).
		Music on radio	Music was provided as a means of providing familiar environmental stimulation based on the preference of the person to facilitate responsiveness: (My mom used to love the music of Vera Lynn) (P1.2.5). (My dad loved country music and he would become very nostalgic when he heard Don Williams music) (P1.2.4). (My dad didn't really have a great appreciation for music) (P1.2.6).
		Entertainment groups	Once a month there was a group of people who came to do activities with them for example playing music, holding birthday parties or just playing games with them (P1.2.5).
Verbal communication			
Language content Semantics)	Discussion topics Naturalistic everyday conversations		• I used to talk about what happened at home (P1.2.1, P1.2.3, P1.2.6) • I told him/her about his/her friends that came to visit (P1.2.1, P1.2.3, P1.2.4) • We used to talk about someone who is worried about him/her (P1.2.1-P1.2.7) • The responsibility fell on me to tell him that his mother and my mother and father passed away (P1.2.1) • I reassured him/her that I loved him/her and enjoyed being there (P1.2.1-P1.2.7) • I also used to talk about everyday things (P1.2.1-P1.2.7) • When talking to my mom I used to also mention the other people at the care facility (e.g., Did you see that lady's hair and did you notice that lady shouting? [P1.2.6]) • I talked to my mom/dad about my children (P1.2.4, P1.2.5, P1.2.6, P1.2.7) • Sharing familiar positive memories was very important to me (e.g., Do you still remember this and that….? [P1.2.1-P1.2.7]) • I explained to him what happened and how he ended up in the hospital (P1.2.7) • I used to tell him his name and age, where he is, the time, day of the week and date. (P1.2.7)
	Environment		• I would name all his body parts while massaging him (P1.2.3). • I would tell him about the trees, flowers and how the lawn has gone green (P1.2.1). • I used to talk to him about things in his environment that were familiar to him (P1.2.4). • I would comment on her physical appearance (P1.2.5). • I would talk about the terrace and the home where he obtained care (P1.2.6).
	Passing on		• I know you are tired; we will be ok if you leave (P1.2.4). • You don't need to hold on anymore (P1.2.4). • I want you to rest (P1.2.4).

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Sub-theme	Codes	Examples of Verbatim Quotations from Participants with Participant Numbers
Language form (Syntax)	Using simple subject-object-verb sentences	I used to use simple sentences to communicate with him for example I saw your brother today (P1.2.1-P1.2.7). I used to comment on how she looked e.g., Your hands are so dry today (P1.2.5). I used to inform him on how my week was, e.g., Yesterday, I went to the shop and I saw this person (P1.2.1). The language of communication was either English (n=4) and Afrikaans (n=3) when familiar communication partners spoke to the persons with acquired neurological conditions. Communication partners used sound structure characteristics of these languages.
Language use (pragmatics)	Anticipating communication	I used to guess what he wanted to say (P1.2.1). I used to guess what she wanted to say and only got it right half of the time (P1.2.2). She would get so frustrated when I couldn't guess what she wanted (P1.2.6). Sometimes I couldn't understand what he wanted and we would go around talking in circles (P1.2.4, P1.2.5, P1.2.7).
	Including person in interaction	I would always include him in conversations and prepare unfamiliar communication partners on communicating with him (P1.2.1). I used to include him in normal daily activities (e.g., taking him outside to eat lunch with us at home) (P1.2.3). I would invite my parents-in-law over for dinner to include my mom in family life (P1.2.2). We would braai at our home and he would be present during the interaction even though he didn't contribute we wanted to include him (P1.2.6).
	Taking communication turns	I provided opportunities for him to communicate (P1.2.3). I just responded to what my dad was talking about at the time even when it didn't make sense (P1.2.4).
	Maintaining conversational topics	When my mom used to think I was her sister I used to just go with it (P5). Because you can't reason with her (P1.2.5).
Communication functions	Social Obtain Information	• When I came into the room, I used to greet him (P1.2.7) • I asked him/her yes/no questions (e.g., is your name ……) (P1.2.1-P1.2.7) • I used to ask her/him about her/his basic needs and wants (e.g., what did you eat today) (P1.2.1-P1.2.7) • When I spoke to him/her I always provided choices (e.g., would you like to wear the red of blue shirt) (P1.2.1-P1.2.7) • I always waited for him/her to confirm his/her answer (P1.2.1-P1.2.7) • I asked him if what he wanted to communicate is more important than the task I am busy with (P1.2.7). • I used to explain the procedure to him (e.g., I am going to change you, bath you, comb your hair) (P1.2.7) • Asking easy everyday questions (P1.2.1-P1.2.7)

Note. Phonology and morphology are not included in this table as communication partners did not mention altering their spoken language in this way.

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3.9.9.2. Communication strategies of persons in an MCS+ reported by communication partners

This section focuses on the information pertaining to the communication partner's perception of the non-verbal communication behaviours that the person in an MCS+ displayed. Figure 3.3 includes a layout of the communication behaviours of persons in an MCS+ as perceived by their communication partners. Kinesics most mentioned by all seven participants, included eye movement as a means to communicate. For example, participant 1.2.7 mentioned that her husband would use eye blinking to answer yes/no questions. Gestures used by persons in an MCS+ included using mostly the upper limbs (hand, arm, and shoulder) to point and tap ("*My dad would tap his finger to follow the rhythm of the music he liked*" [P1.2.4]) with the index finger and to squeeze the communication partner's hand. For both proxemics and chronemics, the persons in an MCS+ were totally dependent on the participants in all seven cases to position them and to perform activities of daily living for them.

The vocalics observed by participants included both vocalisations such as laughing ("*My mom would laugh at my dad when he started singing*" [P1.2.2]) and humming ("*My mom loved singing and would hum to the music*" [P1.2.5]).

Haptics mostly comprised of reflexive behaviour such as fidgeting and restlessness ("*My dad used to get very restless and then my daughter would sing hymns to him as it would help him relax* [P1.2.4]), while the artefacts mentioned by participants included physical objects. Physical objects included both high and low technology communication aids. Although the persons were exposed to both high and low technology communication aids, communication partners lacked confidence when implementing both forms of communication due to the low level of responsiveness of the person, the inconsistency of responses as well as the significant cognitive, motor, linguistic and sensory difficulties of the person.

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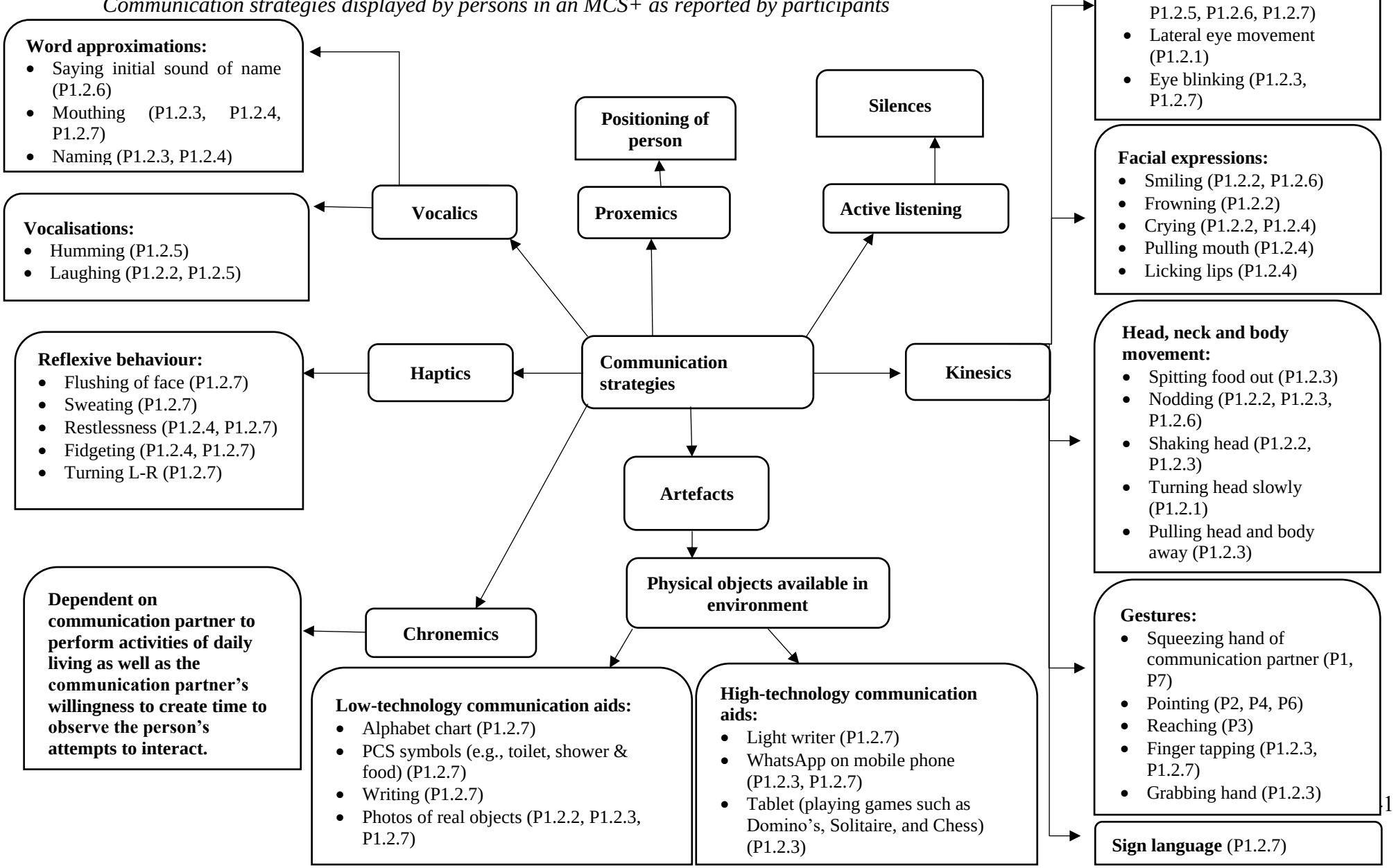
Figure 3.3

Communication strategies displayed by persons in an MCS+ as reported by participants



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3.9.9.3. Communication functions conveyed through unaided communication behaviours by persons in an MCS+

Table 3.8 includes a description of the communication functions that persons in an MCS+ conveyed through non-verbal communication as perceived by communication partners. The communication functions reported were classified according to the communication function categories in the Communication Matrix (Rowland, 2011).

According to communication partners, persons in an MCS+ conveyed a total of 36 communication functions through their non-verbal communication. Level 1 (pre-intentional communication) included six communication functions with most participants mentioning that persons who were minimally conscious expressed components related to physical functioning with reflexive behaviours ("*I could see my dad was uncomfortable as he used to turn L-R in his bed and fidget a lot*" [P1.2.4]). Level 2 (intentional behaviour) also included three communication functions, of which the ability of persons in an MCS+ to convey positive affect was mentioned by three participants while expressing negative affect was mentioned by all seven of the participants ("*My husband used to get irritated with me when I pulled his ear and he would just close his eyes and not respond*" [P1.2.1]). All the communication partner participants mentioned that persons in an MCS+ conveyed communication functions on Level 3 (unconventional communication) which focused on the person indicating intent to communicate, choice-making and expressing wants and needs.

Level 4 (conventional communication) included eight communication functions with active engagement in interaction and following instructions being mentioned by all of the participants ("*We would always organise family gatherings and my mom would smile and look at us*" [P1.2.2]). Communication functions included in Level 5 (concrete communication) were mentioned by less than half of the participants referring to persons in an MCS+ answering concrete questions with word approximations, while Level 6 (abstract communication) included only one communication function, specifically that the person modelled what they required from the partner. Lastly, Level 7 (linguistic communication) included six communication functions observed by participants. The communication function mentioned by more than half of the participants included narratives for which persons in an MCS+ used word approximations, vocalisations, sign language, a Light writer and WhatsApp.

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Table 3.8

Communication functions displayed by persons in an MCS+ as perceived by communication partners

Matrix Level	Nr	Communication Function		Definition	Behaviour Observed by Communication Partner	Mentioned by (Part nr)
Level 1: Pre-intentional behaviour	**1**	Wakefulness and alertness		Displaying signs of coma recovery coma / regaining consciousness.	Prolonged eye gaze	P1.2.3, P1.2.7
	2	Disorientation		Disorientation of person, place and time.		P1.2.3, P1.2.7
	3	No recognition		Not recognising familiar objects or people.	Prolonged eye gaze, eye blinking or frowning	P1.2.5, P1.2.6
	4	Searching behaviour	Object	Searching for an object in the environment.	Lateral eye movement or prolonged gaze	P1.2.7
			Person	Searching for a person in the environment.	Lateral eye movement, reaching, turning head slowly	P1.2.1, P1.2.4, P1.2.5
	5	Expressing components related to physical functioning		Communication regarding the physical functioning of the person.	Reflexive behaviours	P1.2.2, P1.2.3, P1.2.4, P1.2.5, P1.2.6
	6	Expressing	Pain	Physiological expression of pain.		P1.2.3
			Discomfort	Expressing components related to discomfort.		P1.2.2, P1.2.3, P1.2.4
Level 2: Intentional behaviour	**7**	Recognition	Object	Recognising an object such as a photo of a past event or a book.	Smiling, laughing, photos of real objects and people	P1.2.1
			Familiar person	Recognising a familiar person such as a friend, relative or corporate connection.		P1.2.1, P1.2.2
	8	Drawing attention		Focusing the communication partner's attention on a specific object, person or event.	Prolonged eye gaze, pointing, reaching, saying the initial sound or naming the object/person or event	P1.2.2
	9	Expressing affect	Positive	Communicates positive emotions (e.g., happy).	Smiling, laughing	P1.2.1, P1.2.2, P1.2.6
			Negative	Communicates negative emotions and feelings (e.g., anger, stress, fear, frustration).	Frowning, crying, pulling mouth, prolonged eye closure	P1.2.1, P1.2.2, P1.2.3, P1.2.4, P1.2.5, P1.2.6, P1.2.7
Level 3: Unconventional communication	**10**	Communication intent (basic)		Indicating an intent to communicate.	Reaching, grabbing hand, pulling head and body	P1.2.1, P1.2.2, P1.2.3, P1.2.4, P1.2.5, P1.2.6, P1.2.7
	11	Refusing to communicate		Indicating no desire to communicate despite having communication intent.	Prolonged eye closure, pulling mouth, sign language, shaking head	P1.2.7

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Matrix Level	Nr	Communication Function		Definition	Behaviour Observed by Communication Partner	Mentioned by (Part nr)
	12	Comprehending messages (basic)		Understanding the intent of a message produced by a communication partner.	Eye blinking, nodding, vocalizations	P1.2.7
	13	Choice making		Conveying personal preferences to the communication partner.	Eye blinking, nodding, shaking head, pointing, vocalizations	P1.2.1, P1.2.2, P1.2.3, P1.2.4, P1.2.5, P1.2.6, P1.2.7
	14	Expressing basic wants and needs		Expressing wants and needs.		P1.2.1, P1.2.2, P1.2.3, P1.2.4, P1.2.5, P1.2.6, P1.2.7
	15	Beginning communication support		Using unaided communication to represent basic messages.		P1.2.1, P1.2.2, P1.2.3
Level 4: Conventional communi-cation	**16**	Greeting		Following social etiquette rules, e.g., saying "hello" or "goodbye".		P1.2.4, P1.2.5, P1.2.6
	17	Engagement in interaction	Active	Attending to the communication partner through active listening and body engagement.	Prolonged eye gaze, nodding, vocalizations, silences	P1.2.1, P1.2.2, P1.2.3, P1.2.4, P1.2.5, P1.2.6, P1.2.7
			Passive	Being physically present during communication but not actively engaged (i.e., disinterested in communication).	Prolonged eye closure	P1.2.1, P1.2.4, P1.2.5, P1.2.6
	18	Turn taking		Displaying turn-taking (i.e., reciprocity) with communication partners.	Prolonged eye closure, nodding	P1.2.4, P1.2.5, P1.2.6, P1.2.7
	19	Following of instructions		Understanding an instruction by a communication partner.	Gestures	P1.2.1, P1.2.2, P1.2.3, P1.2.4, P1.2.5, P1.2.6, P1.2.7
	20	Functional use of objects		Knowing the function of an object (e.g., using a comb).	Gestures functional use of object	P1.2.7
	21	Requesting	Object	Requiring the communication partner to provide an object (e.g., toothbrush or comb).	Pointing, turning head slowly, prolonged eye gaze, reaching, licking lips, PCS symbols, alphabet chart	P1.2.4
			Action	Requiring the communication partner to fulfil a task (e.g., pointing to the light-requesting the light on/off).		P1.2.4
			Physical presence	Requiring physical closeness from the communication partner.	Reaching, grabbing hand, prolonged eye gaze	P1.2.1, P1.2.2, P1.2.3, P1.2.4, P1.2.7

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Matrix Level	Nr	Communication Function		Definition	Behaviour Observed by Communication Partner	Mentioned by (Part nr)
			Information	Requiring the communication partner to provide more information.		P1.2.7
	22	Responding (basic)		This refers to a voluntary response to a communication partner's initiation to communicate.	Nodding, vocalizations and word approximations	P1.2.1, P1.2.3
	23	Refusing	Object	Requiring the communication partner to provide an object (e.g., food, toothbrush or comb).	Prolonged eye closure, shaking head,	P1.2.3, P1.2.4
			Action	Requesting partner to fulfil a task (e.g., take food away).	Spitting food out, pulling mouth, pulling head and body away, reflexive behaviours	P1.2.5
			Physical presence	Requiring a lack of physical closeness from the communication partner (e.g., requesting the partner to leave).	Prolonged eye closure	P1.2.1, P1.2.2, P1.2.3, P1.2.4
			Information	Requiring the communication partner to provide no information.		P1.2.7
Level 5: Concrete communi-cation	**24**	Imitating/ Repeating		Imitating or repeating an action, object or person.		P1.2.7
	25	Naming		Labelling an object, person or event in the person's environment.	Word approximations, vocalization, gestures	P1.2.2, P1.2.5
	26	Commenting		Providing comments during the conversation.		P1.2.7
	27	Answering	Yes/no questions	Responding to the communication partner's questions (yes/no).	Word approximations, vocalizations, eye blinking, nodding, shaking head, smiling, frowning, squeezing hand.	P1.2.1
			Concrete questions	Responding to general contextual questions focusing on the current environment (e.g., "What are you doing?").		P1.2.4, P1.2.5, P1.2.6
			Abstract questions	Responding to simple abstract questions from the communication partner (e.g., "How do you feel today?").	Lightwriter, WhatsApp, writing, tablet	P1.2.2
	28	Requesting a turn		Initiating interaction or requesting to participate in the conversation.	Grab hand, prolonged eye gaze, silences	P1.2.7
	29	Initiate conversation		Requesting reciprocal interaction from a communication partner.		P1.2.4, P1.2.7
Level 6: Abstract	**30**	Modelling		Using simple gestures to demonstrate what is required of the communication partner (e.g., "*I am hungry*").	Gestures	P1.2.2
Level 7: Linguistic	**31**	Narrative		Telling a story.	Word approximations, vocalizations, sign language, Light writer, alphabet board, writing, WhatsApp	P1.2.4, P1.2.5, P1.2.6, P1.2.7
	32	Arguing		Debating the person's point of view.		P1.2.7
	33	Leading the conversation		Leading the conversation by discussing topics related to the person's concerns or interests (e.g., humour and gossip).	Physical objects such as Light writer, writing, WhatsApp	P1.2.6, P1.2.7
	34	Observing social etiquette		Using words that are socially appropriate or inappropriate.	Alphabet chart	P1.2.4, P1.2.5, P1.2.6

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Matrix Level	Nr	Communication Function	Definition	Behaviour Observed by Communication Partner	Mentioned by (Part nr)
	35	Termination/disengagement	Withdrawing from the conversation.	Prolonged eye closure	P1.2.1, P1.2.2, P1.2.6
	36	Conversational pause	The speaker takes a rest, hesitates, or temporarily stops.	Silences or gesture	P1.2.4, P1.2.5, P1.2.6

Source: A*pplication to Communication Matrix, Rowland (2011)*

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3.9.10. Discussion

From the findings of the research, communication partners are willing and eager to interact with persons in an MCS+, despite the challenges related to restricted interaction. Communication partners naturally use some form of multimodal communication and attempt to adapt to these communication strategies. However, these communication partners are often unsure whether they are implementing and integrating these strategies appropriately. This may be due to the communication partners attempting communication with the person but perceiving the person in an MCS+ as not responding. Alternatively, they may focus on specific communication strategies which they are familiar with (e.g., verbal communication) and may receive limited HCP support to provide them with the confidence to effectively integrate multiple modes of communication during interaction with these persons (Wallace et al., 2014). Preisig et al. (2018) mention that although verbal and non-verbal communication are produced through different channels, they originate from a shared communication intention. Therefore, by integrating multimodal strategies, the opportunity of having successful interaction is increased, because if a communication breakdown occurs in one modality the partner can switch to another, thereby allowing greater communication capacity (Wallace et al., 2014). This phase supports the notion that communication partners use multimodal communication and that they learn this skill over time, but often do not know how to observe and identify subtle communication attempts from the person in an MCS+ during the initial/early stages. If communication partners are supported during the initial phases, early rehabilitation can take place which results in improved emergence of consciousness (Eapen et al., 2017).

The communication partners in this phase did identify some communication attempts of persons in an MCS+ such as kinesics – specifically eye movement was identified as the most prominent means to communicate in particular prolonged gaze and prolonged eye closure. Eye movement is often present during all stages of recovery and is the first sign that the person is recovering consciousness (Ting et al., 2014; Wannez, Heine, et al., 2017).

Another communication means displayed by persons in an MCS+ was vocalics. All the participants mentioned that vocalics such as using a familiar voice and singing to the person were some of the communication strategies they used. Singing in particular was displayed by the communication partner and humming by the person as a communication means. According to Lancioni et al. (2021), this is beneficial as it increases neural activity, accelerates brain plasticity, and avoids sensory deprivation. Music stimulation of the auditory area (which is

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mostly unaffected) also increases the person's recovery process and improves the well-being and general functioning of the person (Lancioni et al., 2021). Additionally, a familiar voice provides personally relevant stimuli (i.e., with emotional, autobiographical, or self-related characteristics) which increases the chance of observing behavioural or brain responses compared to neutral stimuli (Sautet et al., 2022).

Communication attempts of persons in an MCS+ was mostly interpreted as conventional communication which included greeting, turn taking, following instructions, requesting, responding and refusing. These observations of communication partners provide valuable diagnostic information for the classification of persons in an MCS+. Behaviour observation remains the most frequently used method of differential diagnosis in DOC (Carrière et al., 2022). Therefore, by including communication partners can assist HCP in obtaining information on familiar stimuli that the person responds best to, how the person responds to the stimuli and what the response could indicate. Including communication partners in a team approach may also assist HCP to support both familiar communication partners in the initial and extended phases of care. Firstly, by providing information on naturally occurring multimodal communication strategies to communicate with persons in an MCS+ in the initial care phase and secondly, supporting extended care phase familiar communication partners to communicate with confidence. Additionally, HCP can equip communication partners with the skills to observe, identify, and respond to subtle communication attempts as this may improve the psychological state and confidence when interacting with persons in an MCS+ (Ting et al., 2014).

This concludes the excerpt of the published manuscript entitled "Multimodal communication displayed by familiar communication partners to build communication capacity in persons in an MCS+" (Appendix G)

3.9.11. Conclusion Step 1.2

From the findings obtained following Step 1.2, it is clear that communication partners of persons in an MCS+ realise the importance of communicating with these persons. They also appear to acquire some communication skills over time as their observation skills increase and they become aware of which stimuli elicits which specific responses. Despite these findings, communication partners appear to be unaware that they acquired knowledge and skills over time, and often feel helpless and unsure of how to interpret subtle communication attempts. The findings from this step of the Phase 1 thus demonstrates how this uncertainty caused the

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communication partners to lack confidence when communicating with persons in an MCS+. The partners remained unsure of how to scaffold their multimodal communication attempts to meet the needs of persons in an MCS+ and to adequately support them. These findings suggest that communication partners should be included from the earliest stages of assessment and intervention as it may facilitate emergence of consciousness at an increased rate and at an earlier stage (Seel et al., 2013).

Identifying the multimodal communication strategies of communication partners also assists in gaining a deeper understanding of the current communication strategies that they use as well as areas of support specifically related to communication. This also assists in providing a basis for the identification and adaptation of the CPT programme discussed in Chapter 4 and feeds into the next step of the research which aimed at identifying areas of support that communication partners require in the initial care phase that could be remediated by HCPs.

3.10. Step 1.3 Identification of communication partner's support needs

3.10.1. Introduction and aim

Step 1.3 addresses the third sub-aim of the phase. It is an extension of the synchronous online semi-structured interviews conducted with communication partners of persons in an MCS+. While step 1.2 focused on the communication modalities used by communication partners, Step 1.3 focuses on their support needs. This step is an extension of Step 1.2 and hence used the same participants, interviewed in the same way, but with a different focus. The aim of Step 1.3 was to describe the multidimensional stressors of communication partners caring for persons in an MCS+ according to the ecological systems theory, conceptualised by Bronfenbrenner (Brofenbrenner, 1992) and adapted to a framework for care by Pask et al. (2018). Identifying the support needs of untrained communication partners assists in providing insights into factors that may facilitate or create barriers to person-partner communication. These facilitators and barriers related to communication can also provide targets or goals for that should be addressed through CPT.

The following information was adapted from an excerpt of the article that has been submitted and that is currently under review entitled: "Support needs of familiar communication partners caring for persons who are minimally responsive: An ecological systems approach" (Kuyler et al., under review-b).

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3.10.2. Rationale

This research aims to describe these multidimensional stressors according to the ecological systems theory, conceptualised by Brofenbrenner (1992) and adapted to a framework for care by Pask et al (2018). This theory describes stressors as integrated within multiple interacting social environments which change over time (Giovannetti et al 2015). These systems include the microsystem (i.e., characteristics related to the unpaid partner as a person and the relationship with the person in an MCS+), mesosystem (i.e., interactions that occur between the unpaid partner, the paid partners (e.g., care facility staff and HCPs), exosystem (i.e., services and the system level components which the unpaid partner is not directly related to but that can influence their care experience), macrosystem (i.e., components related to how the societal and cultural contexts are embedded within the other systems) and chronosystem (i.e., changes in needs, circumstances and environment over time) (Pask et al 2018).

Unpaid partners operate within a larger environmental context (i.e., the exosystem) in which they interact with the person in an MCS+ in the microsystem, as well as with HCPs in their attempts to access services such as rehabilitation (i.e., the exosystem). Interaction with extended family and friends (i.e., the mesosystem) as well as with acquaintances and other members of the larger community while attempting to deal with disability stereotyping (i.e., the macrosystem) might also be negatively affected (Chandran et al 2016; Pask et al 2018). Furthermore, unpaid partners may experience difficulty in maintaining their own social relationships with family and friends, as their time is consumed with their care-taking responsibilities (Covelli et al 2016; Moretta et al 2014; Zylberman et al 2016). Caring for a person in an MCS+ may therefore lead to partners feeling inadequate, fearful, anxious and depressed which may increase their psychological stress in the microsystem. This may cause unpaid partners to lose hope, decrease their quality of life and result in isolation within the mesosystem (Covelli et al 2016; Moretta et al 2014; Zylberman et al 2016).

From this discussion, it is clear that unpaid partners experience challenges across different systems over different periods of time (i.e., the chronosystem). Identifying these challenges timeously will enable HCPs to provide adequate support and respite to reduce the perceived care responsibilities. The main aim of this study was therefore to identify the multidimensional support needs of unpaid partners by focusing on the lessons they had learnt throughout their care process.

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3.10.3. Participants

Please note that the participants, methods and materials are exactly the same as in Step 1.2 and will thus not be discussed here. Please note participants are numbered according to the step, for example as this is Step 1.3. participants numbers will comprise C1.3.1 and so forth.

3.10.4. Data analysis

Upon feedback of member checking from the participants, the six phases for thematic analysis by Clarke and Braun (2013) were followed. These phases include: i) the three authors started by familiarising themselves with the transcripts and reviewing the data to gain a deeper understanding of the participants' perspectives (Nowell et al., 2017; Scharp & Sanders, 2019); ii) data reduction was performed to systematically select only information that aided in addressing the main aim. This process was followed by inductive reasoning to categorize the data that occurred recurrently (Lawless & Chen, 2019; Nowell et al., 2017); iii) the authors searched to identify similarities in the data and formulated themes (Clarke & Braun, 2013); iv) the authors collaborated to review and reflect on the coherence and applicability of the themes until a consensus agreement was reached (Nowell et al., 2017); v) themes were defined and named in a constructive manner while also linking it to the ecological systems theory by plotting it either in the micro-, meso-, macro-, exo- and/or chronosystem (Brofenbrenner, 1992; Nowell et al., 2017); and vi) writing up the data to provide evidence of the identified themes by reporting compelling examples and relating these themes to the research question and aims (Clarke & Braun, 2013).

3.10.5. Findings

The findings are discussed according to the multidimensional needs of communication partners included in Table 3.9.

3.10.5.1. Support needs of communication partners caring for persons in an MCS+

In the microsystem, participants mentioned the relationship with the person, their own personal characteristics as well as psychological stressors, physical-, environmental- and financial concerns. Participants specifically mentioned that their relationship with the person was important but that they needed support. Two participants mentioned that acting in the best interest of the person required support in managing challenging behaviour and identifying the persons' communication attempts. One participant noted that "I really wish I could read my dad's mind and understand what he was trying to communicate to me" (C1.3.6). Participants

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also mentioned that the unpredictability of caring was a great contributor to their psychological distress with one explicitly stating that "It wasn't easy" (C1.3.1).

Within the mesosystem participants referred to the multidisciplinary team interactions that occurred between them, the care staff at the facility and HCPs. Participants specifically mentioned two main themes, namely communication with HCPs, and social contacts. According to the participants the HCPs often did not provide sufficient information, for example "The doctor didn't tell me what was wrong with my mom" (C1.3.5). Most participants felt that they became socially isolated and lost contact with their friends and family due to the time-consuming nature caring tasks and activities.

The exosystem consisted of participants mentioning limitations in accessing services and, or organizations that could provide additional support. Participants specifically mentioned that HCP did not make appropriate referrals which increased their burden as communication partners. Table 3.9 includes a detailed description of participants' support needs.

Participant C1.3.7 mentioned that the macrosystem should address negative attitudes such as social stigma or prejudice from unfamiliar communication partners towards persons with acquired disabilities. This specific participant was greatly affected by the ignorance or misinformation of unfamiliar communication partners and how this may impact their ability to communicate with persons who are disabled, generally.

Finally, participants also mentioned components in the chronosystem as the person in an MCS+ needs change from initial admission to the hospital to the time that they are discharged home or to a care facility. These changing needs related to the persistence of their minimally conscious state.

3.10.5.2. Lessons learnt from the caring process

All participants reported that they as communication partners experienced burdens specifically related to the unfamiliarity and unpredictability of their situation. However, participants also mentioned that the caring process had changed their life perspectives and that they experienced many enjoyments in the process as well. The seven participants were each asked to mention one life lesson they learnt through the caring process and these are included in Figure 3.4.

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Figure 3.4

Valuable lessons learnt during the caregiving process: Examples from communication partners themselves

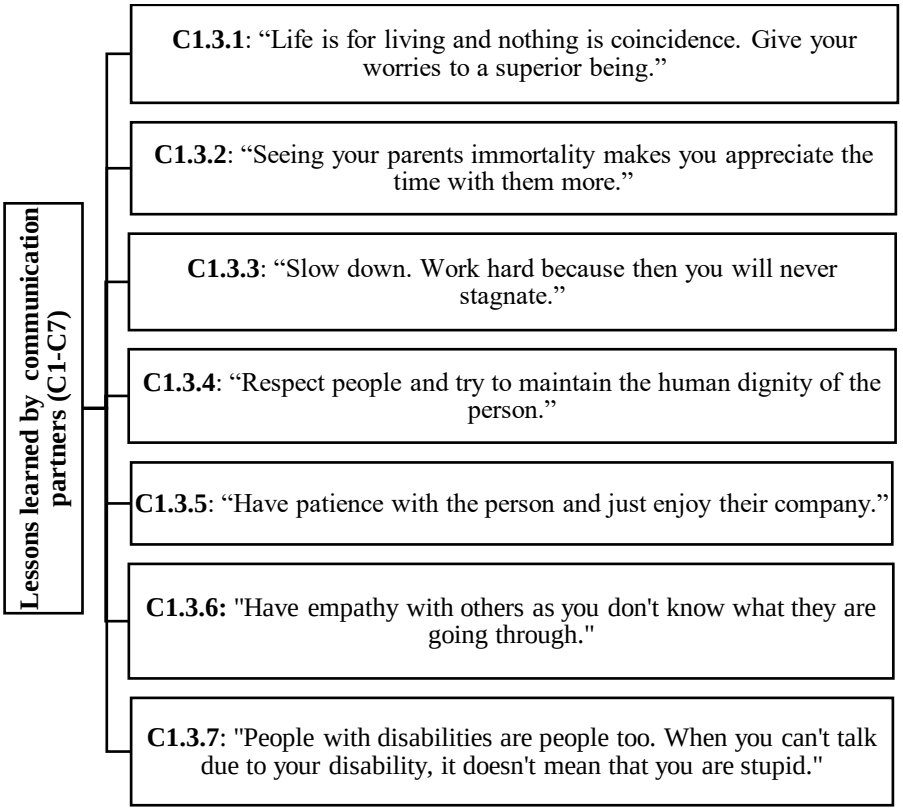

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Table 3.9

Support needs experienced by communication partners during care for persons in an MCS+ as classified according to ecological systems theory

Main Themes	Sub-themes	Verbatim Examples
Microsystem		
Relationship with person who is minimally responsive	Changing person-communication partner roles and bond	• You have to work on your relationship with the person (C1.3.7).
	Acting in best interests of person	• I really wanted to do what is best for my husband (C1.3.1, C1.3.7). • I wanted to fight for my son because it was about him not about myself (C1.3.3). • We wanted to provide the best care for my dad because he was a good person (C1.3.4, C1.3.6). • I wanted to help my mom maintain the quality of life that she had before she got sick (C1.3.2, C1.3.5).
	Managing aggressive behaviour in person	• My dad used to get so aggressive and attack my mom and that was really hard for me to see because you can't keep them accountable as they don't understand what they are doing (C1.3.4). • It was so hard adapting to the personality changes, because my dad was so kind before he got sick but started showing aggression towards others during his sickness (C1.3.6).
	Overcoming communication challenges with the person	• I really wish I could read my dad's mind and understand what he was trying to communicate to me (C1.3.6). • Communication was a big problem for me and my husband (C1.3.7).
Personal characteristics (Personal characteristics that influence caregiving)	Personal expectations of the caregiving process	• HCP are supposed to support you, but they didn't do it (C1.3.3). • We didn't know what the future held but no one communicated anything to us (C1.3.6). • They didn't tell me anything. I had to do my own research (C1.3.5). • The people who were supposed to help us failed us (C1.3.6). • We had no idea how we were going to get my mother home (C1.3.2). • We had a lot of hope that he would recover but it just didn't happen (C1.3.1). • We thought if he was being cared for by a trained communication partner, he would show improvement but his physical state just regressed (C1.3.4).
	Personality	• I am a fighter and I will fight for my son (C1.3.3). • I was doing this for my husband because he would have done it for me (C1.3.1). • I had to do my best for my mom because she was very special to me (C1.3.2).
Psychological stressors (Emotional and psychological components experienced due to care)	Compassion fatigue	• Seeing your loved one fade away, how it's affecting him and not being able to do anything was really stressful (C1.3.4).
	Frustration	• It was very frustrating when you are trying to look after your needs but the person just thinks of their own needs (C1.3.7).
	Anxiety	• My mom started hallucinating and this stressed me out because I didn't know what was wrong (C1.3.5).
	Self-doubt	• I can't do this and I am not cut out for it (C1.3.1).

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Main Themes	Sub-themes	Verbatim Examples
	Self-blame	• I felt like it was my fault (C1.3.6).
	Unpredictability	• Not knowing what is going to happen next was really stressful (C1.3.1, C1.3.4). • The whole situation was so unpredictable and it forces you to realize that things are out of your control (C1.3.6).
	Attitude	• I have no hope that he will improve we are just waiting for him to pass on (C1.3.1). • I had to talk to myself to just remain patient with him (C1.3.6).
	Subjective experience of caregiving	• It was not easy (C1.3.1). • My whole life changed and I had lost my purpose when she passed away (C1.3.2). • I feel like I have been to hell and back (C1.3.3).
Physical concerns (Physiological wellness of the communication partner)	Physical health of communication partner	• I hurt myself when I had to lift him and my shoulder never really recovered (C1.3.4, C1.3.5). • My dad almost fell as he had to carry my mom and lift her into the car (C1.3.2). • I was my son's communication partner 24 hours, 7 days a week. I was with him the whole time and only left to bath and eat. I barely slept and was worn out (C1.3.3).
Environmental concerns (Components within the environment of the communication partner)	Living arrangements	• I wanted to place him in a care facility that I can visit daily (C1.3.1). • I had to put her in a care facility as I was not able to look after her full time (C1.3.5).
	Environmental adaptations	• The healthcare practitioner came to my house and made suggestions such as putting a handle and bench in the shower and organising a ramp for her wheelchair (C1.3.2). • I think they weren't honest with us at the care facility as they locked the doors of the patient's rooms (C1.3.6).
	Transport	• Luckily our neighbour's car had a hoist for a wheelchair and we bought the car from him (C1.3.3). • My father really needed a hoist that could assist my mom to get in the car (C1.3.2).
	Physical safety concerns related to person	• I was really concerned about the safety of my dad as he used to just walk out the door and didn't tell anyone where he was going (C1.3.6).
	Assistance to adapt to increased daily responsibilities	• I had to also look after both our parents while he was in the care facility (C1.3.1). • I had to go shopping for my dad to make sure he has all the things he needs (C1.3.6). • When you have children of your own it is often hard to focus on the care of your parent (C1.3.2). • I had to take care of the children and my husband as well (C1.3.4, C1.3.5). • I really had to juggle getting the kids to school, cooking dinner and making sure my husband was ok (C1.3.7).
Financial concerns (Financial burdens or needs of the communication partners)	Funding support	• We didn't have the finances to get a communication partner for my mom (C1.3.5). • There were various additional costs that the medical aid did not pay (C1.3.1). • My mom didn't have medical aid. So, she couldn't afford private doctors and specialised care (C1.3.4). • It was a big burden financially. I think my mom could have been better off if the lawyer gave her the right advice (C1.3.6). • The medical aid didn't pay for transportation from one medical facility to another (C1.3.2). • We had to pay everything from our own account and are still awaiting funds from the Road Accident Fund (C1.3.3).

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Main Themes	Sub-themes	Verbatim Examples
		• Finances were a burden but we thought communication was a bigger burden (C1.3.7).
HCP (Healthcare person providing support to the communication partner)	Limited provision of information	• She explained why my husband needed physio but didn't seem interested as she mentioned that he won't improve (C1.3.1). • The doctor didn't tell me what was wrong with my mom (C1.3.5). • I had to organize my own MRI and CT scans with other doctors as the doctor treating my son just spoke to me on his discharge and not during his hospital stay (C1.3.3). • The healthcare practitioner didn't tell me what she was doing with my dad in therapy (C1.3.6). • Nobody told us what to do next or what to expect we were very unprepared (C1.3.2, C1.3.7).
	Perceived level of care provided by HCP	• I didn't feel supported by the HCP (C1.3.1, C1.3.2, C1.3.7). • The speech therapist got impatient with my son as he spit out his yogurt. She didn't realize that he hated the flavour of it (C1.3.3). • It seemed like they were performing Chinese torture on my son during splinting of his knee (C1.3.3).
	Not being heard	• Nobody listened to me (C1.3.1, C1.3.5). • They didn't even ask me how I was doing (C1.3.3).
Social contact (Experiences of social entities and relationships influencing the communication partners experience)	Family	Facilitators: Involvement • My husband was very supportive and always understood when I said I needed to go see my mom/dad (C1.3.5, C1.3.6). • My parents also went to see my husband (C1.3.1). • My family supported me through the process and they were very involved (C1.3.7). Barriers: Conflict • My brother took my mom to the doctor but he didn't tell me anything about the appointment and just said nothing was wrong. He didn't contribute financially towards my mother's care I had to take all the responsibility (C1.3.5).
	Faith community	Facilitators: Involvement • The people at church really understood my mom's condition and they were so patient with her. They also came to our house and supported by providing meals and just being there for us (C1.3.5). Barriers: Conflict • My parents had contributed to the church a lot and were always involved in charitable activities. However, the pastor did not even come to see my mom during my dad's illness and didn't support her at all (C1.3.6).
Mesosystem		
	Access to other communication partners with shared experience	• There was one lady whose son was in the bed next to my husband. She really supported me. She would send me updates if I weren't there to make sure I knew what type of care my husband was getting (C1.3.1). • There was a lady that was recently widowed and she started talking to my dad because she knew my mom had passed away. This seemed to help her to process the grief of her husband's passing (C1.3.2).

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Main Themes	Sub-themes	Verbatim Examples
	Ability to interact socially	• The nurse who looked after my son used to WhatsApp me to send me updates on how my son is doing. This made the caregiving experience a lot better (C1.3.3). • I could continue my social activities because my mom was in a care facility (C1.3.5). • My mom became so isolated because she couldn't go out anymore as my dad would embarrass her (C1.3.4, C1.3.6). • I still had to visit my husband daily but I could continue with normal living (C1.3.1). • I really tried to include my son in our family gatherings and would take him to a tea garden to get out a bit. I didn't really visit with many friends during this time (C1.3.3). • We often invited my parents for dinner so my dad could get a break and would then spend time with my mom (C1.3.2).
Exosystem		
	Limited access to services	• We didn't know who to contact and where to obtain the services (C1.3.1, C1.3.2). • I wish I knew of a place where we could get trained communication partners for my dad (C1.3.4). • I wish the medical aid paid for a speech therapist to assist my mom with her communication (C1.3.5).
Macrosystem		
	Community stereotypes	• The people used to think my husband is stupid because he was not able to communicate and I would think you can talk to him like a normal person he is not stupid (C1.3.7).
Chronosystem		
	Changing needs of communication partners	• All communication partners need change over time according to the specific stage of recovery that the person is in (C1.3.1-C1.3.7).

Source: *Bronfenbrenner, 1992; Pask et al., 2018*

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3.10.6. Discussion

HCPs need to support both the person and the communication partner within multiple integrated systems to ensure holistic care and to facilitate improved quality of life (ecological systems approach) (Antony et al., 2018). According to Chinner et al. (2021), the person in an MCS+ experiences behavioural, communication and social challenges which may impact the communication and the caring experience of communication partners. From the findings of the synchronous online semi-structured interviews' communication partners required continuous support during the caring process. The communication partners caring experience evolves from initial admission to the hospital until discharge home and can impact their communication with persons in an MCS+.

During the evolution of communication partner's caring experience, they maintained the stance that they wanted to act in the best interest of the person, as their relationship with the person was important. However, substantial discrepancies existed between the concept of best interest for communication partners and for HCPs (as perceived by communication partners). This is supported by Lond and Williamson (2022) who mentioned that this occurs due to unmet communication partners expectations which results in a negative caring experience.

According to communication partners' perspectives this negative caring experience may be ameliorated by their resilience, personality or their coping strategies, but cannot be completely alleviated without adequate support from HCPs. Some communication partners reported that HCPs were engaged during the caring process whilst others reported minimal involvement from HCPs relating to either the provision of information or practical support during activities of daily living. Eaton et al. (2020) mentioned that communication partners' perspectives of disengagement of HCP may be due to poor communication that results in misunderstandings, misperceptions and missed opportunities for HCPs to provide adequate support. When communication partners experience feeling unsupported psychological distress increases which also increases their perceived care responsibilities.

Additionally, communication partners reported that they had poor involvement in social activities, generally due to care responsibilities and time related to the care, which resulted in feelings of not being heard. Some communication partners in the current study reported that they were socially engaged while some explained that they became isolated, experienced associative stigma (embarrassment over behaviour of person). This caused them to avoid social

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gatherings due to the broader community's perception and behaviour towards persons in an MCS+. Mfoafo-M'Carthy and Grischow (2020) mention that due to the community's behaviour towards persons with disability, it is evident that disability is a socially constructed phenomenon, that stems from intentional/unintentional attitudes and barriers of society rather than from the impairment itself.

This concludes the excerpt of the manuscript currently under review entitled: "Support needs of familiar communication partners caring for persons who are minimally responsive: An ecological systems approach" (Kuyler et al., under review-b).

3.10.7. Conclusion of Step 1.3

Step 1.3 showed that untrained communication partners experience challenges within the microsystem and mesosystem with limited challenges in other systems. This may be the results of the care responsibilities brought about by the person' s condition and the impact thereof on the immediate environment. However, the separation of these systems is merely an academic endeavour to avoid unnecessary duplication, and it should be emphasised that these systems are intricately interwoven, greatly impacting each other. Therefore, due to their multidimensionality and integration a substantial impact is seen on the holistic functioning of the communication partner. The multidimensional support needs can greatly impact on communication partners and how they communicate with persons in an MCS+. However, poor person-partner communication may also add to their care responsibility and how they experience care responsibilities (Wittenberg-Lyles et al., 2012). Additionally, these support needs may impact their conformity during interaction, the role they take in communication and the topics they discuss during interaction (Wittenberg-Lyles et al., 2012). Therefore, careful consideration should be given to these support needs by HCPs to ensure that untrained communication partners receive adequate support. These communication partners require support in a manner that extends only one component of rehabilitation (e.g., communication) by bridging and accommodating all the different ecological systems. In this specific population of communication partners, HCPs should listen to the voices of communication partners as persons in an MCS+ are not able to advocate for their own needs. Step 1.3 of this study assisted in gaining a deeper and broader understanding of the support needs of communication partners who care for persons in an MCS+, in terms of how this relates to communication.

The findings from Phase 1 (Step 1.1-1.3) will be used as the foundation for identifying and adapting a CPT programme (Chapter 4) to address the needs identified in this exploratory

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phase. This will ensure that the CPT programme is applicable to the target population and that it targets communication in a holistic manner, thereby bringing about long-term sustainable improvement that will ultimately enhance the quality of life of all stakeholders.

3.11. Conclusion of Phase 1 and recommendations for Phase 2

As communication is a process that involves both a sender and receiver, this phase considered both the person in an MCS+ and their partner. Therefore, the findings from Phase 1 assisted in identifying the unaided communication behaviours displayed by persons in an MCS+ as well as the communication functions accessed by these behaviours. Thereafter, the multimodal communication strategies used by communication partners of persons in an MCS+ as well as their support needs were identified. These findings will lay the foundation for Phase 2 in guiding the identification and adaptation of a CPT programme. Stakeholder perspectives were identified in Phase 1 for example the communication strategies and support needs of the target population. Phase 2 will begin with a review of adult learning principles and trainee engagement targeted in the characteristics of CPT. As adult learning and engagement in training is based on the needs of participants (e.g., need to know and role of prior experience) and assists in the implementation of the skills taught in the programme as well as the maintenance of these skills. These are important considerations for the selection of an E^3BP CPT intervention. Additionally, Phase 2 includes the identification and discussion of an E^3BP CPT intervention to ensure the fidelity of the programme is maintained during the adaptation phase. Phase 2 will conclude with interviews with clinicians with a special interest in neurorehabilitation to obtain their perspectives on the adaptation of the identified CPT intervention.

3.12. Summary of chapter

Chapter 3 outlined the methodology for the study namely a qualitative exploratory collective case study design with three sequential phases each comprising distinct steps. Additionally, the aims, advantages and disadvantages of this methodology was highlighted. Ethical considerations were also discussed as well as techniques for improving trustworthiness in this phase of the study. Data from two different data sources, namely a scoping review (Kuyler et al., 2022b) and synchronous online semi-structured interviews with communication partners of persons who are/were minimally conscious were utilised (Kuyler et al., 2022a).

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Step 1.2. showed that communication partners of persons in an MCS+ use natural multimodal communication strategies to communicate with these persons. Additionally, communication partners reported that persons in MCS+ often use unaided communication behaviours to access a range of communication functions, thereby supporting the findings of the scoping review. Step 1.3 suggested that due to a lack of adequate support by HCPs, these communication partners often experience the care responsibilities as multidimensional within integrating ecological systems. These support needs may impact person-partner communication as well as result in increased experience of care responsibilities for communication partners.

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CHAPTER 4: PHASE 2 - INTERVENTION IDENTIFICATION AND ADAPTATION

Methodology, Results, and Discussion

4.1. Introduction

Chapter 4 is the second of three chapters outlining the research methodology, results, and discussion of each of the three phases of this study. Chapter 3 discussed Phase 1 (i.e., Exploratory Phase), which included the identification of unaided communication strategies displayed by persons in an MCS+; multimodal communication strategies used by communication partners of persons in an MCS+; and their support needs that impact communication. This chapter describes Phase 2, Intervention Identification, and Adaptation. This phase consists of two distinct steps (Step 2.1: Identification of an intervention based on E^{3}BP principles; and Step 2.2: Adaptation of intervention). Each of the two steps comprise of two parts. Step 2.1 entails an umbrella review focusing on the identification of CPT programmes – specifically programmes that employ adult learning principles and trainee engagement and are regarded as being an E^{3}BP intervention. Step 2.1 also includes a description of the design and content of the identified intervention (TBI Connect). As with Step 2.1, the second step (Step 2.2: Adaptation of intervention) also consists of two parts. The first part explores the approach that was utilised to adapt the E^{3}BP intervention (namely Intervention Mapping*),* thereby ensuring that the adapted programme is applicable to the target population (communication partners of persons in an MCS+). The second part of the adaptation step entails synchronous online semi-structured interviews with clinicians who have a special interest in neurorehabilitation to identify components of the programme that require adaptation. This chapter will explain the different steps in more detail.

Figure 4.1 below provides an outline of the chapter and requires conjunctive viewing with the other chapters as the study design is sequential. Phase 2 is included in a block to indicate the focus for this chapter.

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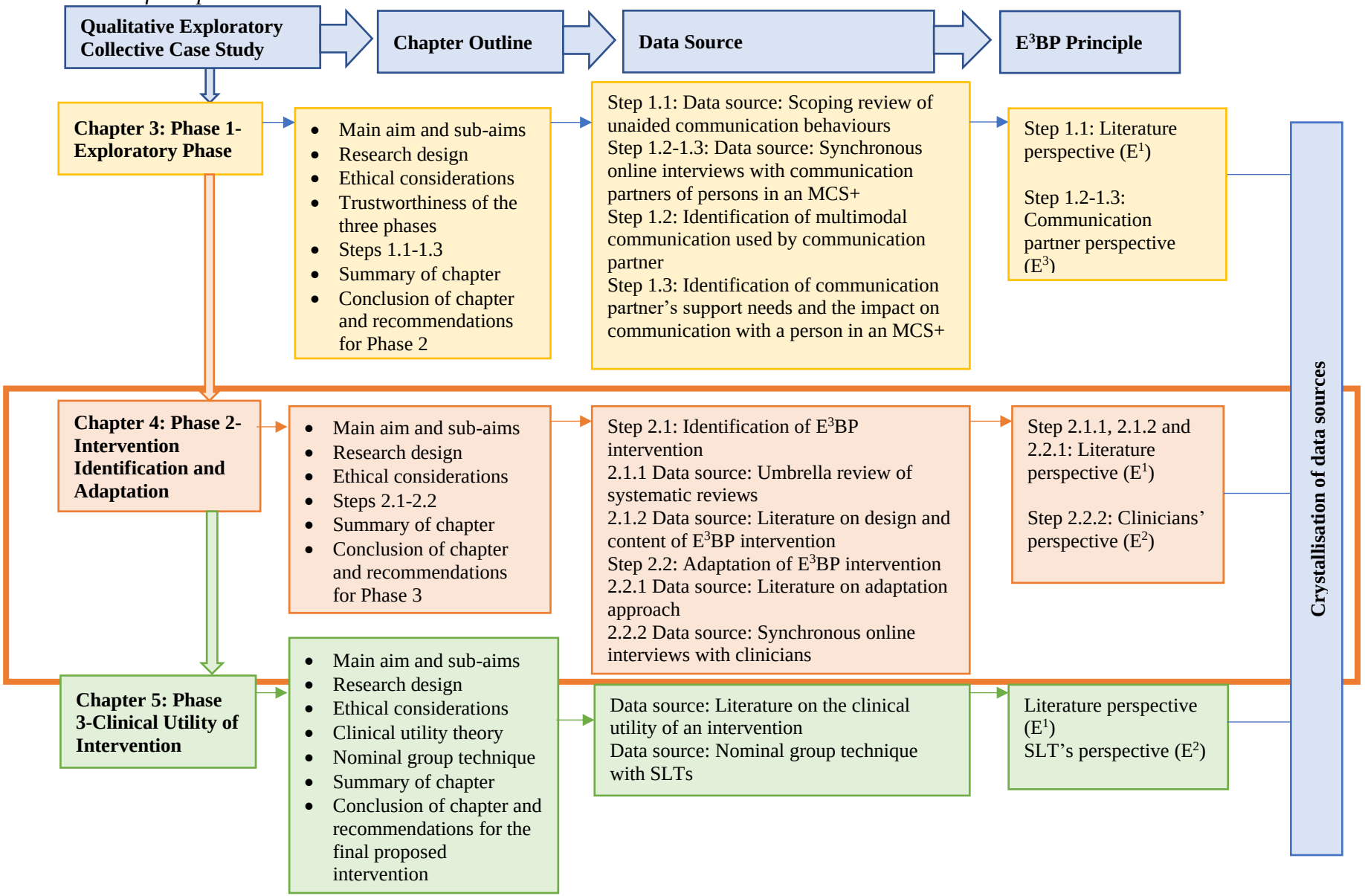
Figure 4.1

Outline of Chapter 4



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Chapter 4 begins with the main aim of the study followed by the aim and sub-aims of Phase 2 that will be the focus of this chapter. The research design and ethical considerations for this phase are discussed, whereafter each of the two steps are sequentially discussed. As explained earlier, Step 2.1 (E^3BP intervention identification) consisted of two separate parts, while Step 2.2 (E^3BP intervention adaptation) also included two parts. Each step includes a conclusion with implications for the next step.

4.2. Research aims

The main aim of this study is to identify and adapt an evidence-based intervention in the form of a communication partner training programme to facilitate interaction between communication partners and persons in an MCS+. In identifying the programme, preference was given to a programme that may empower communication partners to observe, assess, interpret, and respond to the communication behaviours displayed by these individuals.

4.2.1. The main aim of Phase 2

The main aim of Phase 2 is to identify a CPT programme based on E^3BP principles and to adapt this programme based on the recommendations by clinicians with a special interest in neurorehabilitation.

4.2.2. Sub-aims of Phase 2

To address the main aim of Phase 2, five sub-aims were formulated for this phase. The first three sub-aims were related to the identification of the intervention (Step 2.1), while the last two sub-aims were related to the adaptation of the intervention (Step 2.2):

Step 2.1 – Intervention identification

i) To identify the characteristics of CPT programmes that address adult learning principles and trainee engagement strategies.

ii) To identify an E^3BP intervention that addresses these characteristics identified in sub-aim i.

iii) To identify the content and design of the selected E^3BP intervention.

Step 2.2 – Intervention adaptation

iv) To identify clinicians' perspectives on the TBI Connect and adaptations required to ensure that the CPT supports the needs of partners caring for persons in an MCS+.

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v) To adapt the identified CPT programme based on the literature (Phase 1), perspectives of communication partners (Phase 1), and the perspectives of clinicians (sub-aim iv).

4.3. Research design

This research study follows a qualitative exploratory collective case study design with three distinct phases each comprising of different steps. Phase 2, the Intervention Identification and Adaptation phase, includes a qualitative research design consisting of two main data sources, namely an umbrella review of systematic reviews (Step 2.1) and synchronous online interviews with clinicians with a special interest in neurorehabilitation (Step 2.2).

This phase commenced with the umbrella review of systematic reviews to synthesise evidence from existing systematic reviews on characteristics of CPT while utilising the findings and conclusions as raw data (Damery et al., 2016; Ioannidis, 2009; Veronese et al., 2018). This umbrella review only included systematic reviews of CPT programmes and extracted data regarding the characteristics of these programmes that address adult learning and trainee engagement. This review concluded by identifying a potential E^3BP intervention programme (namely the TBI Express) that would be suitable for adaptation for persons in an MCS+. The advantages of umbrella reviews relate to their value in synthesising evidence from multiple systematic reviews into one meta review, utilising the findings and conclusions of systematic reviews (Damery et al., 2016; Ioannidis, 2009). As such, umbrella reviews also assess the quality of the studies included by ensuring that only the highest level of evidence is included (Damery et al., 2016). One limitation of umbrella reviews may be that the characteristics of the interventions are not mutually exclusive and the grouping of these characteristics may be complicated by the variability in programme characteristics (e.g., length and frequency of an intervention vary from one intervention to the other) (Damery et al., 2016; Veronese et al., 2018).

The limitations of the umbrella review were addressed by including perspectives from clinicians in synchronous online semi-structured interviews in Step 2.2. Adding these perspectives allows the identification of characteristics such as frequency and length of intervention by capitalising on the experiences of clinicians who work with the population daily. Hence, synchronous online semi-structured interviews were conducted as the study aimed to obtain insights into the unique perspectives and expertise of clinicians (Adeoye-Olatunde & Olenik, 2021). While, semi-structured interviews are focused, they allow flexibility in exerting autonomy to explore additional ideas that are presented during the interview

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(Adeoye-Olatunde & Olenik, 2021; Kallio et al., 2016). A disadvantage of semi-structured interviews is that the set-up and process may be time-consuming (Adams et al., 2015; Kallio et al., 2016). However, in this phase the duration of the process was contained as the interviews were conducted online, using a strict cut-off time.

4.4. Ethical considerations

As Step 2.1 did not involve human participants, the ethical considerations discussed in this section only refers to Step 2.2.

4.4.1. Principle of informed consent

Informed consent relates to the right of the individual to make an autonomous decision as to whether to participate in research or not (Fields & Calvert, 2015). For informed consent to transpire, adequate information disclosure in an understandable format, voluntary choice, and decision-making capacity needs to be considered (Fields & Calvert, 2015; Nijhawan et al., 2013). The clinicians were provided with letters of informed consent which included the title and rationale of the phase as well as a detailed description of the phase aims and exactly what was expected from participants. It was reiterated that ethical principles would be upheld and all necessary information was disclosed in the letter of informed consent (Appendix H1-H3) and repeated prior to commencing with the interview. Additionally, the clinicians had able decision-making capacity as they all held at least a bachelor's degree in their relevant fields, indicating their cognitive capacity to make decisions.

4.4.2. Principle of voluntary participation and withdrawal

This principle is linked to informed consent but specifically relates to clinicians' personal willingness to participate in the phase. Participants were ensured during the interview as well as in the preceding letter of informed consent, that participation is voluntary and that they may withdraw their participation at any time during the data collection procedures without any negative consequences. No participants opted to withdraw.

4.4.3. Principle of privacy (confidentiality)

Confidentiality can be defined as an agreement made to maintain access control to the participants information (Cooper & McNair, 2015). This phase respected participants' confidentiality by explaining to the participants that access to their information is limited to the researcher and supervisors. Additionally, participant numbers were used during data collection

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procedures and stored on a password protected computer. No third party had access to identifying information of participants. Due to the relatively small sample size, demographic data were also presented in ranges or as group data and did not specify individual participant information when reported (Morse & Coulehan, 2015).

4.4.4. Principle of beneficence

To ensure that all the participants benefitted equally from participating in this research, an interview script (Table 4.10 on page 4-52) was developed. The interview script increased the transparency of the data collection procedures ensuring that participants received all the information (Hofmann, 2009). All the participants were interested in the topic and benefitted from the phase by contributing knowledge to the field of disorders of consciousness, however, also obtaining more information on the topic at hand to improve their own knowledge and skills.

4.4.5. Principle of non-maleficence

All research procedures were structured to ensure that no harm was caused to participants (Newman & Kaloupek, 2009). The content of the interviews was of such a nature that no sensitive information that may lead to emotional vulnerability was required from the clinicians.

4.5. Intervention Identification (Step 2.1)

Step 2.1 focused on the identification of a suitable intervention programme and includes two parts namely; Step 2.1.1 which is discussed first (umbrella review of systematic reviews which focuses on identifying characteristics of a CPT programme that addresses adult learning principles and trainee engagement strategies as well as the identification of an E^3BP intervention that includes these characteristics) followed by Step 2.1.2 (providing literature on the design and content of the identified E^3BP intervention).

Several of the following paragraphs were adapted from an excerpt of the manuscript currently under review entitled "*An umbrella review of systematic reviews: Characteristics of CPT that facilitate learning in communication partners of adults with acquired neurological conditions*" (Kuyler et al., under review-a).

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4.5.1. Umbrella review (Step 2.1.1)

This step focused on identifying characteristics of CPT that address adult learning principles and trainee engagement strategies. Additionally, these characteristics provided a foundation to select an E^3BP intervention for communication partners of persons in an MCS+, by means of an umbrella review of systematic reviews (2.1.1). This specific umbrella review was prompted due to the discrepancies in current literature regarding the application of adult learning and trainee engagement in CPT, as evidenced by the results of the earlier systematic reviews which had been conducted (Cruice et al., 2018; Eggenberger et al., 2013; Simmons-Mackie et al., 2010).

CPT thus aims to equip the communication partner with the skills and knowledge to observe, acknowledge and accommodate the communication attempts of these adults by capitalising on communication techniques and tools that these adults understand (Jensen et al., 2015). Such techniques and tools can include a range of communication strategies to support interaction such as providing structure by using a communication support that the person understands, providing them with opportunities to communicate, and setting up the environment to facilitate interaction, using cueing (e.g., providing visual, tactile, or auditory cues when the person has word-finding difficulties during interaction), and employing expectant time delay strategies (e.g., actively waiting and giving the person sufficient time to respond). Employing such techniques create positive experiences and typically lead to more successful interactions (Behn et al., 2021; Cruice et al., 2018). It is important to train communication partners to create successful interaction, as adults with acquired neurogenic communication disorders often perceive these partners as one of the most prominent communication barriers to their participation (Croteau & Le Dorze, 2006; Emerson & Enderby, 2000). These partners tend to speak for the person rather than supporting the person to make their own contribution during interaction (Croteau & Le Dorze, 2006). Additionally, adults with acquired neurogenic communication disorders commonly experience their communication partners as acting uncomfortable and awkward around them, as misunderstanding them, as providing limited interaction opportunities, and as being unaware of how to support them (Jensen et al., 2015). Often, when adults with an acquired neurogenic communication disorder experience improved communication participation or engagement, their self-reported health outcomes, subjective well-being, and quality of life increase (Simmons-Mackie et al., 2010). These qualities are understandably also reflected by the communication partner as

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communication is co-constructed (Kagan et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016).

However, even when including the communication partner as well as the adult with an acquired neurological disorder, the success of the CPT programmes may still be affected (Van Rijssen et al., 2021). Various factors can influence the success of the training such as andragogy (i.e., the use of adult learning principles), the teaching style of the trainer (e.g., social learning strategies employed, materials used, presentation of information), and trainee engagement (Cruice et al., 2018; Van Rijssen et al., 2021). These factors may impact the quality of the training and the training outcomes as well as predict training transfer (Moore et al., 2013). In this review, emphasis is placed on the components of CPT programmes that target adult learning principles and trainee engagement to promote the successful transfer to other settings. Research has shown that learning in adults occurs when they are self-directed, autonomous, motivated, interested and cognitively engaged in the content of the programme (Moore et al., 2013; Rangel et al., 2015). Knowles (1984) suggested six critical adult learning principles, namely: a) having a need to know which relates to understanding the reason and value of training and applying it to current life objectives; b) being orientated to learning by applying knowledge in the current situation; c) readiness to learn by relating life and developmental tasks to the social usefulness of the content; d) building on prior experience to connect content to own life experience; e) internally motivated relating to the experience of needs, interests, and benefits satisfied through learning; and f) self-concept reflecting an internal locus of control that dictates responsibility for own life and decisions (Caruth, 2014; Mews, 2020). According to Tessier et al. (2020), these principles have been criticised in literature as not including participant experience in training. To address this and ensure that training is effective, these adult learning principles proposed by Knowles (1984) were embedded in trainee engagement.

Trainee engagement refers to being actively involved in the learning experience (Moore et al., 2013; Rangel et al., 2015). Frade and Veiga (2014) described engagement in three domains, namely: a) cognitive engagement which refers to using metacognition to plan, monitor, and evaluate the completion of tasks such as applying learning strategies and effort on tasks; b) behaviour engagement which reflects on adhering to the training protocol, the effort needed to persist, concentration, contributing to tasks and attention; and c) emotional engagement which suggests a subjective state where the trainee is completely engaged and experiences a sense of belonging and value. As learning is a continuous process, these six

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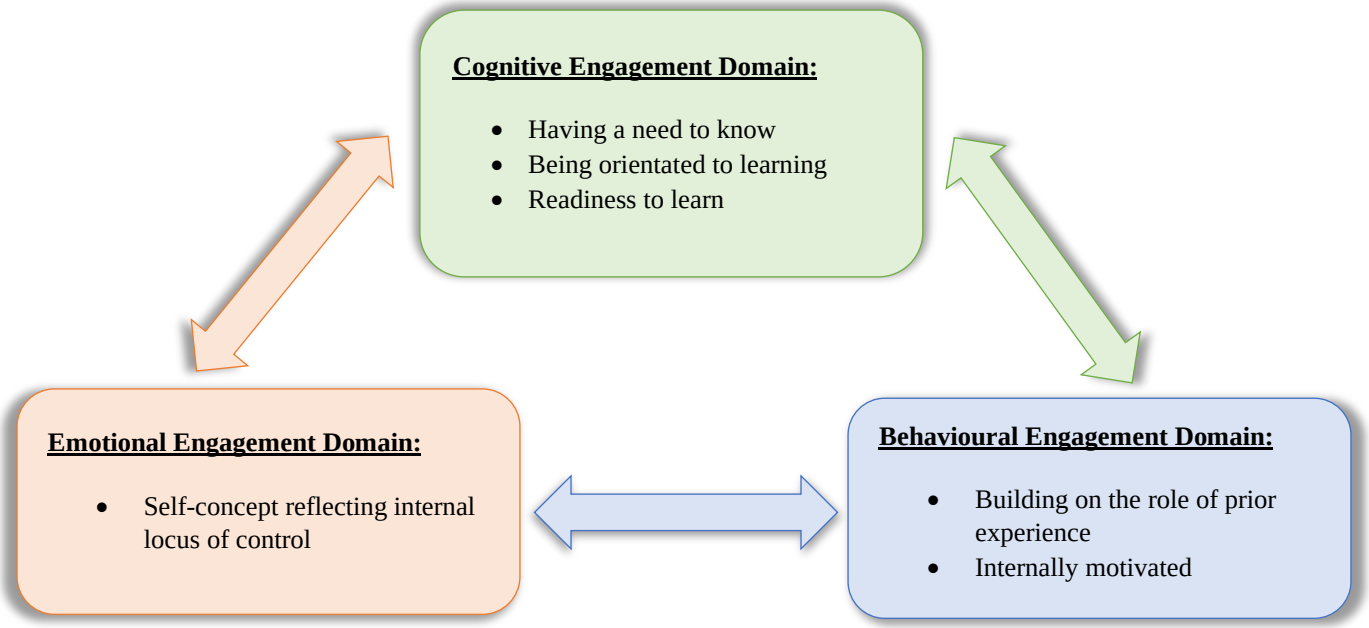
principles of adult learning (Knowles, 1984) can also be embedded in the three domains of trainee engagement (Frade & Veiga, 2014), in order to provide the conceptual framework for this review, and is presented in Figure 4.2.

Figure 4.2

Adult learning principles embedded in trainee engagement for continuous learning



CPT programmes that are founded on a combination of adult learning principles and embedded in the three domains of engagement, may foster an autonomous, self-directed, and practical application of skills and knowledge targeted in such training programmes for transfer to various natural communication settings. It is of pivotal importance that CPT be based on current evidence as this evidence informs clinical decision-making for SLTs (McCurtin & Clifford, 2015; Wiseman-Hakes et al., 2020). Therefore, the aim of this umbrella review was to identify the characteristics of CPT that address adult learning principles and trainee engagement in training. This umbrella review also assisted in the identification of an E^3BP intervention programme which can be adapted for communication partners of persons in an MCS+.

4.5.2. Method

The population, exposure and outcome approach was used to ensure that this umbrella review included information relevant to the main aim, namely to identify characteristics of CPT programmes (exposure) that incorporate adult learning principles and trainee engagement for

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familiar or unfamiliar partners of adults with various acquired neurogenic communication disorders – of both a chronic and neurodegenerative nature (population) to facilitate the acquisition of skills (outcomes).

Following the appropriate selection of relevant search terms, relevant interfaces, namely Ebscohost, Scopus, ProQuest, and Cochrane were used to access databases such as Medline, CINAHL, PubMed, Psycharticles, Academic Search Complete, Humanities Source, Health Source: Nursing/Academic Edition, Taylor and Francis, APA PsychArticles, and APA Psychinfo. Reference lists of studies relating to the topic were also screened to identify additional sources (Khalil et al., 2016; Manafò et al., 2018; Tricco et al., 2018). Search terms included Boolean operators (OR; AND) and truncation and were used in all fields – including keyword, title, abstract, subject terms, and mesh terms. This aided in the quality control of searches and potentially minimised errors during data entry (Varker et al., 2015).

A total of 11 systematic reviews were included for the full-text selection. The title and abstract selection procedures were replicated for the full-text selection phase. During this phase, 95% consensus was obtained between the authors. After synchronous online discussions, a final consensus of 100% was obtained. Only three systematic reviews were excluded as they had limited information on characteristics of CPT programmes which resulted in a final inclusion of eight systematic reviews. Table 4.1 describes the eight systematic reviews that were included.

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Table 4.1

Inclusion of systematic reviews

Content	Keywords	Inclusion	Exclusion	Rationale
Population: Familiar or unfamiliar communication partners of adults (e.g., 18 years and older) with acquired neurogenic communication disorders of both a chronic and neurodegenerative nature	*Familiar partners*: Caregiver OR spouse OR partner OR carer OR family OR paid OR unpaid OR untrained OR informal. *Unfamiliar partners*: Caregiver OR carer OR healthcare practitioner OR trained OR formal	Both trained (healthcare practitioner) and untrained (family, partner, or friend) partners of persons with acquired neurological disorders were included. Acquired neurological disorders include TBI, CVA, brain cancer or tumours, dementia, and Alzheimer's disease and other neurodegenerative disorders (i.e., Parkinson's disease, Amyotrophic Lateral Sclerosis)	Communication partners of adults with cerebral palsy, autism spectrum disorder, cognitive and learning disorders, and suchlike were excluded	Communication partners of adults with acquired neurological disorders require adequate support and training to effectively facilitate communication interaction with these adults (Bradley, 2015)
Exposure: Structure and layout of CPT programmes	Communication OR conversation OR interaction AND Intervention OR training OR education	Systematic reviews on CPT are included. These systematic reviews need to include characteristics of CPT (e.g., duration of programme, duration of training sessions, training strategies based on adult learning principles and withdrawal) as well as the layout of the sessions (e.g., includes theoretical and practical information during sessions)	All studies that targeted other dyad such as practitioner-caregiver communication and practitioner-practitioner communication were excluded. Studies targeting high technology communication aids were excluded (e.g., virtual reality training; peer simulation; training aimed at improving physical functioning, leisure activity; or activities of daily living)	Training communication partners may enhance their awareness of potential barriers and facilitators of communication (Behn et al., 2021)
Outcome: Acquisition of skills	The outcomes of the studies should have suggested decreased negative emotions or attitudes toward communication, an increase in knowledge and skills related to communication and suchlike		Systematic reviews not related to said components were excluded	Many similarities exist between the different CPT programmes targeting TBI, aphasia, and dementia (O'Rourke et al., 2018). However, discrepancies exist as limited implementation details were discussed to replicate the studies (Cruice et al., 2018; Eggenberger et al., 2013; Simmons-Mackie et al., 2010)

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4.5.3. Data analysis

A data extraction instrument was compiled to extrapolate data relevant in addressing the aims of the review (Smith et al., 2011). The first author conducted the data extraction and transferred the raw data to an excel spreadsheet (Dawson-Hahn et al., 2017). The focus of this review is to provide a detailed account of the different components and characteristics of CPT programmes and the relation it has to adult engagement and learning. A deductive approach to content analysis was used to analyse the data based on previous theory (adult learning principles and engagement types) (DeFranco & Laplante, 2017). Initially codes were identified and sorted by their similarities and differences abstracting them into categories and eventually sub-categories (education) (Lindgren et al., 2020). These codes relate to labels attached to a phrase or short sequence of text (e.g., diagnosis, symptoms and impact on functioning, and health).

This was followed by the process of abstraction (different constituents were classified to a higher level) and interpretation (moving from descriptions of manifest content to latent content) which resulted in the formation of themes and sub-themes (Lindgren et al., 2020). In this review the categories are organised into themes (i.e., need to know) and sub-themes (i.e., topic). The three authors independently coded the data and collaborated to ensure that a 100% inter-rater agreement occurred when establishing categories, sub-categories, themes, and sub-themes.

4.5.4. Findings

The CPT programmes mentioned most frequently for treating persons with a TBI in the eight systematic reviews as included in the umbrella review was the TBI Express (Behn et al., 2021; Wiseman-Hakes et al., 2020); for persons with dementia the MESSAGE (Morris et al., 2018; Nguyen et al., 2018); and for persons with aphasia, the Supported conversations for persons with Aphasia programme (Simmons-Mackie et al., 2016). All these CPT programmes included both the partner and the adult with an acquired neurological disorder. Additionally, six of the CPT programmes were presented by SLTs, or by other HCPs such as psychologists and nurses (2 reviews) with three reviews not specifying who conducted the training. The findings will be discussed according to the adult learning principles and trainee engagement concepts. Thereafter, the TBI Express that was identified as the most relevant CPT programme that can be adapted for the population of the current phase (namely persons within MCS) will be discussed.

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4.5.4.1. Characteristics of CPT programmes focused on adult learning principles and trainee engagement (cognitive engagement domain)

Three adult learning principles that facilitate cognitive engagement were identified in all the reviews, namely (i) having a need to know (topics of CPT); (ii) readiness to learn (cognitive learning); and (iii) being orientated to learning (learning strategies used in the CPT programmes). The 'having a need to know' principle refers to trainees' understanding the rationale for training and the feasibility during the partner's current life situation. 'Being orientated to learning' reflects the trainee's application of knowledge in the current situation, whereas the 'readiness to learn; principle indicates that the partner (or trainee) realises the need to learn and is prepared to participate in learning activities related to the current situation.

Table 4.2 provides a summary of the characteristics of CPT related to cognitive engagement as related to the three adult learning principles mentioned earlier, namely the 'need to know', 'orientation to learning' and trainees' 'readiness to learn'. These three adult learning principles are shaded in green in Table 4.2. The codes for these findings are presented in Table 4.2.

Firstly, with regards to the 'having a need to know' principle, the programmes focused mostly on components such as provision of information on the background of the disorder, specific information on the programme, its purpose and information on communication (strategies on verbal and non-verbal communication). Furthermore, as part of the 'having a need to know' principle, materials that are both static (text materials) and dynamic (visual and audio output and audio output only) were used. Of the latter, PowerPoint presentations and video-recordings or training videos were used in all the studies.

Secondly, the 'being orientated to learning' adult learning principle was addressed in all the reviews. This included learning strategies to assist in the application of newly acquired skills in the context related to the partner and person (e.g., modelling/demonstrating, repetition of information/revision, role-play).

Thirdly, the programmes addressed the trainees' 'readiness to learn'. This component facilitated cognitive learning in all the reviews through self-awareness and self-monitoring.

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Table 4.2

Characteristics of CPT programmes focused on adult learning principles and trainee engagement (cognitive engagement domain)

Themes (adult learning principle)	Sub-themes Components of Training	Category	Sub-Category	Code
Content of CPT programmes				
Having a need to know (understanding the rationale for training and the feasibility during the partner's current life situation)	Topics (topics addressed in the programme)	Education (providing information and increasing awareness for the partner)	Disorder	• Diagnosis, symptoms, and impact on functioning and health (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Effect of disorder on communication (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Future planning for changing needs of person as the disease progresses (Nguyen et al., 2018) • Person-centred care (Nguyen et al., 2018)
			Programme	Components (e.g., purpose, structure and layout) (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020)
			Communication	• Successful and failed communication (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Communication strategies that support non-verbal and verbal communication (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Negative communication strategies that cause barriers (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Managing different situations/contexts (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020)
			Behaviour	• Managing challenging behaviour (McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010) • Caregiver attitude towards person (Eggenberger et al., 2013)
			Psychological aspects	• Emotional components (e.g., depression and anxiety of partners) (McGilton et al., 2009) • Maintaining personhood (Simmons-Mackie et al., 2016) • Maintaining autonomy and independence (abilities-focused) (Nguyen et al., 2018; Simmons-Mackie et al., 2016)

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Themes (adult learning principle)	Sub-themes Components of Training	Category	Sub-Category	Code
				• Counselling (Nguyen et al., 2018; Simmons-Mackie et al., 2010) • Self-care and relaxation (Nguyen et al., 2018)
			Cognition	• Memory strategies (Nguyen et al., 2018) • Cognitive stimulation (Nguyen et al., 2018) • Perspectives on tools or programmes (McGilton et al., 2009)
			Environment	• Environmental adaptations (Nguyen et al., 2018; Simmons-Mackie et al., 2016) • Multisensory and motor stimulation (Nguyen et al., 2018) • Safety (Simmons-Mackie et al., 2016) • Music (Nguyen et al., 2018) • Participation strategies (Behn et al., 2021)
	Materials (materials used to facilitate the learning of new skills)	Dynamic material (material that changes)	Visual and audio output	• Video recordings/training videos (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • PowerPoint presentations (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • DVD (Morris et al., 2018; Nguyen et al., 2018; Wiseman-Hakes et al., 2020) • Case studies (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020)
			Audio only output	• CD (Wiseman-Hakes et al., 2020) • Audio recordings (Behn et al., 2021; Morris et al., 2018; Simmons-Mackie et al., 2016)
		Static material (material that remains the same)	Text	• Information sheets/fliers (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Manuals (Behn et al., 2021; Nguyen et al., 2018; Wiseman-Hakes et al., 2020) • Workbooks (McGilton et al., 2009; Nguyen et al., 2018; Simmons-Mackie et al., 2010) • Booklets (Eggenberger et al., 2013; Nguyen et al., 2018; Simmons-Mackie et al., 2010) • Handouts (Behn et al., 2021; Eggenberger et al., 2013; Nguyen et al., 2018) • Vignettes (Eggenberger et al., 2013; Nguyen et al., 2018) • Recommended educational readings (Eggenberger et al., 2013; McGilton et al., 2009) • Caregiver guides (Eggenberger et al., 2013) • Cue cards (e.g., with communication techniques, memory cards, reminder cards) (Eggenberger et al., 2013; Nguyen et al., 2018) • Memory books (Eggenberger et al., 2013)

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Themes (adult learning principle)	Sub-themes Components of Training	Category	Sub-Category	Code
				• Posters (Nguyen et al., 2018)
Being orientated to learning (application of knowledge in current situation)	Teaching strategies (strategies used to facilitate the learning of new skills)			• Demonstration/Modelling (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Repetition/Revision (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Hands-on-practice (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Workshops (Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Feedback/Mentorship/Supervision (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Video/audio recording of interaction between caregiver and person (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Case discussions (i.e., brainstorming, planning, problem solving, and analysis of videos) (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Role-play (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Reflection (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Observation (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Provision of instructions (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Rehearsal (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020)

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Themes (adult learning principle)	Sub-themes Components of Training	Category	Sub-Category	Code
				• Games (Wiseman-Hakes et al., 2020) • Exercises (Wiseman-Hakes et al., 2020)
Readiness to learn (partner realises the need to learn and is prepared to participate in learning activities related to current life situations)	Cognitive learning (cognitive processes employed by the participant to learn new skills)			• Self-awareness (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Self-monitoring (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020)

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4.5.4.2. Characteristics of CPT programmes focused on adult learning principles and trainee engagement (behaviour engagement domain)

Two specific adult learning principles related to behaviour engagement were included in the reviews of CPTs, namely internally motivated and building on the role of the trainee's prior experience. This data is presented in Table 4.3. CPT programmes incorporating internally motivated principles were supported by the format of the training and included aspects such as the adaptation of the programme, programme length, the maintenance of skills and intervals of withdrawal of training, the structure of the training sessions, and the strategies employed to facilitate behaviour modification.

The TBI Express was the only programme mentioned in the reviews that allowed for the adaptation of the content and length (Behn et al., 2021). Five reviews included a withdrawal of training at an interval of three months for trainees to generalise skills to their real-life contexts (Behn et al., 2021; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Wiseman-Hakes et al., 2020). Great variability existed with the length of the programme and it appears as if each programme based the length of training on the needs of the trainees. All of the CPT programmes included in the review used a structure that commenced with lectures followed by practicing the newly learned skills taught in training through mentorship. All the trainees included in the training programmes appeared to demonstrate persistence and motivation to complete the CPT and a minority received gratification such as certificates of completion when the training was completed (Eggenberger et al., 2013; Wiseman-Hakes et al., 2020). The findings of this review supporting building on the role of prior experience, included the various theoretical models that served as justification for the development of the different CPTs. Conceptually, all the reviews were based on the social model of disability.

4.5.4.3. Characteristics of CPT programmes focused on adult learning principles and trainee engagement (emotional engagement domain)

Emotional engagement in CPT programmes was related to the self-concept reflecting internal locus of control in trainees and includes training aspects that centre on social connection and self-reported outcomes. Table 4.4. includes more detail on these concepts. All the reported CPT programmes included both individual and group support and the most typical mode of delivery was face-to-face training. The majority of the reviews utilised self-reported outcomes including improved knowledge, skills and attitudes, self-efficacy, facilitated self-

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reflection, and increased satisfaction with the course (Morris et al., 2018; Nguyen et al., 2018; Wiseman-Hakes et al., 2020).

The CPT programmes mentioned most frequently for treating persons with a traumatic brain injury (TBI) was the TBI Express/TBI Connect (Behn et al., 2021; Wiseman-Hakes et al., 2020); for persons with dementia the MESSAGE (Morris et al., 2018; Nguyen et al., 2018), and for persons with aphasia, the Supported conversation for persons with aphasia Conversations programme and Supporting partners of people with aphasia in relationships and conversation (Simmons-Mackie et al., 2010; 2016). These programmes content and structure mostly included adult learning principles that were imbedded in trainee engagement. Appendix A includes the comparison on the different learning principles and trainee engagement concepts included in the different programmes. Table 4.5 includes a comparison of the different programmes.

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Table 4.3

Characteristics of CPT programmes focused on adult learning principles and trainee engagement (behavioural engagement domain)

Theme (adult learning principle)	Sub-theme	Category	Definition	Code
Building on the role of previous experience (the participants' ability to connect the content of the CPT to their own life experience)	Content of CPT	Theoretical model	Theoretical model that forms the basis of CPT and facilitates partner behaviour modification	• Supported conversation (Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016) • Social model (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Snoezelen-multisensory environmental intervention (McGilton et al., 2009) • Nursing child assessment satellite training model (McGilton et al., 2009) • Participation model (Behn et al., 2021; Wiseman-Hakes et al., 2020) • Functional behavioural approach (Wiseman-Hakes et al., 2020) • Behavioural supervisory model (McGilton et al., 2009)
Internally motivated (the participants' experience of needs, interests and benefits satisfied through learning)	Format of CPT	Adaptation	Whether the programme is implemented as prescribed or if it was adapted	• Adapted TBI express (length and content) (Behn et al., 2021) • Unspecified adaptations (Morris et al., 2018; Wiseman-Hakes et al., 2020) • Not adapted (Morris et al., 2018; Wiseman-Hakes et al., 2020) • Not specified (Eggenberger et al., 2013; McGilton et al., 2009; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016)
		Length of programmes	The range of length of the CPT	• 1–24 weeks (Behn et al., 2021) • 1–8 weeks (Eggenberger et al., 2013) • Cognitive components 1–3 days; Behavioural components-3–4 weeks; Psychological components 3–6 months (McGilton et al., 2009) • 1–16 weeks (Morris et al., 2018) • 1–17 weeks (Nguyen et al., 2018) • 1–12 weeks (Simmons-Mackie et al., 2010) • 1–20 weeks (Simmons-Mackie et al., 2016) • 1–10 weeks (Wiseman-Hakes et al., 2020)
		Maintenance of skills	Maintenance of skills after withdrawal and follow-up sessions	• Maintenance (Behn et al., 2021; Eggenberger et al., 2013; Morris et al., 2018; Nguyen et al., 2018; Wiseman-Hakes et al., 2020) • Not specified (McGilton et al., 2009; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016)
		Interval of withdrawal	Timing of maintenance	• 3 months (Behn et al., 2021; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Wiseman-Hakes et al., 2020) • 6 months (Behn et al., 2021; Eggenberger et al., 2013; Morris et al., 2018; Nguyen et al., 2018) • 9 months (Behn et al., 2021; Nguyen et al., 2018)

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Theme (adult learning principle)	Sub-theme	Category	Definition	Code
		Structure	Structure of the training sessions	• Lecture and practice opportunities (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020)
		Participant persistence	Activities during training sessions that allowed for behaviour modification of partners	• Motivation and gratification (e.g., certificate of completion) (Eggenberger et al., 2013; Wiseman-Hakes et al., 2020) • Mentoring by course provider or facilitator (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Persistence to complete course (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020)

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Table 4.4

Characteristics of CPT programmes focused on and adult learning principles and trainee engagement (emotional engagement domain)

Theme (adult learning principle)	Sub-theme	Category	Code
Self-concept reflecting internal locus of control	Format of CPT (format of CPT that allows for social connection)	Mode of delivery	• Face-to-face (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Video conferencing (Behn et al., 2021; Wiseman-Hakes et al., 2020)
		Type of support	• Individual (Behn et al., 2021; Eggenberger et al., 2013; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Group (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020)
	Self-reported outcomes (outcomes related to participants self-reports)	Affect upon course completion	• Decreased depression (Eggenberger et al., 2013) • Improved general affect (Eggenberger et al., 2013) • Positive attitude (McGilton et al., 2009) • Satisfaction with training (Morris et al., 2018; Nquyen et al., 2018; Wiseman-Hakes et al., 2020) • Improved confidence (Simmons-Mackie et al., 2016)
		Self-reported competence	• Self-reflection (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Self-efficacy (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020) • Increase knowledge, attitude, and skills (Behn et al., 2021; Eggenberger et al., 2013; McGilton et al., 2009; Morris et al., 2018; Nguyen et al., 2018; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016; Wiseman-Hakes et al., 2020)

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Table 4.5

Comparison of CPT programmes

#	Programme	**Adult learning principles embedded in trainee engagement domains mentioned in reviews**								
		Cognitive engagement			**Behaviour engagement**		**Emotional engagement**	**Individual or group**	**Adaptable**	**Evidence**
		Having a need to know	Being orientated to learning	Readiness to learn	Building on the role of prior experience	Internally motivated	Self-concept reflecting internal locus of control			
1	TBIconneCT	✓	✓	✓	✓	✓	✓	Individual	Yes (length and content)	Single case experimental design (Behn et al., 2021)
2	TBI Express	✓	✓	✓	✓	✓	✓	Group	Yes (length and content)	Randomized control trial (Behn et al., 2021)
3	Supporting partners of people with aphasia in relationships and conversation (SPPARC)	✓	✓	✓	✓	✓		Group	Exact script	Experimental study of six cases (Eriksson et al., 2016)
4	Supported conversations for persons with Aphasia	✓	✓	✓	✓	✓		Group	Exact script	Controlled Trial (Simmons-Mackie et al., 2010; 2016)
5	Maximise attention, watch your expression and body language, keep it simple, support their conversation, assist with visual aids, get their message, encourage and engage in communication (MESSAGE)	✓	✓	✓	✓	✓		Individual	Exact script	A controlled pretest posttest study (O'Rourke et al., 2018)

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4.5.5. Discussion

The aim of this review was to identify the specific adult learning principles embedded in trainee engagement facilitated by the characteristics of CPT programmes targeting both familiar and unfamiliar partners of adults with acquired neurogenic communication disorders. Despite the diverse evidence base and variations within and across reviews in terms of the characteristics, duration, and intensity of interventions, some positive trends were evident. From the findings of this study, it appears as if the majority of CPT programmes included all the principles of adult learning across different domains of engagement in training. The CPT programmes included in this review appear to include aspects of cognitive engagement which can facilitate the immersion of trainees in in-depth reflective learning processes that are situated in realistic problem-solving tasks (Hospel et al., 2016). The findings of the current review support the notion that communication-partner training incorporates cognitive engagement as the trainees are expected to use cognitive and metacognitive strategies during the training to understand and master related knowledge and skills respectively. Additionally, findings suggested that cognitive engagement can be facilitated through trainee motivation by being orientated to learning and to use deliberate and sustained attention during CPT which requires a mental effort. The findings of this review also confirmed that readiness to learn was a learning principle that can enable cognitive engagement of trainees due to trainees' application of metacognition and self-regulated learning. This can allow trainees to engage in effortful tasks with purpose and for continued use of strategies (Hospel et al., 2016).

The CPT programmes mentioned in the studies also appear to target behaviour engagement facilitated by the participation of trainees, their motivation to complete the training and their involvement during learning activities (Hospel et al., 2016). Trainees' internal motivation can be supported by their ability to set learning objectives based on their individual needs. In particular, Chinnasamy (2013) suggested that the mentorship that trainees receive facilitate their ability to identify their own need for learning and allowed them to identify others as well as their own experiences as the greatest resource for learning. CPT programmes appear to particularly focus on this aspect due to the application of both the adult and the partner who can identify each other as resources for learning. Additionally, seven systematic studies included the review focused on training of both familiar and unfamiliar communication partners. This may benefit adults with an acquired neurogenic communication disorder as it can facilitate the creation of an inclusive society, an accessible environment, and also reduces

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participation barriers within different environments for these individuals (Tessier et al., 2020), which is in line with the social model of disability.

Moreover, by founding CPT programmes on the social model, prior experiential origins can be targeted and environmental barriers to facilitate behaviour engagement can be reduced (Hospel et al., 2016). One critique of adult learning principles is that it does not include the social or cultural aspects of learning (Ekoto & Gaikwad, 2015). According to Booth et al. (2019), communication is a dialogical process which is dictated by socio-cultural and socio-historical influences and therefore should be considered during CPT. To address these influences, the authors of CPT programmes appear to employ the social model of disability.

Emotional engagement included in CPT programmes related to the emotional reactions of trainees during and after the training (Hospel et al., 2016). From the findings of this review, emotional engagement in CPT training appeared to allow trainees' to feel supported which can greatly influence their self-reported outcomes (Hospel et al., 2016). Emotional engagement can also closely relate to trainees feeling satisfied with their learning. Learning satisfaction can encompass both face-to-face and/or blended trainings. Additionally, trainee satisfaction can be influenced by their subjective perceptions of learning experiences as well as their expectations of learning (Ekoto & Gaikwad, 2015). The subjective experience of training can impact on the generalisation of training, maintenance of learnt skills and the effectiveness of the programmes (Passer et al., 2009; Smidt et al., 2007). The majority of CPT programmes appear to target trainee experiences through self-reported questionnaires where trainees commented on positive experiences and skills maintained for months after the initial training period and withdrawal of training. Lastly, generalisation of learnt skills in CPT programmes can be influenced by communication partners reported positive outcomes and application to real-life contexts.

This concludes the excerpt from "An umbrella review of systematic reviews: Characteristics of CPT that facilitate learning in communication partners of adults with acquired neurological conditions" (Kuyler et al., under review-a).

4.5.6. Conclusion of Step 2.1.1

The umbrella review shared that three main programmes were mentioned. These CPT programmes were specific to acquired neurological conditions of persons with TBI such as the TBI Express (Behn et al., 2021; Wiseman-Hakes et al., 2020); for persons with dementia the MESSAGE (Morris et al., 2018; Nguyen et al., 2018); and for persons with aphasia or CVA, the Supported Conversations for persons with Aphasia (Simmons-Mackie et al., 2016). From

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these three CPT programmes, the TBI Express was the only programme that allowed adaptation to the length of the programme as well as the content of the training materials. The other programmes had to be implemented as developed (O'Rourke et al., 2018). Additionally, the TBI Express was based on E^{3}BP principles that focused on including adult learning principles and trainee engagement strategies. According to O'Rourke et al. (2018), when comparing the MESSAGE, Supported Conversations for persons with Aphasia and TBI Express programmes, the TBI Express was the only programme that focused extensively on the provision of information, knowledge, behavioural skills, and skill-building techniques. From the findings of the umbrella review, the TBI Express emerged as the most suitable programme to be adapted for the population of the present study (communication partners of persons in an MCS+). The relevance of this programme to the study at hand is discussed in the next step.

4.6. Step 2.1.2

Following the umbrella review, the TBI Express was identified as the most suitable E^{3}BP intervention for this study as the TBI Express includes the characteristics which were most relevant to this study. Before attempting to adapt this programme, an in-depth analysis of the programme's design in terms of its structure and format as well as its content was undertaken. This also informed the decisions regarding which aspects require adaptations.

4.6.1 Introduction

During the implementation of the TBI Express the authors noted that although the TBI Express was deemed to meet the requirements of an E^{3}BP intervention, not all communication partners of persons with TBI were able to participate in group training sessions due to their location (considerable distance from clinic where group was conducted) (Rietdijk, Power, Brunner, Attard et al., 2019). Hence, the authors of the TBI Express adapted it to not only accommodate group designs but also single-subject designs (TBI Connect) (Rietdijk, Power, Brunner, Attard et al., 2019). This single-subject design appeared more suited for the population of this study as the population of communication partners caring for persons in an MCS+ is relatively small and a group-based CPT programme may not meet the needs of this unique population. As the TBI Express was used to develop the TBI Connect, it is assumed that the same evidence-base can be applied to the TBI Connect (Behn et al., 2021; O'Rourke et al., 2018; Wiseman-Hakes et al., 2020).

Thus, for the purposes of this study, the TBI Connect programme was deemed more appropriate for the population of the present research. Rietdijk, Power, Brunner and Togher

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(2019) suggests that the TBI Connect includes trainee engagement as well as adult learning principles (provision of information, knowledge, behavioural skills, and skill-building techniques) which are beneficial for long-term implementation in different contexts. The TBI Connect is adaptable which further justifies its adaptability to suit the needs of communication partners of persons in an MCS+ (Behn et al., 2021; O'Rourke et al., 2018; Wiseman-Hakes et al., 2020). In the following section, the TBI Connect is discussed in detail as it pertains to the design and content of the programme as well as the adaptation required for communication partners of persons in an MCS+.

4.6.2. Design of the programme

Considering the methodological design of a CPT programme is important as it provides insights into the structure and format of the programme, to ensure appropriate implementation. The design of the CPT programme should be considered when adapting a programme to meet the needs of a target population. Many similarities exist between the different CPTs that target patients with TBI, Aphasia, and Dementia. For example, providing information on the specific disorder, and explaining positive and negative behaviours that either enhance or prohibit communication has been incorporated into most CPTs (O'Rourke et al., 2018). Various systematic reviews were conducted on CPT, however, discrepancies were identified as limited implementation details were discussed to replicate the studies (Cruice et al., 2018; Eggenberger et al., 2013; Simmons-Mackie et al., 2010). Table 4.6 includes the common design components mentioned in these systematic reviews (left-hand column) and highlights how the TBI Connect programme addresses these components (right-hand column). Design components are related to the structure and format of CPT. The structure of CPT includes a pre-test and commitment to the programme, post-test and long-term commitment, generalisation of strategies, post-training support, follow-up, and additional activities (Table 4.6). In Table 4.6, the form of the CPT refers to the format and mode of delivery, location, length of programme, and materials. Table 4.6 also assists with the improved reporting of E^3BP intervention to ensure appropriate implementation in clinical practice (Beavers et al., 2020; Behn et al., 2021; Hoffmann et al., 2014). The latter is needed because when describing interventions and reporting on them, more information than simple labelling or listing of components is needed. For complex interventions, details of key features, including dose, duration, mode of delivery, and essential processes are needed to describe and critically discuss each component of the intervention (Cruice et al., 2018; Hoffmann et al., 2014).

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Table 4.6

Design of the identified CPT programme (TBI Connect) according to its structure, content, materials, and format

Component	Specification	TBI Connect
Structure of programme		
Pre-test and commitment to instructional programme	• Trainers take pre-test measurements of communication partners' spontaneous use of the targeted communication strategy and the communicative participation of the individuals in the natural environment (Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015; Mann et al., 2015). • Trainers introduce the targeted communication strategy and the training protocol to communication partners (Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015; Mann et al., 2015) • Trainers and communication partners discuss communication partners' pre-test strengths and weaknesses in implementing the targeted communication strategy (Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015; Mann et al., 2015). • Communication partners commit to participating in the instructional programme in order to acquire the targeted strategy (Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015; Mann et al., 2015). • The clinician is often proposed as the expert and the locus of power for change, whose perceptions of what constitutes positive or negative communication behaviour tend to determine training goals and processes (Horton & Pound, 2018). However, both the clinician (often the SLT), communication partner, and person in an MCS+ are all regarded as trainees in the CPT programme.	• During the initial meeting, the TBI Connect recommends a pre-test consisting of a discussion of broad goals, a pre-training interview and recording of conversation samples (Rietdijk, Power, Brunner, Attard et al., 2019). • The programme also suggests trainer reflection upon completion of the initial interviews and assessment as well as writing a draft of communication goals for the communication partner-person dyad (Rietdijk, Power, Brunner, Attard et al., 2019). • The pre-interview is then followed by Module 1 of the TBI Connect programme which discusses communication goals of communication partners as well as highlighting various components of communication. • The TBI Connect is structured in a lecture format which regards to the SLT as an expert. Each session includes opportunities for practice (Behn et al., 2021; O'Rourke et al., 2018; Wiseman-Hakes et al., 2020). The TBI Connect targets both the communication partner and person with a TBI (Rietdijk, Power, Brunner, Attard et al., 2019).
Content and materials used in programme		
Post-test and long-term commitment	• Communication partners typically provide feedback regarding their experience of the CPT programmes and of their conversation with persons with acquired neurological conditions by completing a feedback form (Finch et al., 2017; Jensen et al., 2015). • The trainers document and review communication partners' mastery of the targeted strategy and check performance against the baseline of communication partners' strategy implementation and the	• The TBI Connect Manual specifies outcome measures such as the discussion of communication, communication interviews and conversational assessments. Additionally, self-report measures are mentioned (Rietdijk, Power, Brunner, Attard et al., 2019). • However, during the single-case experimental design study of Rietdijk, Power, Brunner, Attard et al. (2019), outcomes were measured by self-reports,

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Component	Specification	TBI Connect
	communicative participation of the individuals with the disorder (Finch et al., 2017; Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015). • Trainers elicit feedback on the impact of the communication partners' implementation of the targeted strategy from the individuals with the disorder and/or their communication partners (Finch et al., 2017; Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015). • Trainers assist communication partners in generating action plans for maintenance and generalisation of the targeted strategy (Finch et al., 2017; Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015).	questionnaires, exchange structure analysis, and blinded conversation ratings (Behn et al., 2021; Wiseman-Hakes et al., 2020). • Fidelity and long-term commitment are facilitated by keeping track of the communication partner's progress (i.e., session data collection, achievement log, and goal tracking) (Rietdijk, Power, Brunner, Attard et al., 2019). Additionally, for cases where limited progress is shown, overt recapping and frequent review of goals as well as troubleshooting is recommended.
Generalisation of strategy **Post-training support and follow-up**	• Trainer's practice implementing the targeted communication strategy across a wide range of settings and plan long-term implementation (Kent-Walsh & McNaughton, 2005). • Post-training support and follow-up is needed during the implementation to support communication partners (Cruice et al., 2018; Gitlin et al., 2005; Mann et al., 2015). Some programmes included a bi-monthly support or 6-weekly group dialogues for support.	• As part of Module 10, a home maintenance kit is provided for the communication partner-person dyad to facilitate generalisation of skills learnt during training. • The TBI Connect training manual as well as previous reports of participants, strongly recommend a follow-up, however, a structured follow-up is not yet included in the programme. • Rietdijk, Power, Brunner, Attard et al. (2019) performed a single-subject experimental study and recommend a withdrawal period of three months after which a follow-up should be conducted to assess the maintenance of skills through post-test measures.
Additional activities	• Additional activities conducted included a psychologist-led and significant other discussion group, playing language games or accessing resources in an exhibit hall with resources and books (Cruice et al., 2018).	• This is not specified in the TBI Connect programme.
Format of programme		
Format of delivery	• The delivery could be either in a group context or be individually done (Cruice et al., 2018; Kent-Walsh et al., 2015).	• The TBI Connect utilises a single-subject experimental design which focuses on individual treatment of a single communication partner and person dyad (Rietdijk, Power, Brunner, Attard et al., 2019).
Mode of delivery	• The mode of delivery can be face-to-face (in-person or video conferencing), or via telephone or email to support supervision and implementation of goals and objectives (Cruice et al., 2018; Finch et al., 2017). Face-to-face is most frequently used.	• The TBI Connect can either be implemented during video conferencing or via in-person face-to-face sessions (Behn et al., 2021; O'Rourke et al., 2018; Rietdijk, Power, Brunner & Togher, 2019).
Location	• The most frequently used locations involved the hospital, rehabilitation clinic or nursing home, the residence of the participants, community centres or mixed settings (e.g., clinic and home) (Cruice	• The TBI Connect programme can be implemented in various settings, however, the developers suggest a residential setting for its implementation as this is the natural

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Component	Specification	TBI Connect
	et al., 2018; Jensen et al., 2015). The majority of communication partners care for patients at home and therefore this location may be preferrable for communication partners (Swan et al., 2018).	familiar environment for both the person with a TBI and the communication partner (Rietdijk, Power, Brunner & Togher, 2019).
Length of programme	• The content of the CPT programme was spread mostly over a period of 12 weeks with one weekly session of 60 to 90 minutes (Simmons-Mackie et al., 2010). The time range of 10–15 hours, falls within the estimated duration for a CPT programme suggested by Simmons-Mackie et al. (2016). Swan et al. (2018) suggested in their systematic review that the average duration of a programme is 12 weeks. • Behn et al. (2021) also suggests that longer programmes tend to have more significant effects than shorter programmes.	• The TBI Connect programme consists of approximately 10 modules which can be implemented in a range of 13-31 weeks, depending on the needs of the person (Rietdijk, Power, Brunner & Togher, 2019). The authors recommend a weekly session of approximately 1.5 hours (Behn et al., 2021; Rietdijk, Power, Brunner & Togher, 2019). (Adaptation to the length will be discussed in the content section).

Materials	• Materials are used to increase the learning experience and engagement in learning (Frade & Veiga, 2014). Additionally, materials can increase fidelity and generalisation of skills taught in training.
	• Adaptations need to be specified and a manual needs to be produced to aid the implementation and replication of the intervention (Cruice et al., 2018; Simmons-Mackie et al., 2016). Using a manual to guide content sessions can assist in improving the fidelity of the CPT programme (Cruice et al., 2018).
		• The TBI Connect includes a manual which outlines the training and provides a 'how to' implement the training. A USB drive is provided with the manual and accompanying materials (Rietdijk, Power, Brunner & Togher, 2019).
		• PowerPoint slides are included for the module content.
		• Printable handouts for use with participants are provided.
		• Video files of conversation examples accompany each module.
		• Additionally, a YouTube channel has been created which includes:
		  • Conversation example videos for each module
		  • An introduction to TBI Connect for families
		  • Webinars on how-to implement TBI Connect
		  • Updates on research findings related to TBI Connect

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The components mentioned in Table 4.6 are based on the TBI Connects single-case experimental design as mentioned in the trainer manual by the developers (Rietdijk, Power, Brunner, Attard et al., 2019). Such a design consists of a set of experimental methods used to assess the efficacy of interventions with a small sample size and includes repeated-sequential methods (Dallery et al., 2013; Krasny-Pacini & Evans, 2018). It is suggested that a single-case experimental design be utilised to assess the clinical utility during implementation of the E^{3}BP intervention with a novel population (Chapter 5) (Dallery et al., 2013; Krasny-Pacini & Evans, 2018). To maintain the feasibility of using the TBI Connect, its structure and format should remain the same even if adaptations are made to the length of the programme, the content, and the materials used to measure outcomes. Even though the implementation of the TBI Connect was not conducted during this study, these aspects are important considerations for application of the programme with the target population. Other adaptations could include addressing barriers and facilitators in conversational strategies identified as pre-assessment or baseline phase, individualised goal setting and subsequent strategy development and practice (Cruice et al., 2018; Jensen et al., 2015). These adaptations are required to ensure that the programme addresses the specific needs of the target population (e.g., in this study the communication partners of persons in an MCS+) (Cruice et al., 2018; Jensen et al., 2015).

4.7. Content of CPT programme

The content of CPT programmes is based on theoretical underpinnings that assist in conceptualising the content and ensuring that the content meets the needs of the target population. As such, the theoretical underpinnings of CPT programmes as suggested by the umbrella review, were based on the social model of disability. Horton and Pound (2018) suggest three main theoretical conceptualisations of CPT programmes, which are critically discussed in the next section together with a CPT programme theory required for persons in an MCS+ and applied to the TBI Connect. In addition, theoretical underpinnings of the TBI Connect is discussed as well as the content modules included for participant training.

4.7.1. Theoretical underpinnings of CPT

Various theoretical models are used to support the foundation for CPT. These include the Activity-Based Communication Analysis model (Ahlsén & Saldert, 2018); Communication Accommodation Theory (Simmons-Mackie, 2018) as well as Supported Conversation (Kagan, 1998). These models are described in more detail in the paragraphs that follow.

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The Activity-Based Communication Analysis model (Ahlsén & Saldert, 2018) discusses how the context, physical, social, and psychological components of programmes are systematically considered during CPT. This approach aims to increase awareness of the components that influence communication and how it can be supported in various social activities (Ahlsén & Saldert, 2018). This model is used to link the social model approach to the life situation and qualitative analysis of communication behaviour in contexts and social activities. As such, the Activity-Based Communication Analysis model thus considers the goals, roles, physical, and psychological conditions of the communication participants as well as the different social activities (Horton & Pound, 2018). These factors influence the patterns of interaction and by analysing them, the conditions for successful communication may be identified and supportive changes can be made. Although this model includes the psychological conditions that effect communication, these conditions are mostly related to the activity and the emotional impact the communication activity has on the communication participants. This theory does not address pre-existing bias or negative attitudes toward persons with severe communication disorders (e.g., with aphasia or persons in an MCS+), although it does include the individual's personality, mood and psychological state (Ahlsén & Saldert, 2018; Horton & Pound, 2018).

As with the Activity-Based Communication Analysis model (Ahlsén & Saldert, 2018), the Communication Accommodation Theory (Simmons-Mackie, 2018) also focuses on factors that can influence the implementation of communication support in conversation with persons with severe communication disorders – specifically persons with aphasia. The main theme of this theory is that conversation partners adjust their communication to accommodate the person with the disorder by creating, maintaining, or decreasing social distance in interaction (Giles & Ogay, 2007). Although this theory has merit, successful interaction with persons with severe communication disorders is mostly dependent on the communication partner and their perceptions as to what accommodations they perceived as being accurate (Ahlsén & Saldert, 2018; Giles & Gasiorek, 2013). Miscommunication can often occur as the adjustments made by the communication partner may not be appropriate to the cultural, linguistic, or behavioural norms required during interaction with persons with severe communication disorders (Giles & Gasiorek, 2013).

Supported Conversation for Adults with Aphasia (Kagan, 1998) was designed to reduce the psychosocial components of aphasia; however, the principles are also relevant for any adult with a severe communication disorder. The main theme in Supported Conversations for adult

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persons with Aphasia is to establish person-communication partner partnerships and to promote conversational success within these partnerships by improving the knowledge and skills of the communication-partner and utilising appropriate resources (Jensen et al., 2015; Kagan, 1998; Kagan et al., 2018). Supported Conversations for adults with Aphasia targets social participation considering the individual, communication partner, communication activity, participation, and the environment and as such, focuses on individuals who have regained some form of verbal communication by adapting the communication partner's method of communication to support functional communication (Ahlsén & Saldert, 2018; Kagan et al., 2018; King & Simmons-Mackie, 2017). Hence, Supported Conversations for adults with Aphasia may not be appropriate for persons in an MCS+ as the persons typically do not use spoken language because of their level of alertness.

4.7.2. Theoretical model relating to persons in an MCS+ and the TBI Connect

For communication to be successful between persons in an MCS+ and their communication partners, an observation approach focused on identifying all communication behaviours (including unaided forms) as well as using expectant delay, may be more successful. The ideal assessment of a CPT is in the observation context (Finch et al., 2017; Kent-Walsh & McNaughton, 2005). Horton and Pound (2018) suggest that using an observation approach can inform social learning. This approach focuses on learning through observation and experience by restructuring prior knowledge and can therefore be used as an instructional technique on which new opportunities for learning are created. Using the social learning approach can therefore assist researchers in determining the causal factors of behavioural change. This is targeted by the intervention and behavioural change techniques and can be refined according to the intervention and needs of the population (Davis et al., 2015). Additionally, the mechanisms of behavioural change can be investigated to evaluate the effect of the intervention as well as how the behavioural change is established through the intervention, inherently also evaluating the unsuccessful components of the intervention (Davis et al., 2015).

Using a social learning approach requires the communication partner to attend to the presented information (attention), to observe, assess and interpret the information, followed with an appropriate response (Haberstroh et al., 2011; Horton & Pound, 2018). Additionally, the communication partners should store the information (retention), access the information (reproduction), and practice the learnt behaviour to facilitate behavioural change and self-motivation (motivation) (Eriksson, Forsgren et al., 2016; Haberstroh et al., 2011; Horton &

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Pound, 2018; Kent-Walsh & McNaughton, 2005). The social learning approach should be and is, the foundation of learning within the TBI Connect as this facilitates the carry-over of newly learnt information to naturalistic settings (Horton & Pound, 2018). Furthermore, a CPT that is based on a social learning approach assists the partner to believe that they have the capability to perform behaviours to produce the desired outcome from the person and as such, will increase the partner's learning and engagement in the intervention (Passer et al., 2009).

Hill et al. (2009) mention that the social learning approach incorporates the context (partner interaction, individual/group sessions, group size and resources) as well as the culture and characteristics of the person (individual learning styles, self-efficacy, and motivation). CPT programmes such as the TBI Connect incorporate the social learning approach by focusing on the context by targeting interactions through the provision of opportunities to practice strategies taught in the programme and supporting the trainee through mentorship and feedback (Behn et al., 2021; Hill et al., 2009; O'Rourke et al., 2018; Wiseman-Hakes et al., 2020). Additionally, the context is targeted as a CPT can either use an individual strategy (TBI Connect) or a group strategy (TBI Express), depending on the needs of the trainee (Behn et al., 2021; Hill et al., 2009). TBI Connect also provides resources and materials to facilitate adult learning and engagement in the programme (Hill et al., 2009; O'Rourke et al., 2018). Various methods of delivery are available (online and face-to-face) that may facilitate connection building by addressing the unique cultural factors relevant to the trainees within the TBI Connect (Hill et al., 2009). The specific characteristics of trainees are also targeted as their beliefs are taken into consideration through joint goal-setting and other teaching strategies that are used to accommodate individual learning styles, self-efficacy, and motivation (Hill et al., 2009; Rietdijk, Power, Brunner & Togher, 2019). The social learning approach is therefore well established as the basis of the TBI Connect. Following, the content of CPT is discussed in detail as well as the possible adaptations to the programme.

4.7.3. Content of TBI Connect programme

The content of most CPT programmes is based on clinicians providing information, building skills, and facilitating social support (O'Rourke et al., 2018). During CPT, the clinician provides feedback, behavioural reinforcements, instructions, problem solving techniques, and explains how the tracking of the programme's development is done (Behn et al., 2021; O'Rourke et al., 2018). Strategies that facilitate communication often include creating opportunities to communicate, often by setting up the physical environment to create such

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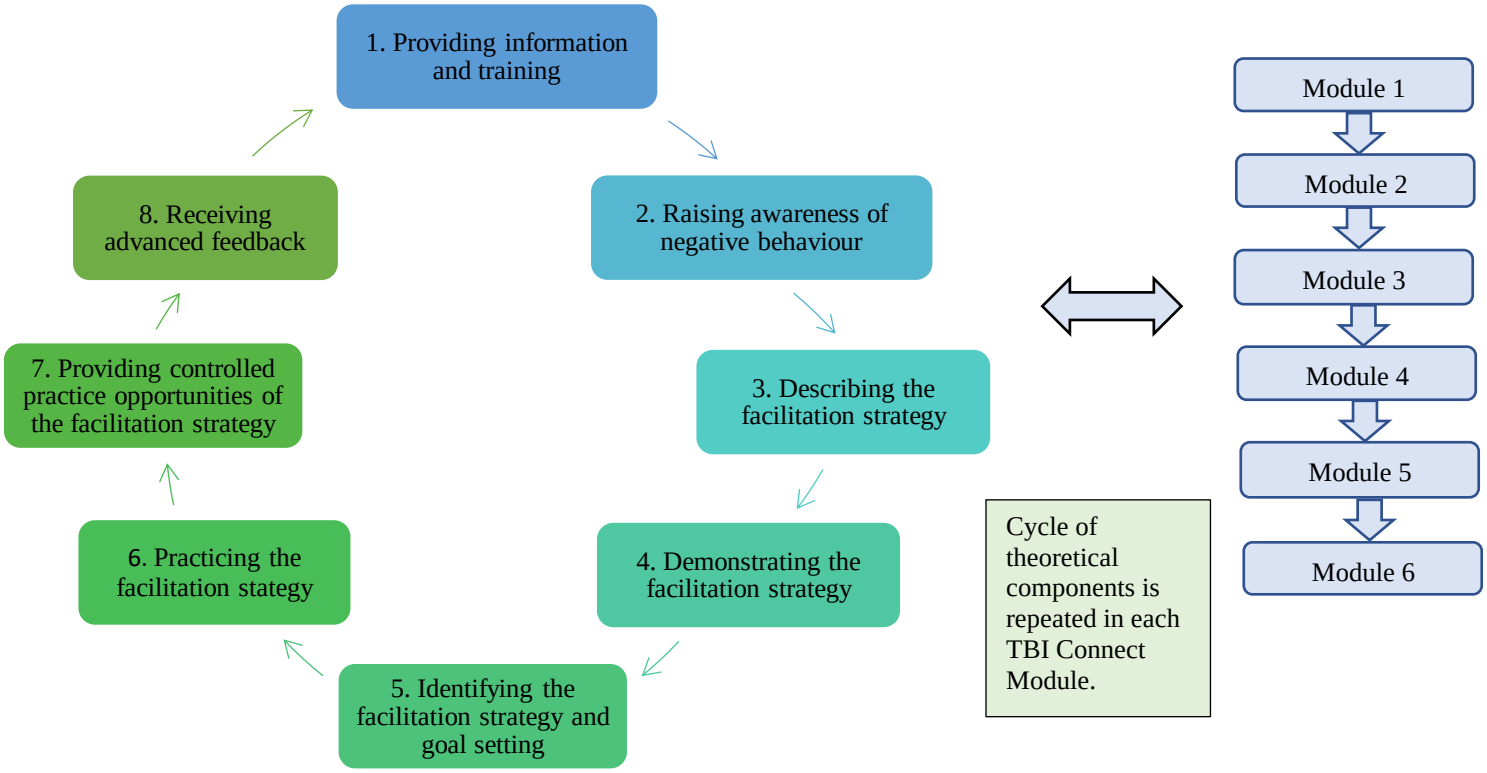
opportunities, and addressing challenging and distracting behaviours (Wiseman-Hakes et al., 2020). The programmes for adults with severe communication disorders such as TBI, Aphasia, or dementia typically focuses on various constructs such as cognitive-linguistic skills, social participation, and communication as separate entities and targets both the individual and the communication partner (Behn et al., 2021; O'Rourke et al., 2018). Figure 4.3 includes theoretical concepts common to various CPT programmes as well as reference to which of these concepts are included in the TBI Connect modules.

Figure 4.3

Theoretical constructs included in CPT programmes



Each of these theoretical constructs are now unpacked in more depth.

4.7.3.1. Providing information and training

This entails the provision of information and training which could include highly specific or general information as well as a personally tailored advice book (Cruice et al., 2018; Eggenberger et al., 2013; Eriksson, Forsgren et al., 2016; Haberstroh et al., 2011; Horton & Pound, 2018; Jensen et al., 2015). Training typically involves providing information on the

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specific disorder, what communication is, and describes the impact of the disorder on communication as well as the communication strategies that could successfully be used with this population (Finch et al., 2017). Other components that are addressed include strategies to increase engagement, facilitating observation skills to enable the partner to observe, acknowledge and reveal competence as well as establish and/or increase communicative access (Jensen et al., 2015).

4.7.3.2. Raising awareness of negative behaviour

Raising awareness of the negative behaviour focuses on partner behaviour that cause participation barriers (such as negative behaviour and attitude as well as limited communication skills of communication partners) is critical (Cruice et al., 2018; Eriksson, Forsgren et al., 2016). Negative behaviours may include but are not limited to, dominating communication; over reliance on yes/no questions; taking on the majority of the roles; providing few opportunities to initiate or take conversational turns; interrupting the person frequently and focusing on communication support instead of focusing on the person or on their message (Kent-Walsh & McNaughton, 2005). The TBI Connect attempts to address negative behaviour during its implementation by reviewing and evaluating video recordings of person-communication partner conversations by the trainees themselves, which can be done with an SLT (Cruice et al., 2018; Jensen et al., 2015). Additionally, role-play could be an effective strategy to improve awareness of the specific communication disability and engaging in conversations (Jensen et al., 2015).

Another aspect that communication partners could explicitly reflect on, is their own behaviour and its impact on behaviour learned by the individual (Cruice et al., 2018). For example, the person with the communication disorder might take on a passive role, if the communication partner is dominant and does not allow communication initiation. Such negative behaviour not only restricts the communication modes that the person will use, but will also reduce the number of communication functions the person attempts to access (Kent-Walsh et al., 2015; Kent-Walsh & McNaughton, 2005). Ultimately, such behaviour by the communication partner may also result in learned helplessness by the person.

4.7.3.3. Describing the facilitation strategy

Trainers describe the target facilitation strategy and its component skills as well as the method for remembering the steps involved in implementing the strategy (Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015). They also discuss the impact of implementing

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the targeted facilitation strategy with both the communication partners and the person-partner dyad (Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015).

4.7.3.4. Demonstrating the facilitation strategy

Demonstrating the facilitative communication strategy is proposed to be done through modelling by SLTs and by showing videos that demonstrate the target facilitation strategy (Cruice et al., 2018; Finch et al., 2017; Jensen et al., 2015; Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015).

4.7.3.5. Identifying the facilitation strategy and goal setting

This entails both the identification and selection of target behaviour to facilitate communication as well as goal setting. It is proposed that observing videos is an effective training strategy to identify communication strategies that facilitate interaction (Cruice et al., 2018; Eriksson, Forsgren et al., 2016; Kent-Walsh & McNaughton, 2005). The strategies that facilitate communication include: using multimodal communication (including unaided communication such as eye gaze, facial expressions, and gestures such as pointing); engaging with the person; using open-ended questions; modelling communication strategies; reducing the speech rate and complexity of speech; utilising yes/no questions; using visual supports (including aided communication such as objects, pictures, or symbols); writing keywords or providing prompts to write; drawing pictures; providing access to low technology communication boards (i.e., pictures with basic needs); using expectant delay; administering patience and understanding; and using a supported conversation method (e.g., Supported Conversations for persons with Aphasia techniques, dialogue books as well as culturally and linguistically appropriate pictorial supports) (Jensen et al., 2015; Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015; Mach et al., 2022; Mann et al., 2015). Another effective strategy is setting up the environment to promote communication by creating different communication opportunities (Kent-Walsh et al., 2015).

4.7.3.6. Practicing the facilitation strategy

Communication partners can be encouraged to practice naming and describing all steps required to implement the target strategy (Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015).

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4.7.3.7. Providing controlled practice opportunities of the facilitation strategy

Practicing the strategies in a controlled manner increases confidence and knowledge when communicating with persons with communication disorders (Finch et al., 2017; Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015). Strategies can be practiced through role-play (Cruice et al., 2018; Eriksson, Hartelius et al., 2016; Jensen et al., 2015). Naturalistic conversations that include feedback from the SLT (verbal and visual) during and after training, or coaching is also an effective strategy (Finch et al., 2017). SLTs can also provide scaffolding in controlled environments by using graded fading of prompting by the partner (Kent-Walsh & McNaughton, 2005). Practice can also include homework to encourage reflection on the usefulness of the strategy and for generalisation.

4.7.3.8. Receiving advanced feedback

Communication partners should practice implementing the targeted strategy in multiple situations within the natural environment, with gradual fading of prompting and feedback (Kent-Walsh & McNaughton, 2005). Figure 4.3 includes theoretical concepts common to various CPT programmes. The next section focuses on specific content of the TBI Connect modules as shown in Table 4.7. Although the original TBI Connect consists of 10 modules, only six were selected for the current phase (i.e., to train communication partners of persons in an MCS+) as the content of the modules focused on elaboration of communication and revising the interactions and skills obtained in training. These skills were not relevant for the target population (at this time) due to the minimal verbal responses typically provided by persons in an MCS+ as a result of their fluctuating levels of arousal, communication partners are not expected to attempt to facilitate longer conversations with these individuals.

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Table 4.7

Existing content of TBI Connect programme

TBI Connect Programme Content	
Module 1: Introduction • Setting the scene for the processes and content within the TBI Connect • Discussing communication goals • Tuning in to various aspects of interaction (via videos) *These slides include* • Discussing expectations of training • Discussing the outline of the programme • Discussing why communication partners should be included • Discussing the topics that will be covered • Discussing the main goals of training • Discussing the participant's individual/specific goals • Discussing the format of a session (i.e., what happens during a session) • Discussing the importance of the trainee participation • Discussing homework activities • Becoming an 'interaction watcher' (i.e., observation skills) • Practicing interaction • Reviewing practice interaction • Recording the interaction at home • Sending the practice interaction to the instructor • Doing homework.	**Module 2: TBI and communication** • Discussing and reviewing homework activities based on interaction videos supplied by participants • Background information on TBI *These slides include* • Identifying the 'ingredients' required for effective interaction (getting something done, listening, sensitivity, easy, enjoyment and teamwork) • Discussing common problems with communication after TBI, difficulties with flexible thinking, awareness, reasoning, self-control, organising, memory, attention, emotion, motivation, how the ingredients for good interaction can be applied and positive changes in interaction when these ingredients are applied accurately • Reviewing homework interaction video as well as discussing both positive and negative components of interaction • Practicing interaction for homework Trainer compiles session summary and sends to the participant.
Module 3: Playing your role • Understanding communication situations that require a 'formula or a 'script' to follow • Exploring strategies for playing a particular part/role • Changing the approach depending on context • Generating key words to define one's ideal communication approaches *These slides include* • Discussing and reviewing the homework activity based on interaction videos supplied by trainees • Describing situations in which interactions have scripts and those which are spontaneous • Underlining the importance of partners playing their part on all situations • Defining and describing what components affect interaction in different situations (who we talk to, where we talk, why we talk (as well as why persons in an MCS+ communicate), how we communicate to a person in an MCS+ and adding personality to different roles) • Showing videos to facilitate understanding of information • Practicing new skills • Reviewing practice of new skills • Providing a homework activity Trainer completes session summary and sends emails to participants.	**Module 4: Effective speaking and listening** • Understanding communication as a cooperative process involving effective speaking, listening, and turn-taking • Discussing personally relevant strategies for the above • Reviewing progress *These slides include* • Discussing and reviewing homework activity based on interaction videos supplied by trainees • Describing the function of communication and role of both the listener and speaker during interaction • Discussing what happens if a message is not communicated effectively • Discussing what the trainee is an expert on • Assisting the person with the communication disorder in becoming an expert in communication • Showing videos to facilitate understanding of information • Practicing new skills • Reviewing practice of new skills

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TBI Connect Programme Content

Module 5: Collaboration	**Module 6: Putting it all together**
• Watching resource video examples for evaluating 'working together' and supporting one another • Discussing personally relevant strategies for the above *These slides include* • Discussing and reviewing homework activities based on interaction videos supplied by the trainee • Discussing the importance of collaboration • Differentiating between positive and negative collaboration • Identifying a metaphor to describe interaction • Discussing different metaphors for providing support • Highlighting teamwork (positive and negative teamwork) • Providing thinking support (i.e., information) • Providing emotional support • Asking positive questions • Facilitating positive turn taking • Practicing new skills • Reviewing practice of new skills.	• Discussing achievements • Discussing next steps and reviewing resources for maintaining and continuing progress *These slides include* • Discussing and reviewing homework activities based on interaction videos supplied by the trainees • Explaining the communication maintenance kit • Summarising achievements • Providing a home maintenance plan • Providing a toolkit of communication strategies • Providing information to persons who are uninformed • Setting new goals • Showing videos to facilitate understanding of information • Practicing new skills • Reviewing practice of new skills.

4.7.3.9. Conclusion Step 2.1.2

From this step of Phase 2, it is clear that the content of the TBI Connect includes all the theoretical constructs suggested for effective E^{3}BP intervention. It also includes characteristics of E^{3}BP intervention that incorporate adult learning principles and trainee engagement. Although both the design and content of the TBI Connect include many aspects that are evidence-based, the design of the programme requires shortening and the content requires adaptations as the principles may not be applicable to communication partners of persons in an MCS+, in its current form.

4.7.4. Conclusion from Step 2.1

From the findings of the umbrella review and the description of theoretical constructs from literature to identify an intervention that is evidence-based, it can be concluded that the TBI Connect programme is an appropriate E^{3}BP intervention. The evidence supports the application and implementation of the TBI Connect for communication partners of persons with TBI. As evidence only suggests effective implementation for this population, it cannot be implemented as is for communication partners of persons in an MCS+. Persons with TBI often regain verbal communication to maintain social interaction, however, persons in an MCS+ may display subtle unaided communication behaviours rather than verbal communication. The TBI Connect therefore presents certain shortfalls for implementation with communication partners of persons in an MCS+. This necessitated potential adaptations for this specific population

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under investigation and their communication partners. The adaptation process is addressed in Step 2.2.

4.8. Step 2.2: Intervention adaptation

The second step of Phase 2, the intervention adaptation, is discussed and set out in two parts. Firstly, a discussion is included on the Intervention Mapping approach which guides the adaptation process of the TBI Connect (Step 2.2.1). This step is then followed by the second step that aims to identify what and how adaptions are required as seen from perspectives of clinicians with a special interest in neurorehabilitation. This was achieved by means of synchronous online semi-structured interviews (Step 2.2.2).

4.8.1. Introduction to Intervention Mapping (Step 2.2.1)

Intervention Mapping assists in ensuring that the adaptation of a new programme is evidence-based by integrating existing programmes with proven research rigor with those that are used in clinical practice (Escoffery et al., 2019). Since the E^{3}BP intervention mentioned earlier is not necessarily multifunctional, adaptations to the content, delivery, logistics, training, and evaluation of the programme are needed to ensure applicability to the target population (i.e., communication partners of persons in an MCS+). Despite the necessity of these adaptations, the fidelity and effectiveness of the programme needs to be maintained by using a an E^{3}BP approach or protocol (Escoffery et al., 2019). In a scoping review conducted by Escoffery et al. (2019), the Intervention Mapping approach or protocol (Bartholomew et al., 2011) was suggested as an effective means to guide the programme adaptation process to facilitate lasting behavioural change. Intervention Mapping also guides the design of multidimensional health promotion intervention and implementation strategies (Fernandez, Ruiter, et al., 2019). It is based on E^{3}BP principles which include a dyad of the highest level of evidence (literature), as was done in Step 2.1 of this phase of the research as well as stakeholder perspective and clinical expertise (which is done in Step 2.2.2 of this phase) (Bartholomew et al., 2011; Escoffery et al., 2019; Fernandez, Ruiter, et al., 2019; Kok et al., 2016; Koul & Corwin, 2011). The main aim of Intervention Mapping is to develop strategies to improve the adoption, implementation, and maintenance of clinical guidelines and E^{3}BP intervention (Fernandez, Ten Hoor, et al., 2019). This approach includes six steps as shown in Table 4.8 (Bartholomew et al., 2011; Escoffery et al., 2019; Fernandez, Ten Hoor, et al., 2019; Kok et al., 2016; Koul & Corwin, 2011) and each step acts as a building block for the following step (Kok et al., 2016).

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The Intervention Mapping approach has various benefits specifically for the current study as its main aim is to adapt an existing CPT programme to be suitable for communication partners of persons in an MCS+. The six steps in this approach can therefore guide the process of programme adaptation ensuring the fidelity within the study as well as facilitating behavioural change based on theory (Bartholomew et al., 2011). These six steps, the characteristics of each of these six steps as well as its relevance to the current research are included in Table 4.8.

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Table 4.8

Intervention Mapping for adapting an E³BP intervention: Application to study

Intervention Mapping (Bartholomew et al., 2011)	Characteristics of Steps (Escoffery et al., 2019)		Application to Study
Steps	**Characteristic**	**Definition**	
1. Establish a detailed understanding of the problem	**Assess the target population**	• Identify behaviour risks and determinants of the target population using interviews, needs assessment, or logic models • Assess the capacity to implement the programme	This step was completed during Phase 1 and included a scoping review and in-depth interviews. The aim of the scoping review was to identify the unaided communication behaviours. Furthermore, synchronous online interviews were conducted with communication partners of persons in an MCS+ to identify their multimodal communication strategies as well as their support needs. This assisted in understanding the communication partners' challenges.
2. Describe the behavioural and environmental outcomes, create objectives for change in the determined behaviour and specify the targets of the programme	**Understand the intervention**	• Identify and review E³BP intervention and the programme materials • Understand the theory behind the programmes and the core elements (i.e., content)	This step was completed as part of Phase 2. Step 2.1 focused on the identification of characteristics in CPT that include adult learning principles and trainee engagement. This step also focused on the identification of an appropriate E³BP intervention by using an umbrella review of systematic reviews. Additionally, the rationale for the CPT programme was discussed as well as the design and content. Based on the above-mentioned recommendations, the TBI Connect CPT programme was selected.
	Select the intervention	• Select the programme that matches the target (i.e., new) population	
3. Identify the theory- and evidence-based behavioural change methods that influence the determinants of behaviour and translate to practical applications that fit the context	**Decide what needs adaptation**	• Decide whether to adapt the original programme or develop a new programme • Select E³BP intervention using new target population • Retain fidelity on core elements • Systematically reduce mismatches between the programme and the new population	This was addressed during Step 2.2 (Phase 2) of the study which focused on the adaptation of the TBI Connect programme. After describing the approach that guided the adaptation, synchronous semi-structured interviews were conducted with clinicians in Step 2.2 to determine what aspects of the programme they perceive need adaptation and how adaptations should be made to ensure applicability to the target population. Step 2.2.2 (Phase 2) included synchronous semi-structured interviews with clinicians with a special interest in neurorehabilitation. During this step, clinicians were asked if they would consider advocating for the implementation of the adapted CPT programme within their practice. All clinicians agreed that such a programme is of high need as no similar programmes exist that they were aware of. Clinicians invited the researcher to provide training at their practice once the programme had been finalised. They
	Consult with experts	• Consult content experts, including original programme developers • Incorporate expert input into the programme	
	Consult with stakeholders	• Seek input from the organisation where programme is to be implemented	

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Intervention Mapping (Bartholomew et al., 2011)		Characteristics of Steps (Escoffery et al., 2019)		Application to Study
	Steps	**Characteristic**	**Definition**	
			• Identify stakeholders that will be able to advocate the implementation of the programme in the new setting	were complimentary in their feedback, stating that such a programme had been needed for a long time.
4.	Combine the intervention components into a coherent programme that uses delivery channels that fit the context	**Adapt the original programme**	• Develop an adaptation plan • Adapt the original programme content through collaborative efforts • Make cultural adaptations continuously through piloting • Identify core components responsible for change that should not be modified	Phase 2 concluded with the adaptation of the TBI Connect programme based on data from Phase 1 and 2. Phase 3 aimed to ensure that the fidelity of the TBI Connect programme is not compromised and to identify the clinical utility of the programme. This process included a nominal group technique with SLTs. The author of the TBI Connect programme has also been contacted to request her participation within the programme adaptation to ensure that fidelity of the programme is not compromised during adaptation. They have mentioned that they will review the study upon completion.
		Train staff	• Select and train staff	
5.	Develop implementation strategies to facilitate adoption, implementation, and maintenance of the programme	**Test the adapted materials**	• Pre-test adapted material with stakeholders • Conduct readability tests • Pilot test adapted E^{3}BP intervention in new target population • Modify E^{3}BP intervention if necessary	<u>Steps 5 and 6 fall beyond the scope of the current PhD study. However, to ensure maximum uptake of the programme, the following future recommendations are suggested</u>: • Training of staff within the relevant context. • Identifying and testing materials. • Implementing the Connect+ programme with the target population. • Evaluating the maintenance of skills taught during the programme.
6.	Plan both the process and outcome evaluation to assess programme implementation and efficacy or effectiveness	**Implement**	• Develop an implementation plan • Identify implementers • Develop a scope, sequence, and instructions • Execute adapted E^{3}BP intervention	
		Evaluate	• Document the adaptation process and evaluate the process • Write evaluation questions, measures, and evaluation of design • Employ an empowerment evaluation approach to improve the programme implementation	

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In addition to the six steps described above, Intervention Mapping also applies three principles during the programme planning process, namely participatory planning, the eclectic use of theory, and an ecological systems approach for understanding the problem and intervening to address it (Bartholomew et al., 2011; Fernandez, Ten Hoor, et al., 2019; Kok et al., 2016). Participatory planning refers to equity in decision-making and community and stakeholder involvement through all phases (Bartholomew et al., 2011; Fernandez, Ten Hoor, et al., 2019; Kok et al., 2016). Participatory planning was addressed in the current study through the stakeholder interviews in Phase 1 as well as the interviews with clinicians with a special interest in neurorehabilitation in Phase 2 (Step 2.2.2) and a planned nominal group technique with SLTs in Phase 3, which informed the adaptation of the programme to ensure applicability.

The eclectic use of theory is needed to guide the selection of appropriate theories that would allow a deeper understanding of the problem area (Bartholomew et al., 2011; Fernandez, Ten Hoor, et al., 2019; Kok et al., 2016). In this research the eclectic use of theory was addressed as a systematic analysis and was undertaken to critically understand the different theories to support CPT and eclectically select the most relevant components of the different theories to meet the needs of the population (Phase 2, Step 2.1). From these existing theories, the social learning approach appeared to be the most suitable and well-established foundation for CPT.

The final principle of the Intervention Mapping approach includes analysing the bio-psychosocial needs of the target population that may impact the implementation of the programme (Bartholomew et al., 2011; Fernandez, Ten Hoor, et al., 2019; Kok et al., 2016). This was addressed in Phase 1 (Step 2.2) of the current study where Bronfenbrenner's bio-psychosocial model was implemented to identify the needs of communication partners during synchronous online interviews (Bronfenbrenner, 1979).

4.8.2. Conclusion of Step 2.2.1

Step 2.1.1 demonstrated the importance of identifying an E^{3}BP approach (i.e., Intervention Mapping) to guide the adaptation of the identified CPT programme. By utilising the Intervention Mapping approach to adapt the TBI Connect, the data from the different phases are crystalised to ensure that all stakeholder perspectives are included ensuring optimal application for the target population. As part of the stakeholder perspectives, Step 2.2.2 is initiated in the next section to include the perspectives of clinicians with a special interest in neurorehabilitation.

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4.9. Interviews with clinicians (Step 2.2.2)

This section includes synchronous online semi-structured interviews with clinicians with a special interest in neurorehabilitation and it forms the final step of Phase 2. The interviews aimed to identify clinicians' perspectives on the TBI Connect and adaptations required to ensure that the CPT supports the needs of partners caring for persons in an MCS+.. This assisted in aligning the programme with the needs of communication partners caring for persons in an MCS+.

4.9.1. Rationale

E^{3}BP is essential when providing healthcare services to patients and families (Larsen et al., 2019). One way of ensuring E^{3}BP is through a process of crystallisation. Crystallisation refers to a qualitative framework or approach that allows a researcher to examine a phenomenon multidimensionally through multiple lenses (De Vries, 2018; Ellingson, 2014; Manning & Kunkel, 2014; Tobin & Begley, 2004). The crystallisation approach aims to: i) provide information on a phenomenon by generating a complex interpretation; ii) utilise and integrate different methods to analyse data along a continuum; iii) make use of more than one data source; iv) reflect on the process; and v) avoid a singular truth (De Vries, 2018; Ellingson, 2014). Additionally, crystallisation aids the researcher in providing rich and thick descriptions of the phenomenon by means of multiple data sources and is an extension of triangulation (De Vries, 2018; Ellingson, 2014; Tobin & Begley, 2004). In this study, focus is placed on the multidimensionality of the phenomenon supported by different perspectives (literature, perspectives of communication partner, clinicians, and SLTs) and different data sources (literature [scoping review; umbrella review]; synchronous online and face-to-face semi-structured interviews, and a nominal group technique). During Phases 1 and 2, the perspective from literature was provided as well as perspectives of communication partners caring for persons in an MCS+. Both the previously mentioned perspectives (literature and communication partners) were obtained to inform E^{3}BP; this section focuses on the perspectives of clinicians with a special interest in neurorehabilitation.

E^{3}BP entails an integration of clinical knowledge, experience, current best evidence, and stakeholder perspectives (Young et al., 2014). During the provision of healthcare services, clinicians are continuously expected to integrate knowledge and skills (using multiple sources) to increase E^{3}BP (Thomas et al., 2014). Thereafter they are expected to apply these concepts in their provision of patient care (Young et al., 2014). According to Thomas et al. (2014), there

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is often a gap between the knowledge translation and clinical practice which in turn, affect knowledge translation. To improve knowledge translation in the discipline of DOC (and specifically persons in an MCS+), this section of Phase 2 aimed to identify clinicians' perspectives on components pivotal for CPT for persons in an MCS+.

4.9.2. Research design

A qualitative research design consisting of synchronous online semi-structured interviews with clinicians with a special interest in neurorehabilitation was employed to address the main aim of Step 2.2 of the research. This method aided in obtaining clinicians' perspectives on what adaptations were needed and how adaptations should be implemented for the TBI Connect to ensure that the newly adapted programme can be regarded as an E^3BP intervention.

4.9.3. Participants

4.9.3.1. Recruitment and selection

For the selection of potential participants, specific selection criteria were used. The clinicians were required to be knowledgeable in their clinical field (measured as having a relevant degree in the field of neurorehabilitation) and informed regarding the research topic with relevant experience of at least 4 years within the field (measured as the clinical skills that had been acquired through working in a neurorehabilitation context) (Baker et al., 2006; White et al., 2021). These concepts were given a numerical value to ensure that all the clinicians met the minimum criteria to participate in this phase of the research. Regarding qualifications, the clinicians obtained the following scores: a bachelor's degree yielded a score of 1; a master's degree a score of 2; and a PhD a score of 3. The following scores were awarded for experience: i) 1 to 5 years yielded a score of 1; ii) 6 to 10 years a score of 2; iii) 11 to 15 years a score of 3; and iv) 16 years or more a score of 4. Participants required a minimum score of 2 to qualify for participation. Additionally, the clinicians were required to be proficient in understanding and speaking English, as this was the language used during the interviews. All allied health clinicians were included in this study to ensure that communication intervention targets communication holistically, as conventional communication intervention is not adequate for this population.

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4.9.3.2. Sampling

Non-probability snowball sampling was used to identify and recruit potential participants (McMillan & Schumacher, 2014). Snowball sampling is often used when the population cannot be delimited, when the characteristics of the sample is rare, or when their perceptions cannot be generalised for the complete population (Dragan & Isaic-Maniu, 2013). This sampling method was selected as it assisted in identifying participants from hard-to-reachpopulations (Kirchher & Charles, 2018).

In snowball sampling, specific inclusion criteria are used to identify participants who in turn identify other potential participants whom the researcher may not initially have had access to (Kirchherr & Charles, 2018). Snowball sampling has an element of convenience and is therefore dependent on the professional network of the researcher (Naderifar et al., 2017). Clinicians' who have a special interest in neurorehabilitation and who were in the researcher's network, were contacted via email to request their participation in the phase. These clinicians were located in the Gauteng area and acted as gatekeepers referring other clinicians with a special interest in neurorehabilitation from their own network to the researcher (Namageyo-Funa et al., 2014). A gatekeeper is classified as an individual who assists the researcher in recruiting participants as they consider that the research will have a positive impact on the participants (Creswell & Creswell, 2018). Snowball sampling was continued until data saturation was obtained (Kirchher & Charles, 2018).

4.9.3.3. Participant description

Participant numbers started with an N indicating neurorehabilitation as different participants were used for this Phase 2. In total, 15 potential participants were identified through snowball sampling and all 15 indicated an interest to participate in this phase via WhatsApp messaging. However, when email requests were sent to request potential participants to complete letters of informed consent, five of the participants did not respond to the email request, despite numerous follow-ups. Hence a total number of 10 participants participated in the synchronous qualitative interviews which was sufficient to obtain data saturation (Guest et al., 2020).

As per the selection requirements, all 10 participants were clinicians consisting of four SLTs, three OTs, two PTs, and one social worker (SW). As the research focuses specifically on communication with persons in an MCS+, SLTs were of critical importance as their scope of practice focuses on both verbal and non-verbal communication for persons with

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communication disorders. Clinicians from the other disciplines such as OTs, PTs, and SW were included to ensure holistic management of components not directly related to communication but inadvertently affecting communication. These components include management of positioning, preventing pressure sores, managing lung health (scope of practice-PT), increasing sensory awareness, participating in activities of daily living, providing assistive devices, improving hand movement (scope of practice-OT), counselling of the person and family, organising living arrangements for the person, providing financial aid options, providing guidance regarding the persons will/estate, and bereavement (scope of practice-SW). Including perspectives from the multidisciplinary team resulted in an increased understanding of the potential facilities (i.e., supports) and challenges that communication partners may face when caring for persons in an MCS+.

All the clinicians were female with ages ranging from 28 years to 73 years and a mean age of 40,8 years. Half of the participants spoke English as a home language. The four participants who spoke Afrikaans and the one who spoke Setswana were all proficient in English. All the participants were in full-time employment – mostly in private practice settings which included acute care hospitals, rehabilitation centres, and care facilities (e.g., retirement villages). Most of the participants treated persons in an MCS+ on a daily basis, although each participant treated persons in an MCS+ weekly, monthly, or quarterly. Table 4.9 includes the scores that the participants obtained to qualify for participation as well as demographic information.

Table 4.9

Demographic information of clinicians (N=10)

#	Age	Sex	First Language	Occupation	Degree (Score: 1=BD's; 2=Master's; 3=PhD)	Experience in MCS *(Score: 1= 1-5yrs; 2= 6-10yrs; 3 = 11-15yrs; 4= 16+ years)*	Qualifying Score (degree + experience)	Setting	Frequency of Treating Persons in an MCS+
N1	28yr	F	Afrikaans	PT	Bachelors (1)	5 years (1)	2	Private practice	Quarterly
N2	51yr	F	Afrikaans	OT	Bachelors (1)	30 years (4)	5	Private practice	Daily
N3	31yr	F	Afrikaans	OT	Master's (2)	8 years (2)	3	Private practice	Weekly
N4	30yr	F	Afrikaans	PT	Master's (2)	4 years (1)	3	Private practice	Daily
N5	45yr	F	English	SLT	Master's (2)	13 years (3)	5	Private practice	Monthly
N6	73yr	F	English	SW	Bachelors (1)	18 years (4)	5	Hospice	Daily
N7	40yr	F	English	SLT	Master's (2)	17 years (4)	6	Private practice	Quarterly
N8	29yr	F	Setswana	OT	Master's (2)	5 years (1)	3	Hospital	Daily
N9	53yr	F	English	SLT	Master's (2)	25 years (4)	6	Private practice	Daily

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N10	28yr	F	English	SLT	Master's (2)	6 years (2)	4	Private practice	Daily

Note. Abbreviations: F=Female

4.9.4. Materials and equipment

The materials assist in obtaining the relevant informed consent, biographic information, and identifying components relevant to this phase. This included information in the context and job description of the participants.

4.9.4.1. Letter of informed consent

Clinicians with a special interest in neurorehabilitation within the researcher's network were contacted to potentially participate in the research. These clinicians in turn provided contact details to the researcher and also suggested other clinicians who might be interested in participating upon their consent. A letter of informed consent was sent to these clinicians via email (Appendix H1-H2). This letter included an invitation to participate, provided the rationale for the study, and explained what was expected of them while also explaining their rights as participants. Additionally, participants were assured that there were no anticipated risks related to the research, that participation was voluntary and that they may withdraw at any point in time without negative consequences. They were also assured that confidentiality would be ensured and were informed that the findings will be discussed in the study as well as in academic publications and conference presentations and that the data will be stored securely at the Centre for AAC (University of Pretoria) for 15 years. This ensured that potential participants' rights are protected and that the participants fully understood what was expected of them prior to providing consent (Creswell & Plano Clark, 2018; Josselson, 2013). No personal information of any participant was accessed without their written consent (Fisman, 2016), which is similar to the protection of personal information act of the South African constitution.

4.9.4.2. Biographic questionnaire

A biographic questionnaire (Appendix H3) was developed to obtain descriptive information from the participants. This included participant demographic detail such as gender, age, home language, qualification, job description, and clinical and theoretical experience working with persons in an MCS+. This information assisted in determining whether participants met the selection criteria for the phase (Sargeant, 2012). Table 4.10 includes the theoretical justification for the questions included in the biographical questionnaire.

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Table 4.10

Theoretical justification of biographic information

Personal Information	
Question	**Theoretical justification**
1. How old are you?	Traditionally, individuals between the ages of 18–22 obtain a higher education qualification from a tertiary institution (Shea & Bidjerano, 2014). Additionally, for HCPs, older therapists may have more experience.
2. What is your gender?	More females tend to complete degrees in healthcare professions (McLaughlin et al., 2010).
3. What is your first language? 4. What other languages do you speak?	Clinicians have multilingual backgrounds; however, English is seen as the predominant language used in medical contexts in South Africa (Henderson & Louhiala-Salminen, 2011).
5. What is your highest level of education?	To ensure that clinicians conduct ethical and E^3BP, the Healthcare Practitioners Council of South Africa (HPCSA) has set guidelines that practitioners have to adhere to (HPCSA, 2016). These guidelines include having a degree from a recognised tertiary institution within the relevant field of the clinicians.
6. What is your employment status? 7. What is your occupation? 8. In what context do you work? 9. How long have you been working in this context? 10. How long have you been working in your discipline?	Clinical experience is associated with clinicians experiencing increased levels of self-efficacy and confidence in their decision-making abilities (Parker-Tomlin et al., 2018). Within clinical practice, novice clinicians make use of analytical decision-making while experts use intuitive approaches during person-centred care (Parker-Tomlin et al., 2018). These approaches vary with level of experience and influence care from initial admission to the critical care unit until discharge home (Latchem & Kitzinger, 2015).
11. How often do you work with persons in an MCS+? 12. Do you work with the person in an individual or group setting? 13. In what setting do you work with the person?	Clinicians assess and treat persons in an MCS+ as part of a team. These individuals require daily therapy from the team (Sautet et al., 2022).
14. Do you provide communication partner support? 15. How do you provide communication partner support (e.g., online, face-to-face)? 16. How often do you provide communication partner support (e.g., once a week)? 17. What guidance do you provide to communication partners?	Communication partners report that they experience various support needs when caring for a person in an MCS+. They may receive face-to-face training, however, feel they were not given the opportunity to practically apply these skills and therefore they continue to require support even after training (Jeyathevan et al., 2020).
Information on prior knowledge and skills	
18. Do you feel that your undergraduate degree prepared you to work with persons in an MCS+? 19. What contributed to your learning in the field of disorders of consciousness most?	Clinicians often perceive themselves as lacking clinical experience which they did not receive with undergraduate programmes (Walker et al., 2013).
20. Have you participated in courses that train you to work with persons in an MCS+? 21. If yes, please specify.	Participating in professional development is essential for clinicians to acquire and apply skills to maintain person-centred care (Manley et al., 2018).
22. Do you feel that you would want more training in this field? 23. What components do you require training on? 24. For individuals with limited knowledge on disorders of consciousness what support is most important to facilitate their learning?	Most allied clinicians require postgraduate training as they experience difficulty with time management, less access to supervision, uncertainty of the healthcare system and patient responsibility and decision-making regarding patient care (Merga, 2016).

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4.9.4.3. Synchronous online script development

An interview script (Table 4.11) was developed based on information obtained from the umbrella review of systematic reviews. This ensured that a pre-set list of both open- and closed-ended types of questions were used to drive the content of the factual questions and that the content obtained from all the stages of Phase 1 was aligned (Gropp et al., 2019; Josselson, 2013; Qu & Dumay, 2011; Silverman, 2013). Questions related to opinions, beliefs, and judgements were also included (Gillham, 2000). Closed-ended questions are usually elicited through task-orientated behaviour of the researcher and aims to obtain estimated characteristics of the population that is comparable, valid, and reliable (Moerman, 2010); while open-ended questions are often used to increase the amount, depth, and elaborateness of information obtained from participants (Louw et al., 2011; Moerman, 2010). Probing techniques as well as recasting questions were used to obtain additional information or to address misunderstandings (Josselson, 2013).

Probing techniques included both verbal and non-verbal techniques used by the researcher to facilitate participant elaboration on questions asked during the interview (Moerman, 2010; Qu & Dumay, 2011). Non-verbal probing techniques include active silence (the researcher remained silent when the participants finished their answer to indicate their conversational turn is not complete), facial expressions (e.g., frowning) or body movements to indicate successful/unsuccessful comprehension of information, or expression of doubt (Moerman, 2010). Verbal techniques included asking probing questions based on spontaneous or structured answers of participants (Moerman, 2010; Qu & Dumay, 2011). Recasting questions were used as a repair strategy when the researcher was unable to obtain sufficient information from the participants' narratives or when the participant misinterpreted the question asked (Josselson, 2013; Moerman, 2010). The questions were phrased in such a way as to not influence participants' responses to ensure that their unique perspectives were elicited (Josselson, 2013). The language level of the questions was set to enhance the participants' understanding (Qu & Dumay, 2011).

The custom developed interview script was used during the synchronous online interviews to ensure procedural consistency and improved trustworthiness of results across the different participants (Ledford & Gast, 2014). These online interviews were audio recorded with the platform software selected to perform the interviews. This increased the validity of the

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data obtained (Gregory & Radovinsky, 2012). Table 4.11 includes the theoretical justification for the questions included in the interview script.

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Table 4.11

Interview script theoretical justification

Nr	Question Type	Description	Theoretical Justification
Introduction (10 minutes)			
1.	Personal narrative	As explained in the consent letter, my name is Ariné and I am currently conducting my PhD study which is focused on the development of a CPT programme for communication partners of persons in an MCS+.	See Table 3.6 for the theoretical justification
2.	Procedural narrative	I will be referring to my notes to make sure that I remember to ask all my participants the questions!	
3.	Procedural narrative	The interview might take up to 90 minutes.	
4.	Procedural narrative	Thank you for your willingness to share your experiences with me. Your contribution will aid me in adapting a CPT programme for communication partners of persons in an MCS+.	
5.	Sequential narrative	I will now ask you some questions regarding your experience working with persons in an MCS+ and at the end we will conclude with your reflection on the interview process. You are welcome to add any other aspects that you might feel are important for me to understand.	
6.	Procedural narrative	You already completed the informed consent letter, but I want to remind you that I will be audio-recording our interview. Only I will listen to it. I will use it to identify aspects that you think are important and to provide feedback to you.	See Table 3.6 for more information.
7.	Procedural narrative	At times I might ask you to elaborate or clarify some information. Are you ready? Let's get started!!	
Questions (30–60 minutes)			
8.	Open-ended	How would you approach the referral of a patient in an MCS+? *Follow-up question:* • What clinical approach or guidelines do you use to assess and treat persons in an MCS+? • What aspects do you think are important to include in a CPT programme (e.g., additional to the ones mentioned)? • How would you go about setting communication goals with communication partners of persons in an MCS+?	The opening question is meant to direct the participants' attention and facilitate narration of their experience (Josselson, 2013). To ensure that clinicians conduct is ethical and EBP, the HPCSA has set guidelines that practitioners have to adhere to (HPCSA, 2016). These components relate to Module 1 of the TBI Connect programme and focus on introducing and setting the scene for CPT, joint goal setting with communication partners

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Nr	Question Type	Description	Theoretical Justification
		• What aspects do you think are important to introduce in the first session of a CPT programme?	of persons in an MCS+ and tuning into various aspects of communication (Rietdijk, Power, Brunner, Attard et al., 2019).
9.	Open-ended	What do you think the person in an MCS+ finds most challenging? *Follow-up question:* 5. How does this challenge affect communication? 6. How can the person address and maybe even overcome these challenges? 7. What are aspects that you think are important ingredients for good communication? 8. What information should communication partners know when caring for a person in an MCS+?	The loss of consciousness can be brief or slow depending on the severity of the brain damage, with specific effects which include respiratory problems, impaired physical mobility, impaired hydration, impaired swallowing, diminished communication skills, and impaired elimination (Faozi et al., 2021). These questions relate to Module 2 of the TBI Connect which includes components such as background information on persons with communication disorders, identifying important ingredients for good conversation and common communication problems for persons with neurological impairments (Rietdijk, Power, Brunner, Attard et al., 2019).
10.	Open-ended	What are the components that you target during assessment and intervention? *Follow-up question:* • How do you target these components? • Are there specific strategies that you have found worked well for these individuals? • What strategies have you tried that did not work? • How should communication partners change their approach when communicating with persons in an MCS+? • What are keywords in defining ideal communication with persons in an MCS+?	Clinicians are key members of the team working with persons who are minimally conscious. SLTs play a specific role in the communication behaviours of persons in an MCS+ and in how these behaviours emerge, thus also play a vital role in contributing to the assessment of awareness and consciousness (Roberts & Greenwood, 2019). These questions relate to Module 3 of the TBI Connect which include components such as communication situations that require a script, strategies for playing specific parts/roles, and changing the approach depending on the context and generating keywords to define ideal communication approaches (Rietdijk, Power, Brunner, Attard et al., 2019).
11.	Open-ended	How do you communicate with persons in an MCS+? *Follow-up question:* • What communication strategies do you use to support persons in an MCS+? • What communication strategies does the person use? • What topics do you communicate about? • What do you think the person wants to communicate about?	Persons in an MCS+ often use subtle communication such as eye blinking to communicate 'yes' or 'no' answers to this type of question (Kuyler et al., 2022b). SLTs in particular have the necessary knowledge to support communication partners to facilitate communication with persons in an MCS+ (Rasmus et al., 2019; Roberts & Greenwood, 2019).
12.	Open-ended	What environmental adaptations do you recommend that may facilitate increased arousal and wakefulness for these individuals in an MCS+?	Persons who are minimally conscious often respond best to environmental stimulation that is familiar (Lancioni et al., 2019).

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Nr	Question Type	Description	Theoretical Justification
13.	Closed-ended	Are there any objects, sounds, music, textures, tastes, or other components that the person responds best to? *Follow up question:* • How frequently should these stimuli be used? • What should be the intensity? • How should you grade stimuli? • How long should you provide the stimuli at a time?	Multisensory stimulation familiar to the person in an MCS+ that is delivered with the right intensity and which are repeated correctly and accurately can increase the recovery rate of consciousness, thus facilitating the achievement of sensory function and reducing the duration of a coma (Faozi et al., 2021).
14.	Open-ended	When do you find the person to be most responsive?	Identifying the time of day and position in which the person is most responsive will assist in promoting their engagement in intervention and increasing responses (Chatelle et al., 2016; Wannez, Heine, et al., 2017). Questions 11–15 relate to Module 4 of the TBI Connect which includes components such as communication as a cooperative process involving effective listening, speaking, and turn-taking, discussing personally relevant strategies to target communication and reviewing progress of the communication partners (Rietdijk, Power, Brunner, Attard et al., 2019).
15.	Closed-ended	In what position do you think the person is the most responsive (e.g., sitting up or lying down)?	
16.	Open-ended	How do you support communication partners of persons in an MCS+? *Follow-up question:* • What content do you normally target when giving a home programme to communication partners? • What are specific strategies that you would recommend for communication partners at home? • What referrals do you make for best practice and holistic care of the person?	Clinicians should support communication partners of persons in an MCS+ to reduce the negative psychological impact of caregiving (Soeterik et al., 2017). This question relates to Modules 5 and 10 of the TBI Connect which include components such as discussing personally relevant strategies, the communication partner working together with the person in an MCS+, discussing achievements, discussing next steps, and reviewing resources for maintaining and continuing the process. Modules 6–9 have been excluded as these components are not relevant to persons in an MCS+ (Rietdijk, Power, Brunner, Attard et al., 2019).
17.	Procedural narrative	These techniques are used to facilitate discussion between the researcher and participant: *Nonverbal probing techniques:* • Active silence. • Prosody-intonation or melodic patterns used by the researcher during phonation. • Facial expressions (e.g., frowning). • Body movements (e.g., nodding or folding arms). • Vocalisations such mmmm… or humming. *Verbal probing techniques:*	Both verbal and non-verbal probing techniques are used to indicate to the participant that their conversational turn is not complete and that they should provide more information (Moerman, 2010). Verbal probing techniques can also be used as follow-up questions based on previous statements of the participants as well as to summarise information (Moerman, 2010). Maintaining an active presence as well as using non-verbal probing techniques will assist in the analysis of the interviews by providing additional information apart from the verbal information.

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Nr	Question Type	Description	Theoretical Justification
		• Summarising what the participant said. • Repetition of the initial question. • Can you please tell me more? • What do you mean by….? • If I understand you correctly you are saying…. • I would like to hear about that …. • Can you tell me about…. • Could you say something more about that? • Do you have more examples…. • Is it correct that you feel…. • Does this …. cover what you just said. • Oh, I forgot to ask you. • If so, give examples…. • Recasting will also be done if the person misunderstands the questions.	
18.	Personal narrative	*Maintaining an active presence:* • Using vocalisations such as "*hmmm*" or "*uh-huh"*. • Using facial expressions, body language (e.g., nodding) and gestures to indicate active listening to the participant.	Maintaining researcher presence through engagement and active listening is essential as it allows the participants to feel that they are being listened to and facilitates rich narratives (Josselson, 2013).
Final thoughts and self-reflection (10 minutes)			
19.	Procedural narrative	I would like to ask the following questions regarding your experience of this interview:	
20.	Open-ended	Is there anything else that you would like to add?	See Table 3.6 for more information
21.	Open-ended	How did you experience this interview?	
22.	Open-ended	Please comment on the questions asked (e.g., the language and phrasing used)?	
23.	Open- and closed-ended	*Follow-up questions:* • What changes would you recommend regarding the type of questions asked? • What changes would you suggest for the procedures of the interview? • What other changes would you recommend ensuring that other clinicians have a positive experience of being interviewed? • Do you have any additional comments?	
Closing (5 minutes)			
24.	Procedural narrative	Thank you for participating in this interview, I appreciate your time and that you shared your experiences so freely with me.	Showing appreciation to the participant signals the closure of the interview and the return to daily activities (Salmons, 2015).

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Nr	Question Type	Description	Theoretical Justification
25.	Procedural narrative	I will summarise all the information that you so kindly shared with me. Please read through it and see if I accurately captured your answers and comment on whether I accidentally missed something. I will appreciate it is you can send your comments back to me within three days.	This process contributes to member checking and increases the trustworthiness of the results obtained (Birt et al., 2016).

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4.9.4.4. Online platform

A variety of online interviews that could be used to host a synchronous online interview in real-time were investigated, namely Google Meet, Zoom, Skype, and Microsoft Teams (Janghorban et al., 2014; Silverman, 2016). All four of these platforms allow the participants to communicate with video or voice preference and allowed the researcher to record the session, with the purpose of the platform for ease of transcription (Silverman, 2016). Ethically, synchronous online interviews may be preferred by participants as they may withdraw from the interviews by ending the call (Janghorban et al., 2014; Silverman, 2016). Additional consent is also asked by the platform when sessions are recorded. Table 4.12 provides the consideration of the available platforms.

Table 4.12

Online platform selection

Criteria	Google Meet (https://workspace.google.com)	Zoom (https://zoom.us/)	SKYPE (https://www.skype.com/en/)	Microsoft Teams (https://www.microsoft.com/en-za/microsoft-teams/log-in)
Participant safety and anonymity ensured	Yes, linked to email address of participant	Yes, meeting host sends invite via email to participants	Yes, meeting host sends invite via email to participants	Yes, linked to participants Microsoft account
Number of participants	100	100	100	20
Ease of use for participants	Easy	Easy	Easy	Not as user-friendly and easy as competitors in the market
Allows for synchronous real time interaction	Yes	Yes	Yes	Yes
Possibility to record	No, requires admin account	Yes	Yes	Yes
Storage of information from interview	Save transcriptions to researcher's Google Drive	Videos saved on host account	All information is routed through Microsoft servers that monitors and collects information	Server within Google Drive (cloud service)
Cost to use	Free for under 100 participants	Free for under 40 minutes for groups: then requires professional or business account with monthly or annual pricing.	No, requires client programme that is not free. This client programme controls the system	Free if host has a Microsoft account

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Criteria	Google Meet (https://workspace.google.com)	Zoom (https://zoom.us/)	SKYPE (https://www.skype.com/en/)	Microsoft Teams (https://www.microsoft.com/en-za/microsoft-teams/log-in)
Possibility to automatically transcribe	Yes	Yes	No	Yes
Information safety: will not be sold or shared by developer	All information is encrypted and will not be shared by developer.	All information is encrypted and will not be shared by developer.	All information is encrypted and will not be shared by developer.	All information is encrypted and will not be shared by developer.

The platform was selected based on the preference of participants. Some participants indicated a preference for using Google Meet, however, the majority of the participants preferred Microsoft Teams. Even though the Microsoft Teams was not as user friendly as Google Meet, it allowed interviews to be recorded automatically and provided transcriptions of the interviews. Moreover, it is a free platform that allowed the researcher to conduct synchronous online interviews, making it a feasible, convenient method of data collection that allows researchers to reach a wider sample of participants not precluded by time, locations, and social barriers (Tuttas, 2015). Microsoft Teams allows the researcher and participant to meet in real-time and can include multiple participants at once, thus closely resembling face-to-face interviews and allowing participants to communicate over multiple dimensions not limited to text-to-text communication (Tuttas, 2015). The online platform also ensures flexibility and potential customisation to meet the needs of the communication partners (Dahlstrom-Hakki et al., 2020).

4.9.5. Data collection

Prior to data collection, ethics approval from the Ethics Research Committee of the Humanities Faculty, at the University of Pretoria was obtained. As explained in participant recruitment, clinicians in researcher's network (this included SLTs, allied therapists and so forth.) were contacted per email, to request their participation in the phase (Appendix H1-3). Upon receipt of the participant's completed informed consent and biographic questionnaire, a timetable was sent to them to indicate a time and date they found convenient for the interview to be conducted. These clinicians also received a handout including layout of the CPT programme with the number of modules and the topics discussed in each module (Appendix I) which allowed them to provide information on the content and structure of the programme. These clinicians in turn, suggested other potential clinicians from their own professional networks and provided their contact details

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(cell phone number upon their consent) to the researcher. These potential participants were contacted per WhatsApp to acquire information on their interest in the phase after which they provided their email addresses and were sent the informed consent letter and biographic questionnaire. This was followed by the researcher arranging a time and date that was convenient to the clinicians to conduct the online interview.

Synchronous online interviews were conducted with ten clinicians who all currently work in neurorehabilitation (Creswell, 2014; Dworkin, 2012). This smaller sample size allowed the researcher to find deeper meaning and understanding of the participants' perspectives (Dworkin, 2012). All online interviews were conducted in a semi-structured manner on a person-to-person basis using the proposed interview script (Table 4.11) (Salmons, 2009). Due to the semi-structed nature of the interviews, the researcher opted to switch between reading the questions verbatim and using a conversational interview style as this ensured that the aims of the interviews were met while also allowing the clinicians the opportunity to elaborate on their personal perspective (Silverman, 2013). By maintaining the balance between the structured and conversational style, the participants felt that they were respected and they commented that it ensured a positive participant experience of being interviewed (Josselson, 2013). The duration of the semi-structured interviews varied between 50 to 90 minutes with a mean time of 58 minutes.

Conversational notes were made and additional observations were recorded that guided the follow-up questions (Josselson, 2013; Silverman, 2013). Observing the body language of the participants allowed the researcher to adjust the interview procedures and style. This lessened potential discomfort or anxiety of the participants related to the process of being interviewed (Josselson, 2013).

The online interviews put the participants at ease allowing them to share their lived experiences, since their knowledge and understanding is grounded in their experience (Birt et al., 2016). The participants provided information regarding their perspectives on their approach to persons in an MCS+, the professional boards whose guidelines they follow, components to include in CPT, communication strategies, and ideas on providing communication partner support.

As alluded to earlier in the interview script, both verbal and non-verbal probing techniques were used as well as active listening to facilitate detailed discussion by participants (Louw et al., 2011; Moerman, 2010). This ensured that the researcher had an active presence during the

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interview and this motivated the participant to reflect as well as elaborate on their personal perspective (Josselson, 2013; Louw et al., 2011; Moerman, 2011).

The interviews included member checking, to ensure that the results are trustworthy. This was done in a twofold way. First, summaries were made of what the participants said and they were asked throughout the online interview if this was what they had intended to say (Harper & Cole, 2012; Madill & Sullivan, 2018). Second, generated transcripts from Microsoft Teams were used and compared with the audio recordings for correctness. As an added measure for trustworthiness of findings, participants were expected to review the transcript summary within seven days. It was approximated that the review of the transcription took no longer than 30 minutes to complete. This member checking process ensured that the participant's personal experience and perspectives were portrayed and not tailored to the study's perspectives (Birt et al., 2016; Candela, 2019). Through member checking, participants were also allowed to confirm or deny the interpretation of data as well as to provide clarification for the research on specific topics which improved the credibility of the information (Candela, 2019). The participants had the option, if disagreements occurred the researcher adapted the transcript according to the recommendations of the participants to ensure their perspective was portrayed accurately (Candela, 2019). None of the participants mentioned discrepancies when they reviewed the transcripts.

4.9.6. Data analysis

Thematic analysis was employed to identify inductive themes for the qualitative content (Braun & Clarke, 2006; Elo et al., 2014). This method of analysis allowed identification, analysis and reporting of themes found in the data (Braun & Clarke, 2006). Thematic analysis is flexible and aids in providing sequential information that can be linked to the research question (Clarke & Braun, 2013; Braun & Clarke, 2006). Data reduction methods were used once the researcher and an independent coder (research assistant) familiarised themselves with the data to select data relevant in fulfilling the aims of the phase (Creswell, 2014; Miles & Huberman, 1994). This was followed by generating, searching, and reviewing themes (Braun & Clarke, 2006; Nowell et al., 2017). Themes were broadly organised as it relates to the specific modules of the TBI Connect without detailed comments. Once this process was completed, the researcher and an independent coder labelled and defined themes thereby using inductive coding (Braun & Clarke, 2006; Nowell et al., 2017). Pseudonyms and participants numbers were used to label transcripts to maintain

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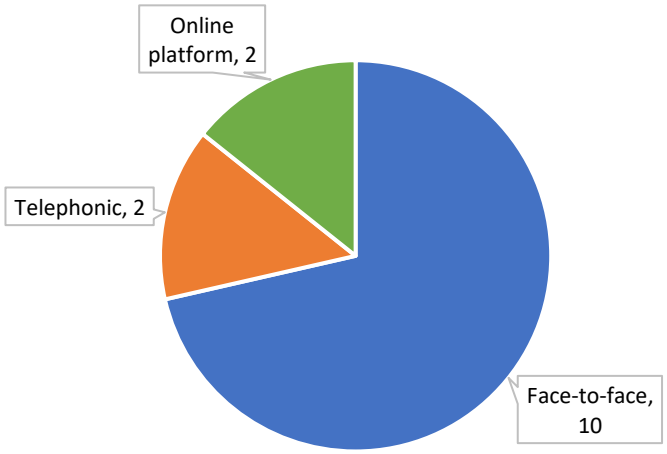
confidentiality of information (Jewitt, 2012) as described as part of the ethical considerations. A 70% consensus was required between the two coders. However, if any disagreements occurred during this process a third independent person was included. The coders obtained an agreement of 80% which ensured an inter-rater reliability (Heilman et al., 2008). The themes identified by the researcher provided valuable descriptive data to adapt the CPT programme.

4.9.7. Participant related findings

The findings of the synchronous online interviews are discussed according to the theoretical modules of the content included in the TBI Connect programme. First, the data related to communication partner support is described followed by the data focused on the suggested content adaptations from clinicians. Table 4.13 includes information on the specific type of support provided by the communication partner.

Table 4.13

Communication partner support provided by clinicians (N=10)

Description	Findings
Clinician's method of communication partner support All 10 of the clinicians provided support to communication partners by means of face-to-face support. Two of the clinicians provided additional online support via various online platforms such as Zoom, Skype, Google Meet, and Microsoft Teams. Additionally, two other clinicians provided telephonic support in addition to face-to-face support via individual WhatsApp messages, group messages and/or telephonic calls.	

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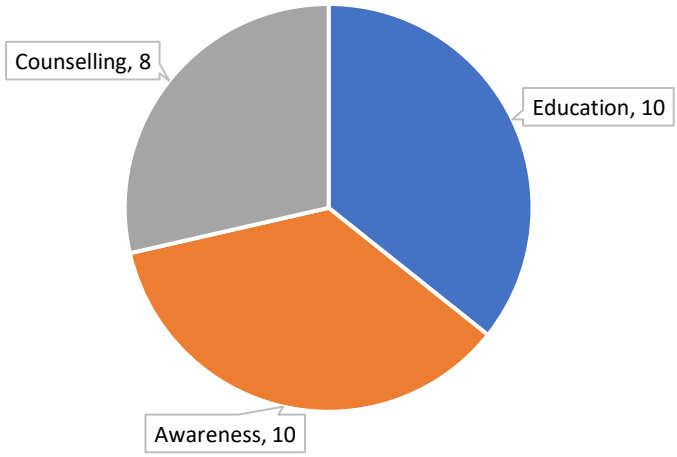
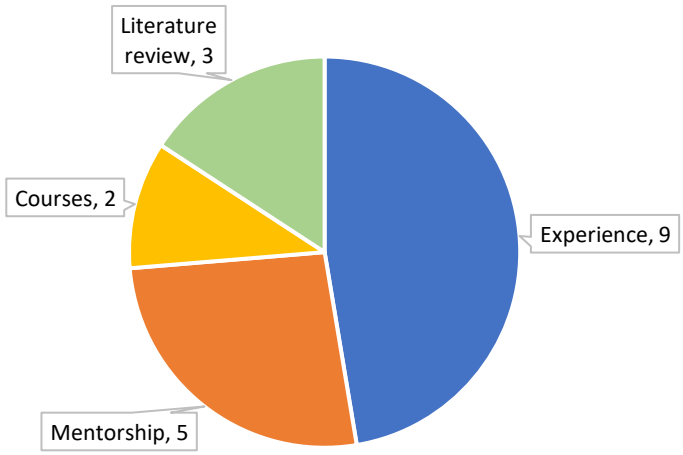
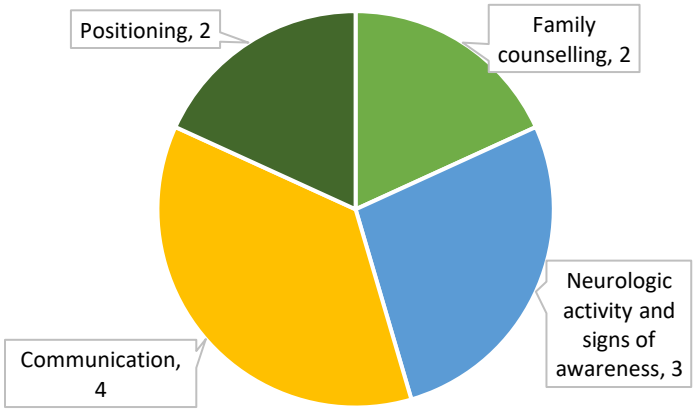
Description	Findings
Content of clinician communication partner support All 10 clinicians provided education and awareness training related to components relevant to their specific disciplines. For example, PTs focused on positioning, preventing contractures, and transfers. OTs focused on activities of daily living, sensory awareness, and routines. SLTs focused on communication and swallowing. Social workers focused on counselling and home-care support. Additionally, eight clinicians reported that they provide some form of counselling to the communication partners.	
Contribution to clinical learning Nine clinicians mentioned that their learning was mostly informed by their clinical experience with persons in an MCS+. Additionally, some (5) stated that they received mentorship from colleagues in the respective fields which aided in their learning and understanding of the condition. Only three clinicians mentioned that they review evidence-based literature to learn more about DOC, while two mentioned that they attended additional courses in neurorehabilitation.	
Training needs All 10 clinicians indicated that they required further training to allow them to provide more effective service delivery when working with persons in an MCS+. This mostly included training on communication (n=4), neurologic activity and signs of awareness and consciousness (n=3), positioning (n=2), and family counselling (n=2).	

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Table 4.13 described the various ways in which clinicians provide communication partner support. From the data in Table 4.11, all the clinicians qualified as having suitable knowledge and experience to suggest adaptations to the TBI Connect CPT programme. Nine of the 10 clinicians mentioned that they did not attend any specific courses that focused on DOC, however, their experience and relevant degrees provided them with a valuable foundation. Additionally, all participants regarded mentorship or supervision from colleagues with experience in the field as the greatest contribution to their learning, apart from working in the field. Most of the clinicians mentioned that they would want to attend training on the topics previously mentioned as part of continuing professional development. A detailed description of the findings regarding the data from the suggested adaptations to the TBI Connect to make it more applicable to the target population (i.e., persons who are in an MCS+) are shown in Figure 4.4. As suggested earlier in the study, the participant numbers start with an N indicating neurorehabilitation.

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Figure 4.4

Content adaptations to modules of the TBI Connect as suggested by clinicians

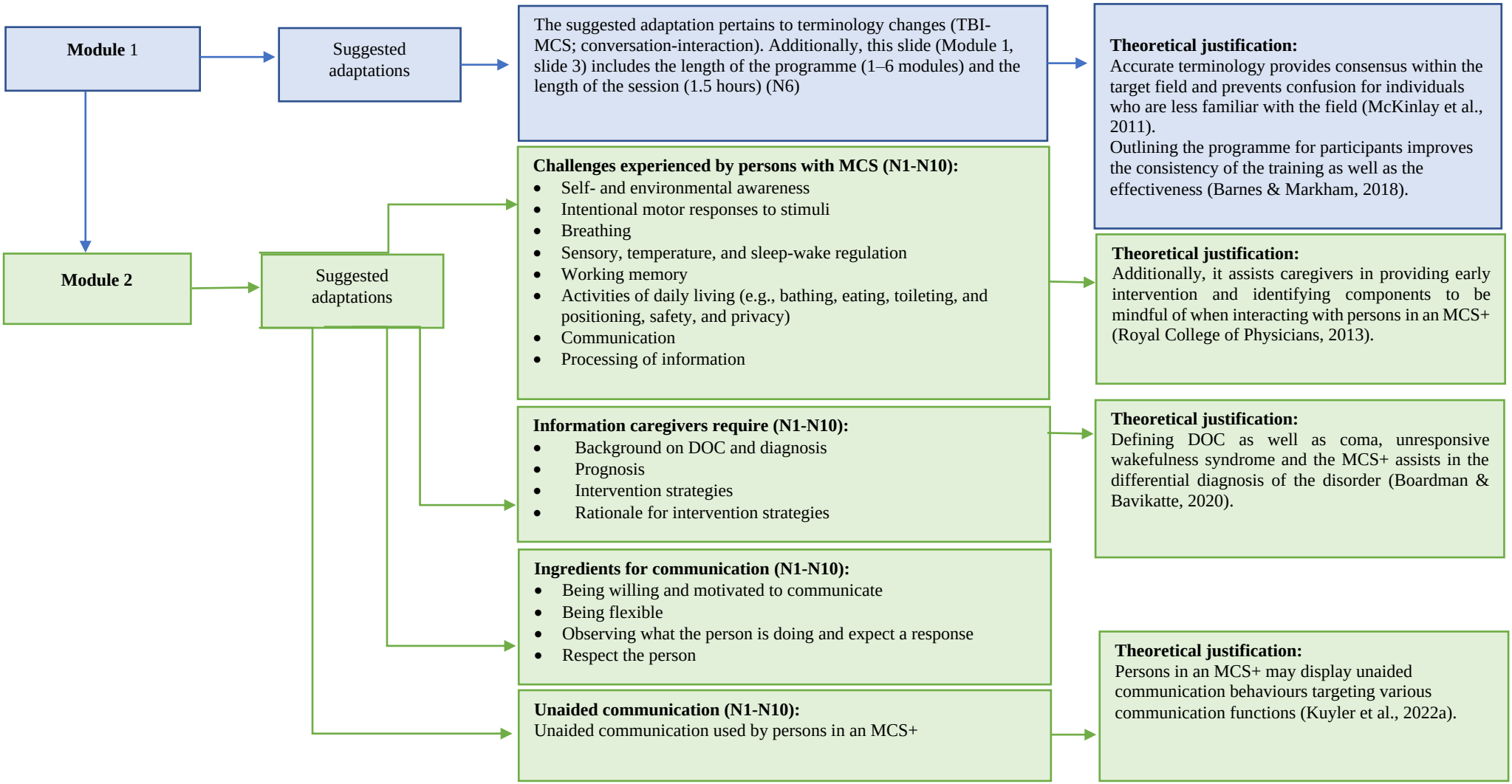

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Figure 4.4 (cont.)

Content adaptations to modules of TBI Connect as suggested by clinicians

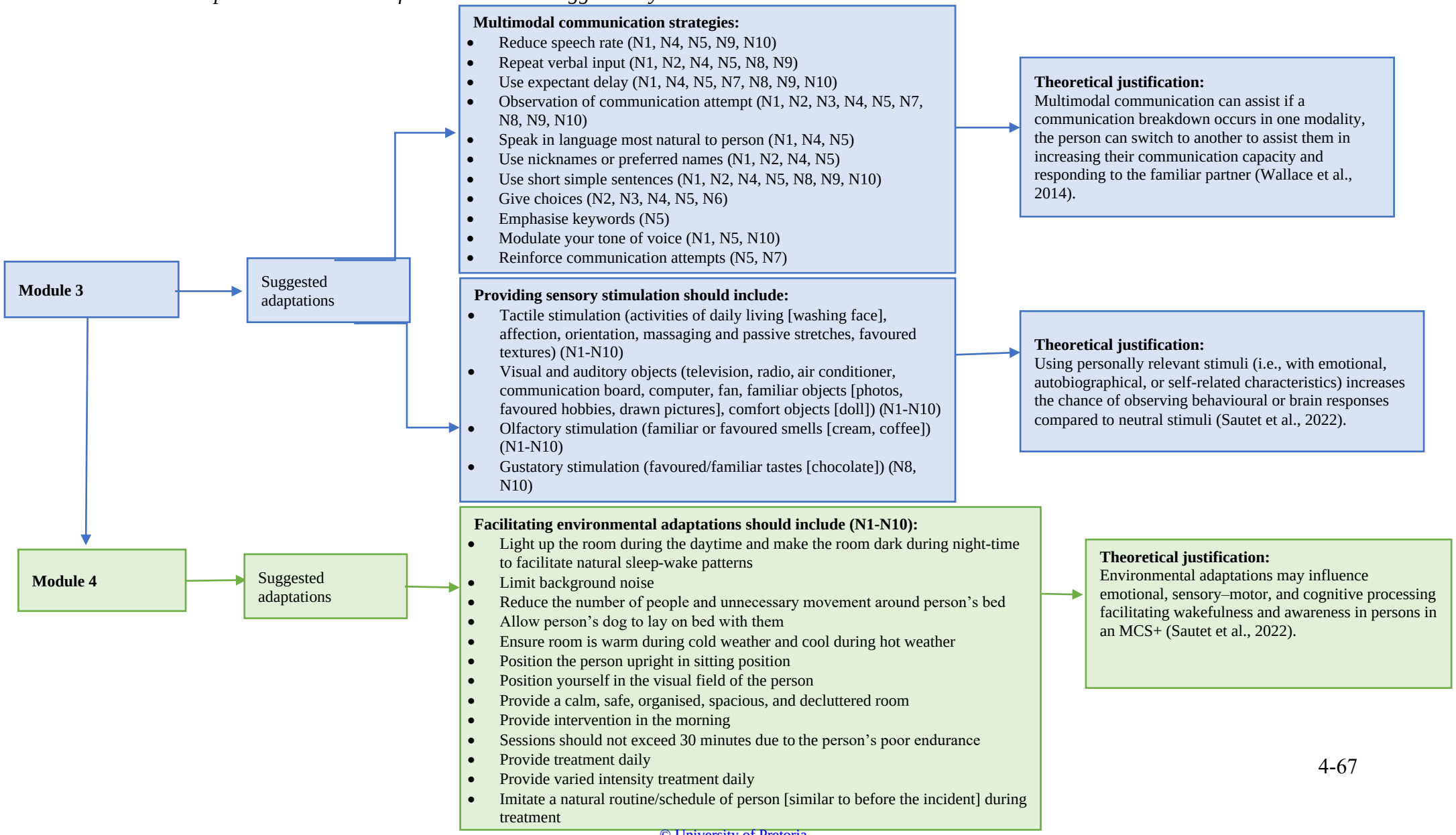

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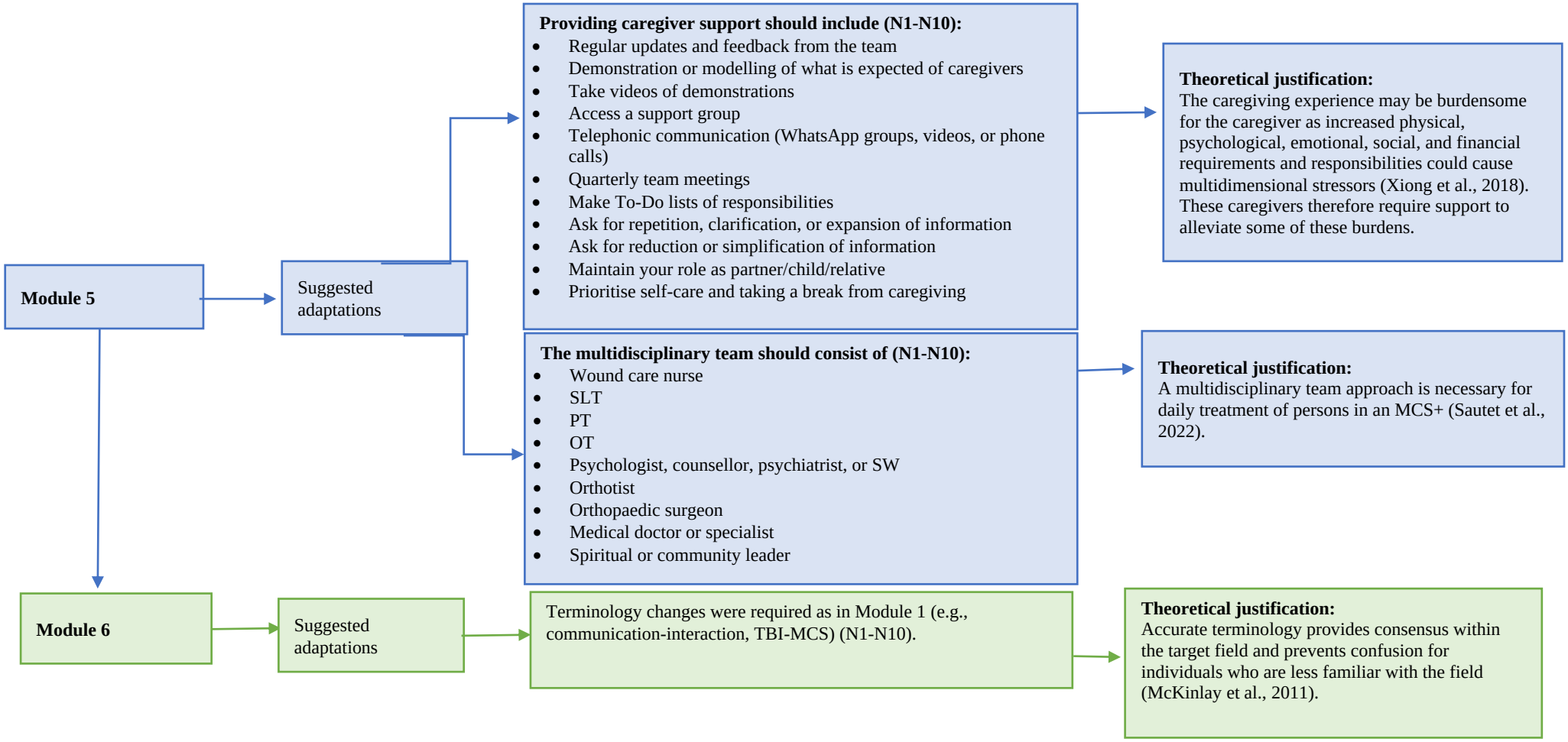
Figure 4.4 (cont.)

Content adaptations to modules of TBI Connect as suggested by clinicians



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4.9.8. Findings from synchronous online interviews

The following findings were obtained from the interviews with clinicians with a special interest in neurorehabilitation:

Module 1 included adaptations related to terminology. As persons in an MCS+ do not use conventional forms of communication such as spoken language, the participants suggested that the term 'interaction' should be used rather than 'conversation' as the former is more inclusive of multimodal communication strategies, which would also encompass the various unaided forms of communication.

Module 2 included suggestions relevant to the multimodal communication strategies displayed by persons in an MCS+ (with an emphasis on unaided strategies) and support the findings of the scoping review conducted in Phase 1. Additionally, participants explained that from clinical experience they perceived the communication challenges experienced by persons in an MCS+ as being similar to that of persons with severe to profound TBI (as per the focus of the TBI Connect), however, that the former group presented with additional challenges such as responding to environmental stimuli, self- and environmental awareness, and communication in general. The participants considered ingredients for communication and information required by communication partners of persons in an MCS+ to be similar to those mentioned in the TBI Connect.

Module 3 included participant suggestions on multimodal communication strategies that could be used by clinicians as well as sensory stimulation activities that they could include in service-delivery. These components were not included in the TBI Connect programme and must therefore be added to Module 3's PowerPoint presentations.

For Module 4, participants suggested that environmental adaptations such as indications to participants of having a clear day (e.g., switching the light on in the room) and night (e.g., switching the light off in the room) to be added to the PowerPoint Presentation as this was not initially added to the TBI Connect programme, yet is relevant to persons in an MCS+.

In Module 5, suggestions proposed by the participants were related to the type of communication partner support strategies that can be applied as well as suggestions of the various people and HCPs who need to be part of the communication partners' team. Although, the TBI Connect programme mentions the importance of teamwork in Module 5, specific

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reference to the different team members was not included, hence the suggestion was a welcome addition.

The final module (Module 6) proposed for the target population, only included suggestions of terminology changes such as in Module 1. For example, it was suggested to replace 'conversation' with 'interaction'.

4.9.9. Discussion

The findings of the synchronous online interviews (Step 2.2.2) are discussed according to the six modules identified in Step 2.1.2 and presented schematically in Figure 4.4. Permission was obtained from the authors of the programme to adapt the original PowerPoint presentation (Appendix J).

Module 1 and 6

From the findings of this phase, the clinicians agreed that these modules required limited changes. The only changes recommended were related to terminology and the outline of the programme to heighten the applicability for the target population. McKinlay et al. (2011) suggest that utilising accurate terminology reduces confusion between clinicians, family members, and other stakeholders.

Module 2

Four categories of information were identified for this module, namely challenges experienced by persons in an MCS+, information needs of communication partners, ingredients for communication and unaided communication. All the participants mentioned that the person in an MCS+ experiences difficulties with self- and environmental awareness, communication and activities of daily living. This is consistent with the diagnostic criteria for persons in an MCS+ (including both MSC- and MCS+), according to the Coma Recovery Scale-Revised and Glasgow Coma Scale. Giacino et al. (2014) mention that the diagnostic criteria of the MCS (including both MSC- and MCS+) include minimal, yet intentional behaviour signs of awareness (self- and/or environmental awareness), signs of following commands, yes/no responses to forced choice questions as well as communication behaviour (typically unaided responses) in response to emotional or familiar stimuli.

All the participants mentioned that in order to address the information needs of the communication partners, aspects that should be included relate to the background of the

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disorder or condition (in this case DOC), intervention strategies (related to each professional discipline and rationale for these intervention strategies) as well as prognosis. These information needs are typically present from initial admission to the hospital, through rehabilitation and discharge – irrespective of whether it is to the home context or to a residential facility. If these needs are not met, they can cause severe psychological distress and prolonged grief disorder in communication partners (Moretta et al., 2014). Moretta et al. (2014) confirm the presence of these information needs during the chronic phase, as communication partners are often concerned whether the person will survive, followed by concerns of assistance as well as changes in activities of daily living and changes in the family structure.

Ingredients for communication mentioned by participants mostly relate to attempting communication with the person and then expecting a response (i.e., by employing an active waiting behaviour). Soeterik et al. (2017) mention that communication partners often have high hopes that the person will recover and that the observed responses of the person in an MCS+ are meaningful. Additionally, these behavioural communication responses (i.e., typically unaided communication) may provide a means of communication for a variety of communication functions (Soeterik et al., 2017).

Module 3

All the participants mentioned that multimodal communication strategies should be used by communication partners when communicating with the person in an MCS+. Purdy and Wallace (2016) confirm the use of multimodal communication with persons with severe communication difficulties which integrate both verbal and non-verbal communication. This form of multimodal communication is often also targeted in multisensory stimulation which includes familiar stimuli that target visual, auditory, tactile, olfactory, and gustatory senses (Sautet et al., 2022). From the findings of the current phase, these sensory stimulation programmes are considered to be cardinal in supporting the level of wakefulness and awareness of persons in an MCS+.

Module 4

The participants included in this phase mentioned the importance of environmental adaptations when communicating with a person in an MCS+. Furthermore, Powell et al. (2017) mention that communication partners typically require support in daily care (e.g., bathing), in instrumental assistance (e.g., meal preparation and transport), in managing challenging behaviour and emotions (e.g., anger, tears or uncontrollable laughter), and in advocating for

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the person's needs (e.g., educating communication partners). To address these needs of the person, various environmental modifications are required – not only for communication but also for structural changes to assist with these tasks. For example, to support communication, the environment should be well lit and spacious (Martinez et al., 2017).

Module 5

The participants mentioned the importance of providing communication partner support and including them as part of the multidisciplinary team. The latter is in alignment with the work of Moretta et al. (2017), who mention that communication partners of persons in an MCS+ often experience psychophysiological distress (depression and anxiety) and prolonged grief disorders which reduce their overall quality of life. Additionally, psychophysiological distress may lead to decreases in cognitive efficiency that could affect the type and level of care that communication partners provide to persons in an MCS+ (Moretta et al., 2017). Clinicians who support communication partners assist them in developing functional coping strategies which leads to reduced perceived psychophysiological distress and improves family relationships (Cruzado & De la Morena, 2013). Additionally, inclusion of communication partners in the multidisciplinary team may also increase diagnostic accuracy during assessment of persons in an MCS+ (Cruzado & De la Morena, 2013).

The participating clinicians mostly reacted positively to the TBI Connect suggesting minimal changes to the content of the programme to make it applicable to the target population. The structure of the content in the training modules were mostly appropriate according to the clinicians although, as expected, some adaptations were required.

4.9.10. Conclusion of Step 2.2.2

From the findings of the interviews, it can be concluded that most participating clinicians deemed the TBI Connect as appropriate for the target population, albeit with some adaptations. Clinicians suggested that the structure of content and design of the CPT programme does not require adaptations, however, the content of the training modules requires some adaptation to align it with the target population. However, most of the original content of the TBI Connect remained the same with the addition of content applicable to persons in an MCS+ and their communication partners. The suggestions made by clinicians confirm the unaided communication behaviours used by persons in an MCS+ as identified through the scoping review in Phase 1 as well as the multimodal communication strategies utilised by

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communication partners identified through the online interviews in Phase 1. This resulted in the triangulation of data sources in Phases 1 and 2.

4.10. Conclusion of Phase 2 and recommendations for Phase 3

Phase 2 identified the intervention (i.e., the TBI Connect) and suggested adaptations from stakeholder perspectives. However, the implementation of the programme and the suggested adaptations can only occur once clinical utility has been determined. According to Lesko et al. (2010) clinical utility is defined as the significance and practicality of an intervention in patient care. This will be addressed in Phase 3 of this study. The aim of Phase 3 is to determine the clinical utility of the Connect+ (adapted TBI Connect) programme by including the perspectives of clinicians.

4.11. Summary of chapter

During the first step of Phase 2, an umbrella review was conducted to identify an appropriate intervention, namely the TBI Connect. Furthermore, the identification step also included a discussion of the theoretical models underpinning CPT programmes as well as the design of the content of the TBI Connect programme. From the literature it appeared that the social learning approach could be used as the most relevant approach to learning and maintaining new skills.

The second step of Phase 2 focused on the adaptation of the intervention by employing the Intervention Mapping approach. The theoretical approach was strengthened by including the perspectives of clinicians with a special interest in neurorehabilitation. The clinicians mostly recommended adaptations to the content of the programme and the structure, by reducing the proposed 10 modules to six, to ensure applicability for the target population. The content of the programme included facilitating communication with persons in an MCS+, observing their unaided communication behaviours when providing a stimulus and then providing multisensory support. This phase concluded by proposing a newly adapted programme, specifically the Connect^{+}.

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CHAPTER 5: PHASE 3: CLINICAL UTILITY OF INTERVENTION

Methodology, Results, and Discussion

5.1 Introduction

This chapter is the final of three chapters each explaining the research methodology followed by the results and discussion of one of the three sequential phases of this study as shown in Figure 5.1. Phase 1 (i.e., Exploratory Phase) was discussed in Chapter 3 and outlined the identification of unaided communication strategies displayed by persons in an MCS+ as well as the multimodal communication strategies used by their communication partners together with the support needs of these partners and the impact on communication.

Phase 2 (Intervention Identification and Adaptation) was discussed in Chapter 4. It identified the principles of CPT that facilitate adult learning and trainee engagement and thereafter identified a CPT that met the E^3BP principles that were set. Chapter 4 also included information on the design and content of the proposed CPT (TBI Connect), a description of Intervention Mapping (i.e., the specific approach that was used to adapt the CPT). Phase 2 concluded with the newly adapted intervention (Connect$^+$) as a result of the interviews with clinicians who have a special interest in neurorehabilitation.

Chapter 5 focuses on Phase 3 which is the final phase of the present research study, namely Clinical Utility of the Intervention. First, it identifies the theory underlying clinical utility. Second, it describes the implementation of a nominal group technique to obtain SLTs' perspectives on the topic in an attempt to ensure the clinical utility of the newly adapted intervention (Connect$^+$). The outline of Chapter 5 is highlighted with a green block in Figure 5.1.

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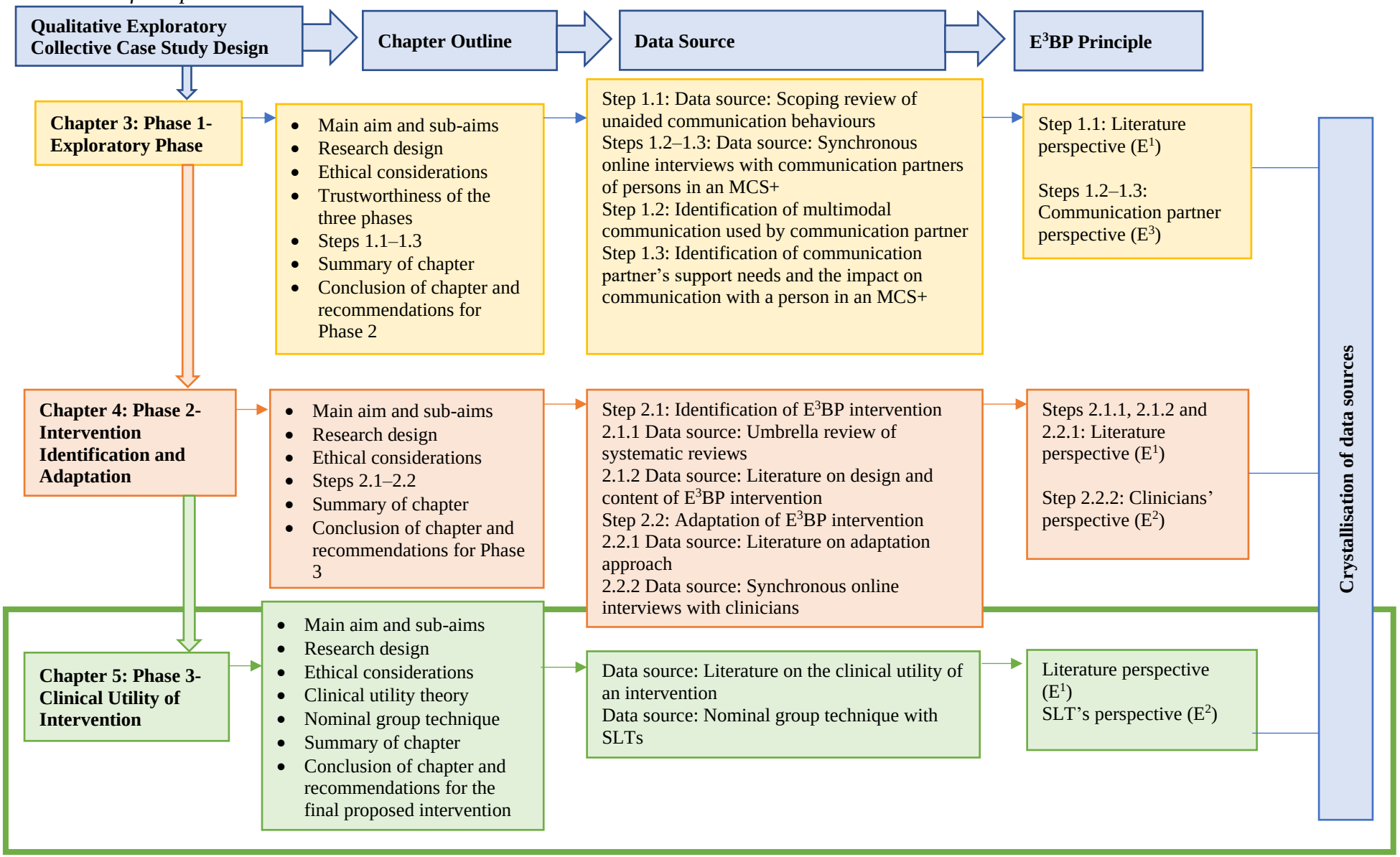
Figure 5.1

Outline of Chapter 5



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Chapter 5 begins with the main aim of Phase 3, followed by the sub-aims for the phase. The research design and ethical considerations for this phase is discussed, whereafter theoretical constructs underlining clinical utility is discussed. Next, the nominal group technique and how it was modified for the purpose of this phase is described. The implementation of the nominal group technique was preceded by a pilot study. Chapter 5 concludes by providing a summary of Phase 3 as well as its implications and recommendations.

5.2 Research aims

5.2.1. Main Aim of Phase 3

The main aim of Phase 3 is to explore SLTs perspectives on the clinical utility of the adapted intervention and to incorporate these perspectives into the proposed intervention.

5.2.2. Sub-aims of Phase 3

To address the main aim of Phase 3, the following two sub-aims were formulated:

i) To identify the theoretical constructs of clinical utility mentioned in the literature and to describe these aspects with application to the current phase.

ii) To obtain a consensus perspective from SLT's on the clinical utility of the Connect+ as well as implementation considerations in a distilled manner. These six constructs include:

- Appropriateness (i.e., the usefulness of information obtained in the programme to address the needs of the target population);
- Accessibility (i.e., the accessibility and affordability of the programme);
- Practicability (i.e., the barriers or facilitators that affect the practical implementation of the programme);
- Training and qualification (i.e., the prerequisites required from both the SLTs and communication partners to ensure successful implementation of the programme);
- Acceptability (i.e., methods and materials used in the programme to promote optimal learning and engagement); and
- Professional utility (i.e., potential concerns of SLTs in implementing this programme and the support required).

5.3 Research design

As outlined in Chapter 3 this study follows a qualitative exploratory collective case study design with three sequential phases each comprising distinct steps. Different data sources

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were employed throughout the three phases to obtain multiple perspectives. Phase 3 uses a nominal group technique that was modified for the specific purpose of this study.

The nominal group technique was preceded by a pilot study, which was a small-scale assessment of the methods and procedures planned for the main study (Hazzi & Maldaon, 2015). A nominal group technique is a form of group interviewing where participants brainstorm to obtain consensus regarding a specific topic (McMillan et al., 2014). As such, it is similar to a focus group and focuses on key concepts such as eliciting stakeholder preferences and exploring new concepts (Hugé & Mukherjee, 2018). The collaborative nature of the nominal group technique increases stakeholder ownership and influences changes in clinical practice as well as policy (Harvey & Holmes, 2012). An advantage of a nominal group technique is that each individual participant obtains an opportunity to share their perspective and the concepts are ranked according to priority within a specific field (Harvey & Holmes, 2012; McMillan et al., 2014). A potential disadvantage of the nominal group technique may be that the facilitator attempts to overcome diversity by creating artificial consensus (Harvey & Holmes, 2012). The afore mentioned was addressed in this phase through member checking by participants to ensure that their opinions were reflected accurately by the researcher who also acted as the facilitator. This technique was selected as it provides individual thinking before group thinking. A nominal group technique also assists in ensuring that participants are more engaged in the session and allows individual and group consensus on less and more important aspects.

5.4 Ethical considerations

As Phase 3 involved human participants, specific ethical considerations were considered during the execution of this phase. Although these considerations overlapped with earlier phases, the specific aspects related to this phase are highlighted in this chapter.

5.4.1. Principle of informed consent

Informed consent relates to the right of the individual to make an autonomous decision as to whether to participate in research or not (Arifin, 2018). In the current phase, informed consent was obtained by considering appropriate and adequate information disclosure, voluntary choice and decision-making capacity (Appendices N1–N3) (Arifin, 2018). The SLTs who participated in Phase 3 were sent an electronic informed consent letter containing a thorough explanation of what is expected of them as well as information on the aim, rationale, and process of the phase. The participants were allowed sufficient time to decide whether they

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want to participate and no form of coercion or external pressure was used. Participants were required to return their signed consent reply slip attached to the letter. Before data collection commenced, it was reiterated that participation is voluntary and that participants could withdraw at any time without any negative consequences. Participants had ample competence and decision-making capacity as the content discussed was related to their scope of practice.

5.4.2. Principle of privacy (confidentiality)

Confidentiality can be defined as an agreement between the researcher and the participants to ensure access control to the participant's information (Cooper & McNair, 2015). In this phase confidentiality was ensured by using de-identifying participant numbers during data collection procedures. The participants were given an explanation on the 'how' and 'for what purpose' participant data would be utilised, how the data storage process was managed and that no third party would have access to any information that could lead to the identification of participants (Arifin, 2018). When reporting the demographic data, it was presented in ranges and individual participant information was not specified (Morse & Coulehan, 2015). Additionally, the online platform allowed the participants to turn off their camera's which allowed them to maintain their confidentiality.

5.4.3. Principle of voluntary participation and withdrawal

This principle relates to the provision of informed consent and includes the willingness of participants to participate in the phase (Robinson & Robinson, 2016). Preceding data collection, participants were requested to complete letters of informed consent (Appendices N1–N3). During the completion of these letters and prior to the nominal group technique, participants were reminded that participation is voluntary and that they may withdraw at any time during the group discussion without any negative consequences. No participants opted to withdraw.

5.4.4. Principle of beneficence

An interview script and research protocol were constructed to ensure that all participants benefitted equally from procedures, thus increasing beneficence (Table 5.1). These procedures ensured that no information was withheld from participants (Hofmann, 2009; Arifin, 2018). Additionally, all SLTs who participated in the phase were provided with the completed Connect+ CPT programme once the study was completed to ensure that their clinical practice benefits from their participation (Arifin, 2018).

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5.4.5. Principle of non-maleficence

No harm was brought to the participants and justice was upheld at all times during data collection procedures (Arifin, 2018; Newman & Kaloupek, 2009). This was done by not discussing sensitive topics that may elicit an emotional response from SLTs. Member checking was conducted to ensure that all information obtained is truthful and reflective of participant perspectives (Birt et al., 2016; Harper & Cole, 2012).

5.5 Clinical utility: Unpacking the theoretical constructs

Clinical utility can be defined as the degree to which an intervention (in this case a CPT programme) enhances understanding of the intervention , improves treatment planning, clinical decision-making, and its usefulness (Bornstein & Natoli, 2019; Keeley et al., 2016; Lesko et al., 2010; Smart, 2006; Umscheid, 2010). Therefore, when considering the usefulness of an intervention, careful consideration should be given to its advantages and disadvantages (Lesko et al., 2010; Smart, 2006). Additionally, the clinical utility of an intervention should facilitate increased communication between the user and the clinician and should increase the understanding of what the intervention entails as well as how it should be implemented. Collectively, these aspects heighten clinical decision-making and result in more effective treatment outcomes (Bornstein & Natoli, 2019; Keeley et al., 2016). This ensures that the intervention is beneficial and that it can be safely implemented in real-world clinical settings in a cost-effective manner (Umscheid, 2010).

The clinical utility of a intervention can be maximised by soliciting stakeholder perspectives (Umscheid, 2010). This chapter describes the perspectives of stakeholders (specifically SLTs) on the clinical utility of the intervention that was identified and adapted for this study, namely the TBI Connect. The adapted version of the TBI Connect will henceforward be referred to as the Connect^{+} CPT. According to Lesko et al. (2010), determining the clinical utility of an intervention includes a consideration of both internal and external constructs. The six constructs of clinical utility are multidimensional in nature (Smart, 2006; Verheul, 2005) and their application to the current phase is discussed as follows:

i) ***Appropriateness:*** Relates to the SLTs' perceptions on the usefulness of information that communication partners obtain during the training programme to address the needs of both the communication partners and the persons in an MCS+.

ii) ***Accessibility:*** Relates to the SLTs' perceptions on the accessibility and affordability of the training programme based on their clinical experience.

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iii) ***Practicability***: Relates to the SLTs' perceptions on the barriers and facilitators that affect the practical implementation of the training programme.

iv) ***Training and qualificatio***n: Relate to the SLTs' perceptions on the prerequisites required of both the SLTs' and communication partners to ensure successful implementation of the training programme.

v) ***Acceptability:*** Relates to the SLTs' perceptions on the methods and materials used in the training programme to ensure its suitability. This construct promotes optimal learning and engagement from the communication partners caring for persons in an MCS+.

vi) ***Professional utility:*** Relates to the SLTs' perceptions on the possible concerns SLTs might have when implementing the training programme and what support is required to ensure successful implementation of the programme.

The application of these constructs in clinical practice is a prerequisite to facilitate changes in practice (Bossuyt et al., 2012). These changes can contribute to improved patient outcomes (Smart, 2006). Determining the clinical utility of the Connect+ intervention is necessary to ensure that SLTs see the Connect^{+} as useful within their clinical practice and to ensure appropriate implementation of the CPT within their clinical practice.

5.6 Nominal group technique

The nominal group was used to obtain a consensus perspective from SLT's on the clinical utility of the Connect+ as well as implementation considerations in a distilled manner. clinical utility of the Connect^{+} CPT for communication partners of persons in an MCS+ was determined by means of a nominal group technique. Subsequently, SLTs who currently work with persons in an MCS+ were included in Phase 3 to determine their perspectives on each of the six constructs of clinical utility described earlier.

5.6.1. Participants

Non-probability purposive sampling was used to identify potential participants (Campbell et al., 2020; Etikan et al., 2016). This specific sampling strategy was selected as it allowed the researcher to select participants who were most likely to generate appropriate and useful information (Campbell et al., 2020; Etikan & Bala, 2017). The participants were sourced through recommendations from Phase 2 as well as through the researcher's professional network. The same specific participant selection criteria used in Phase 2 was used for Phase 3 (see Section 4.3.10.1), except that only SLTs were included in Phase 3, while a range of allied

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healthcare clinicians were included in Phase 2. Although, the same criteria were used, there was no overlap of participants between Phase 2 and Phase 3. Different participants were used for Phase 3 and therefore their numbering is in letters, for example HR.

The SLTs were required to be knowledgeable regarding the field of neurorehabilitation and clinically informed regarding the research topic. This meant that participants had to have a degree in speech-language pathology as well as postgraduate experience working in a clinical setting practicing in neurorehabilitation. In total, 15 potential participants were identified, however, only six indicated an interest in Phase 3 via email. The other potential participants did not respond to the initial and follow-up emails which were sent to them. Prior to the start of the group, one participant withdrew her participation due to personal reasons, however, indicated that she would participate at a later stage if possible. Therefore, five participants were included in the final data collection of whom all consented.

As per the selection requirements, all the participants were SLTs as communication with persons in an MCS+ form part of their scope of practice (Roberts & Greenwood, 2019). However, two of the participants had dual qualifications as both SLTs and audiologists. Four of the SLTs had a bachelor's degree in SLT while one participant held a master's degree. All the participants were female and their ages ranged from 25 to 40 years with a mean age of 30,6 years. Four participants spoke English and one participant spoke Afrikaans as a home language. Four participants were employed in private practice servicing settings such as acute care hospitals, rehabilitation centres, and care facilities (e.g., retirement villages) and one participant was in full-time employment at a government-funded hospital. Four participants were South African residents in the Gauteng province, with one participant working in London (United Kingdom). Participants treated persons in an MCS+ individually on a quarterly (n=2), monthly (n=1), and daily (n=2) basis. Table 5.1 includes the participant description as well as demographic information.

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Table 5.1

Demographic information of SLTs (N=5)

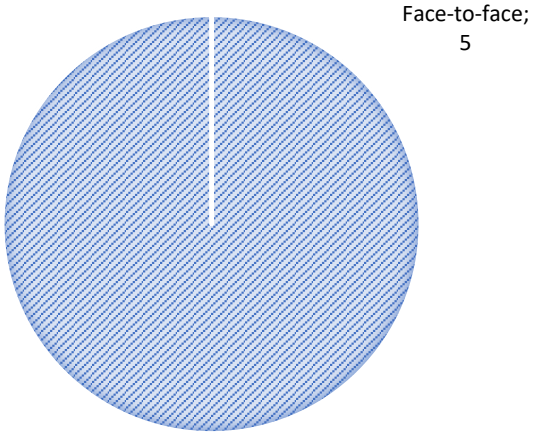
Participant Nr	Age	Gender	Home Language	Occupation	Degree	Experience in MCS	Setting	Frequency of Treating Persons in an MCS+
HR	40	Female	Afrikaans	SLT/A	BD	16 years	Private practice	Quarterly
BD	28	Female	English	SLT/A	BD	6 years	Private practice	Quarterly
SL	35	Female	English	SLT	MD	9 years	Hospital	Monthly
AC	25	Female	English	SLT	BD	3,5 years	Private practice	Daily
CD	25	Female	English	SLT	BD	6 months	Private practice	Daily

Note. Abbreviations: SLT/A= Speech-Language Therapist and Audiologist; SLT =Speech-Language Therapist; BD = Bachelor's Degree; MD =Master's Degree

The SLTs were asked to provide information related to the communication partner support they provide. These results are shown in Table 5.2.

Table 5.2

Descriptive characteristics of the communication partner support provided by SLTs (N=5)

Description	Findings
Clinician's method of communication partner support All five of the SLTs provided face-to-face communication partner support on a weekly basis, using their specific work context. Only one participant also provided communication partner support within the community once a month. Two participants provided treatment to the person in an MCS+ solely as outpatients and three of the SLTs provided support from initial admission to the hospital (inpatient) to discharge home or to a care facility (outpatient).	

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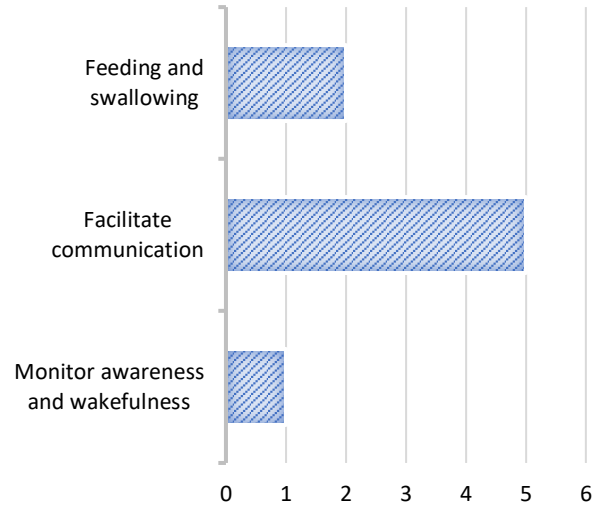
Description	Findings
Content of clinician communication partner support All five participants provided guidance on facilitating a functional means of communication via unaided communication. Additionally, two SLTs counselled communication partners on feeding and swallowing and one SLT taught communication partners how to monitor and identify behavioural signs of awareness and wakefulness.	
Contribution to clinical learning The SLTs mentioned that clinical experience (n=2), reading academic articles (n=2) and attending continuing professional development courses (n=2) were equally important with only one SLT mentioning the contribution of clinical supervision to their learning. The continuing professional development courses related to the National Health System in the UK who provided workplace courses on disorders of consciousness. These included continuing professional development accredited courses as well as webinars on specific topics related to disorders of consciousness (e.g., sensory stimulation or feeding). Some of the webinars were posted on the UK National Health System's website to invite and accommodate international attendees.	

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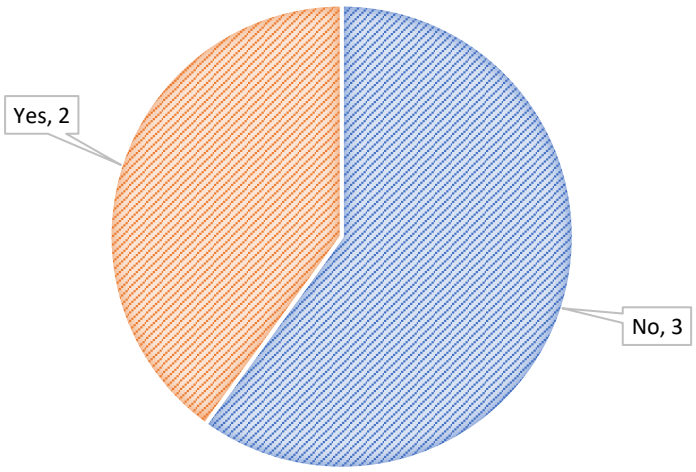
Description	Findings
Training needs Only two SLTs indicated a need for further training. The one therapist required training on optimal stimulation for communication and the other required training on sensory stimulation, passive dysphagia management and augmentative and alternative communication for this population. Most of the participants did not require further training as one therapist indicated that workplace training is sufficient and the two other therapists mentioned the amount and frequency of treatment for persons in an MCS+ do not warrant further training (therapists see the patient annually).	

The SLTs had sufficient knowledge and clinical experience to participate in the group. Additionally, the SLTs were required to be proficient in understanding and speaking English (as this was the language used to conduct the nominal group technique). SLTs mostly implement CPT programmes for adults with acquired neurological conditions and was therefore the focus of Phase 3 (Behn et al., 2021; O'Rourke et al., 2018). Additionally, most of the SLTs were located in South Africa, however, one international expert was selected for the adapted nominal group technique. This SLT was involved in designing guidelines for best clinical practice in speech-language therapy for prolonged DOC and is presumed to provide valuable insight into practical aspects influencing clinical utility of the Connect^{+} CPT (Roberts & Greenwood, 2019). The ideal target size for a nominal group technique is one group of participants ranging from five to seven (Harvey & Homles, 2012; Hugé & Mukherjee, 2017). In this phase, one group of five participants were identified to participate in the adapted nominal group technique. The sample was small, however, sufficient to provide in-depth understanding of the concepts (Campbell et al., 2020).

5.6.2. Materials and equipment

Different materials were used in Phase 3 to conduct the nominal group technique which is discussed in detail in the subsections that follow.

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5.6.2.1. Letters of informed consent

An informed consent letter was sent to potential participants via email (Appendices N1–N2). This letter provided the aim and rationale for the phase and explained what would be expected of them. Additionally, the ethical principles that would be upheld during the phase was explained, namely voluntary participation, withdrawal of participation without negative consequences, storage of information, the use of the participants contributed data and the techniques used to maintain confidentiality. This was to ensure that participants could be informed when deciding to participate or not (Creswell & Plano Clark, 2018; Josselson, 2013). Personal information such as contact information, was only accessed once participants provided written consent to ensure that this phase aligns with the protections of personal information (Fisman, 2016).

5.6.2.2. Biographic questionnaire

The biographical questionnaire (Appendix K3) was similar to the clinician questionnaire used in Phase 2 (Appendix H3). It included participant demographic variables such as gender, age, home language, qualification level, job description, and clinical theoretical experience working with persons in an MCS+. The questionnaire assisted in identifying whether the participants met the selection criteria (Sargeant, 2012).

5.6.2.3. Data collection script

A script (Table 5.3) was developed to collect the data based on Smart's (2006) six constructs of clinical utility. Therefore, six open-ended questions were developed to match these constructs of clinical utility as opposed to the traditional nominal group technique which relies on one to two open-ended questions (Hugé & Mukherjee, 2018). The six questions were phrased in such a way to ensure that the participants' unique perspectives were elicited without influencing their responses (Josselson, 2013). Table 5.3 shows the theoretical justification for the questions included in the interview script.

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Table 5.3

Data collection script for use in the nominal group technique

Nr	Information Type	Description	Theoretical Justification
Personal Introduction			
1.	Personal narrative	As explained in the consent letter, my name is Ariné and I am currently conducting my PhD study, which is focused on the adaptation of a CPT programme for familiar communication partners of persons in an MCS+.	See Table 3.6 for more information.
Ethics			
2.	Procedural narrative	You already completed the informed consent letter, but I want to remind you that I will be video- and audio-recording our session. Additionally, a transcript will be made during our session. Only I will listen to the recording and I will use it identify aspects that you regarded as important and to provide feedback for you.	Reminding participants of informed consent and audio-recordings allows them to apply autonomy during data and that they have certain rights as a research participant (Salmons, 2015).
Procedural Introduction			
3.	Procedural narrative	Thank you again for making time in your schedule to participate.	Preparing individuals allows them to make informed choices by providing knowledge, positive attitudes, and increasing behaviour outcomes (Michie et al., 2020). This assists in providing the SLTs with a need to know why the discussion is important and orientates them which is in line with adult learning principles (Mews, 2020).
4.	Procedural narrative	This session will take approximately 60 minutes and you will receive a questionnaire after the session that will take 5 minutes to complete.	
5.	Procedural narrative	Before we start with the discussions, I want to do a brief PowerPoint presentation. This presentation will provide a background of the TBI Connect CPT programme as well as the suggested adaptations in the Connect^{+} CPT. This will lay the foundation for the questions you will be required to answer later.	
6.	Procedural narrative	• Please ensure that Zoom is open on your desktop. • I will now share the Whiteboard. Please let me know whether you are able to see it. • I will ask you a question after which you need to write an answer privately. You will then have an opportunity to share this verbally with the group. • We will later discuss the most important components and group them together.	

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Nr	Information Type	Description	Theoretical Justification
Questions			
7.	(Accessible)	How accessible do you think this programme is for communication partners and SLTs? Please justify your answer by writing a short comment on a piece of paper. I am going to allow three minutes for this activity – please write down as many comments as you wish. **Procedure:** • Please write down your answers and share your answers with the group. • Once we have captured all the comments, you will each have the opportunity to clarify, and to elaborate as needed. • I will facilitate this process and ask you individually, to ensure that all participants provide their input. • We will then see if we have any similar or duplicate comments, and then group them together. • If you have any questions, please put up your hand and let us discuss it. • Now I want us to collectively group all the comments into themes, I want to encourage everyone to actively participate, and make suggestions of which specific themes are represented by the comments. • Now I want us to collectively rank the themes in terms of its importance.	These components address accessibility and are important to address to ensure that participants benefit from the CPT and adapt their approach to communication (Higginbotham et al., 2007; Smart, 2006). The nominal group technique was selected as it allows collaborative brainstorming of multiple people during one online session. The nominal group technique facilitates the generation of concepts in relation to problems, solutions, or both, which are then discussed and ranked in order of priority by individual participants (McMillan et al., 2014).
8.	(Practicability)	What barriers or facilitators do you think can affect the practical implementation of the training? You will again have three minutes to type your answer on the Whiteboard. **Probing questions:** • How much time do you think should be allocated for each session as well as the complete course? (The same process will be followed with this question)	Short CPT programmes are less effective due to shorter periods spent on skill-building. Programmes of approximately 35 hours tend to show significant effects in maintenance of skills (Behn et al., 2021).
	(Training and communication partners)	What prerequisites do you think are required for the communication partner to promote successful implementation of the training? You will have three minutes to write down your answer. (The same process will be followed as with previous questions)	CPT often targets the person and communication partner and it is therefore important that consensus is obtained by SLTs regarding the criteria for implementation and outcomes of CPT (Cruice et al., 2018; Sirman et al., 2017). Sirman et al. (2017) suggest that there is variability with SLTs regarding the implementation of CPT with communication partners of persons with acquired neurological conditions. CPT should focus on the needs of both the person in an MCS+ as well as the communication-partner (Simmons-Mackie et al., 2016). When these needs and concerns are addressed, communication partners may be more motivated to implement the training programme.
9.	(Acceptability)	What methods or materials would make the training more acceptable to communication partners and promote optimal learning and engagement in the CPT? You will have three minutes to answer the question. **Probing questions:**	

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Nr	Information Type	Description	Theoretical Justification
		• How can the communication partners roles and responsibilities be considered? (The same process will be followed as with previous questions)	
	(Professional utility)	What concerns may SLT's have with the training and how can they be supported? You will have three minutes to complete this task. **Probing questions:** • What concerns may communication partners have regarding the training programme implementation as well as their access to service delivery? • What support do you think communication partners require for successful maintenance of skills learnt in training? (Same process will be followed with all the questions)	Information provided to participants should be concise to enable comprehension (Ennis & Wykes, 2016).
10.	(Appropriateness)	What information will communication partners gain from this training programme that is meaningful or useful to them? You will have three minutes to complete this question. (The same process will be followed with all the questions)	The Connect^{+} CPT focuses on individual treatment of a single communication partner and person dyad (Rietdijk, Power, Brunner, Attard et al., 2019). This emphasises that the training is based on the needs of the communication partner and person which increases maintenance of skills.
Closing			
11.	Procedural narrative	Thank you for participating in this discussion, I appreciate your time and that you shared your experiences so freely with me.	Receiving gratitude for an action ensures a rewarding experience for the participant (Park et al., 2021).
12.	Procedural narrative	I will summarise all the information that you so kindly shared with me. Additionally, I will send this to you as well as a short questionnaire on questions that we were not able to discuss in this group.	Shi et al. (2018) mention that providing visual narratives assist in recalling context and content during interaction. Therefore, providing a written transcript of the discussion may allow participants an opportunity to review the content of the discussion.

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5.6.2.4. Online platform selection

The platform selection was important in ensuring participants comfort when sharing information (Cortini et al., 2019; Johansson, 2019). Specific criteria were required for the successful implementation of the nominal group technique. Amongst these criteria was the participants' safety, confidentiality; their ease of understanding of how to use the platform with an emphasis on the Whiteboard function as well as the synchronicity (Johansson, 2019). The additional items that were not considered in Table 4.11 are shaded. Table 5.4 shows the four platforms that were tried and tested by means of a pilot study, before making the final selection.

Table 5.4

Online interview platform comparison

Criteria	Google Meet (https://workspace.google.com)	Zoom (https://zoom.us/)	SKYPE (https://www.skype.com/en/)	Microsoft Teams (https://www.microsoft.com/en-za/microsoft-teams/log-in)
Participant safety and confidentiality ensured	Yes, linked to email address of participant.	Yes, meeting invitation is sent via email to participants by meeting host.	Yes, meeting invitation is sent via email to participants by meeting host.	Yes, linked to participant's Microsoft account.
Number of participants	100	100	100	20
Ease of use of the platform (Easy, moderate, or difficult)	Easy	Easy	Easy	Difficult, not as user-friendly as competitors in the market.
Allows for synchronous real time interaction	Yes	Yes	Yes	Yes
Possibility to record	No, requires admin account.	Yes	Yes	Yes
Storage of information from group	Save transcriptions to researchers Google Drive.	Videos saved on host account.	Skype information is routed through Microsoft servers.	Server within Google Drive (cloud service)
Cost to use	Free for (under 100 participants).	Free for under 40 minutes for groups then requires professional, business, or large enterprise account for which monthly or annual pricing is available. For one-on-one meetings, 30 hours is free.	No, requires client programme that is not free. This client programme controls the system.	Free if host has a Microsoft account.
Possibility to automatically transcribe	Yes	Yes	No	Yes
Information safety: developer will sell or share info	No, all information is encrypted.	No end-to-end encryption is used.	No	No

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Criteria	Google Meet (https://workspace.google.com)	Zoom (https://zoom.us/)	SKYPE (https://www.skype.com/en/)	Microsoft Teams (https://www.microsoft.com/en-za/microsoft-teams/log-in)
Integrated white board plugin	No (But can be used with Jamboard and Chrome Canvas)	Yes (Zoom Whiteboard)	Yes (Whiteboard only available for business account)	Yes (Microsoft Whiteboard)
How to use	Chrome Canvas is not collaborative only show hosts content (Open new tab in browser) Open Jamboard in new tab during meeting. Select share with link and paste in meeting chat or send separate emails inviting meeting participants to collaborate and edit Whiteboard.	Select onscreen option during screenshare in meeting Administrator access required; Available in and out of meeting	Select onscreen option during screenshare Host of meeting gives access to all attendees in meeting	Download Microsoft Whiteboard plugin from Microsoft store (Free if host has an account) Once plugin is downloaded host selects share Whiteboard during meeting
Access to Whiteboard after meeting	Yes, select save to Google Drive	Host sends images of Whiteboard collaboration via email	Host gives access for all to download	Yes
Automatic save of Whiteboard	Yes	No board is temporary (until meeting is closed) and requires host to select save option	Yes	Yes
Access method	Access through Google Drive	Whiteboards are saved to the cloud	Present-manage content, access in meeting tab on hosts account	Access Whiteboard in Whiteboard tab or in separate Microsoft Whiteboard app
Format of Whiteboard	Image	PDF or PNG	Image	Image
Visual recording	No	Available with free account (includes Whiteboard)	Yes, requires business account	Yes (Recording does not include Whiteboard images)
Audio transcription	Yes	Yes, requires business, education or organisation account, however, does include separate audio file for free account	Yes, requires business account	Yes
Available for personal and group use	Yes	Yes	Yes	No Whiteboard only available for meetings with more than 3 participants
Additional account requirements	No	No	No	No

5.6.2.5. PowerPoint presentation

A PowerPoint presentation (Appendix L) was developed to ensure that all participants have a shared general concept of the proposed Connect^{+} CPT. This provided the participants with baseline knowledge on the original TBI Connect programme as well as the proposed adaptations for the Connect^{+} CPT. This also allowed the participants to make meaningful contributions during the discussion. The PowerPoint presentation started with an introductory YouTube video (https://www.youtube.com/watch?v=2ZnRgcynxsw) on the TBI Connect which was presented by the original authors of the programme (Rietdijk, Power, Brunner,

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Attard et al., 2019). This was followed by a discussion on the design and content changes (based on the recommendations at the end of Phase 2) which resulted in the newly developed Connect^{+} CPT having a new target group, namely the communication partners of persons in an MCS+. Additionally, the presentation slides also included the aims of the programme, expectations of communication partners before, during, and after the training (Rietdijk, Power, Brunner, Attard et al., 2019). The presentation slides concluded with comments on copyright, collaboration with the original authors of the programme as well as fidelity considerations (Highfield et al., 2015).

5.6.3. Pilot study

A pilot study was conducted to evaluate the platforms and its applications prior to the main study suggested for Phase 3. The aims of the pilot study were to determine if changes were required to the proposed method (i.e., the nominal group technique), the proposed platform selected and the applicability of questions selected. The specific aims of the pilot study are shown in Table 5.5.

5.6.3.1. Participant

One participant was involved over multiple sessions to ensure continuity and consistency and ultimately improve the quality and efficiency of the main study (Hazzi & Maldaon, 2015). An advantage of a pilot study is that it informs the feasibility and identifies modifications for the main study (Hazzi & Maldaon, 2015; In, 2017). Additionally, the pilot study allows not only an assessment of the methods or approach to data collection for the main study, but also the materials. This includes the content and format of the materials presented (e.g., the wording of the questions as well as the level at which the information is presented to participants [type of language such as academic/colloquial]) (In, 2017). One participant was selected based on the practical criteria she met such as accessibility, availability and willingness to participate (Etikan et al., 2016), basic computer literacy skills, and access to a computer as well as internet. Having basic computer literacy skills was especially important as one of the foci of the pilot study was on selecting the most suitable online platform.

The pilot participant was a 46-year-old female educational psychologist with clinical and research experience who was enrolled in a PhD in Disability Studies that reflected the skill level of the target participants as well as the fact that she was fully bilingual (proficient in English and Afrikaans). The participant had uninterrupted computer and internet access and was computer literate with a basic knowledge of online platforms. In addition, the participant

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had experience in the data collection strategy that was proposed (namely the nominal group technique).

5.6.3.2. Materials and methods

During the pilot study, the same ethics procedure used for earlier phases of this study was followed in order to obtain consent (Appendices L1–L3). The proposed material was employed, which comprised of a PowerPoint presentation (Appendix L) as well as the data collection (Table 5.3). Additionally, three synchronous online platforms were trialled, namely Zoom, Microsoft Teams, and Google Meet. Skype was not trialled as the platform did not allow access to a Whiteboard application. The Whiteboard application of the platforms was the specific focus of the different trials, since this function forms a critical component of the implementation of the nominal group technique's online brain storming session. It was important for the researcher to also evaluate the ease of sharing PowerPoint presentations and videos on the platform to ensure that the participants are able to hear and see all the information presented prior to the brainstorming session.

5.6.3.3. Data collection

The pilot study participant was invited telephonically to participate in this phase. Upon indicating interest, an informed consent letter (Appendix K1-K2) was sent to the participant via email. The was required to return their written consent form electronically one day before the meeting. Three separate synchronous online meetings, each focused on one of the three proposed online platforms, were scheduled at a time and date convenient to the participant. The meeting links were sent to the participant one day before the meeting via email, thereby reflecting the same method proposed for the study.

5.6.3.4. Findings and recommendations

The specific aims of the pilot study, with the findings and recommendations are included in Table 5.5.

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Table 5.5

Pilot study aims, findings, and recommendations

Nr	Aim	Findings	Recommendations
Technical aspects			
1.	To determine whether the link of the platforms could be sent and opened successfully via Gmail.	*Microsoft Teams*: The participant mentioned that she did not receive the link for the meeting confirmation email sent automatically from the platform, the researcher had to copy the link from the platform to open the meeting. *Zoom*: The researcher copied the link from the platform and sent it via Gmail to the participant. The participant could successfully open the platform without technical difficulties. *Google Meet*: The researcher sent the link via Gmail and the participant could successfully open the link.	Both Zoom and Google Meet could open the link from Gmail effectively.
2.	To determine whether the link could be opened without having a platform account.	*Microsoft Teams*: The Microsoft Teams link could be opened without having an account, however, the participant had limited access to platform features. *Zoom*: The Zoom link could be opened without having an account and the participant had access to all the platform features that was on the host's account. *Google Meet*: The Google Meet link could be opened without having an account and the participant had access to the available platform features.	Both Zoom and Google Meet allowed the participant to join the meeting without having an account, while having access to all the features.
3.	To determine whether participants can join the meeting without the host having to allow them into the meeting room.	*Microsoft Teams*: For the participant to join the meeting, the host has to allow the participant into the meeting. The participant therefore needs to stay in the waiting room until the meeting starts or until the host allows entry into the meeting room. This feature can be adapted, however, requires careful perusal of the settings function that is not easy to find. *Zoom*: Allows the participant to join the meeting automatically when selecting the meeting link. *Google Meet*: Allows the participant to join the meeting automatically when he/she has a Gmail account or works at an institution with a corporate Google account. On rare occasions participants are required to be admitted to the meeting by the host.	Both Zoom and Google Meet allowed the participant entry into the meeting without the hosts approval of admittance.
4.	To determine whether the host required an account of the platform to host a meeting.	*Microsoft Teams*: The host needs a paid Microsoft account to acquire access to the Microsoft Teams platforms and to host a meeting. *Zoom*: With a free account, a meeting of 40 minutes can be hosted. *Google Meet*: The host needs a free Gmail or paid corporate Google account to host a meeting.	A free Zoom and Google Meet account enables a host to conduct a meeting.
Platform features and user-friendliness			
7.	Opening the platform from Google Chrome and enabling audio and video settings.	*Microsoft Teams*: Prior to entering the meeting, the participant and host could enable or disenable both audio and video settings. *Zoom*: Prior to the meeting the participant and host could enable or disenable both the audio and video settings. *Google Meet*: During the meeting the participant and host could enable or disenable both the audio and video-settings.	Both Microsoft Teams and Zoom allowed the host and participant to enable or disenable their video and audio setting prior to the meeting while Google meet only offered this functionality during the meeting.

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Nr	Aim	Findings	Recommendations
8.	Ease of putting video on and off to allow participants to see each other based on preference and convenience of participants.	*Microsoft Teams*: Microsoft Teams has a task bar at the top of the screen where audio and video settings can be enabled or disenabled during the meeting based on the preference and convenience of the participants. *Zoom*: Zoom has a taskbar at the bottom of the page that allows video or audio settings to be enabled or disenabled during meetings. *Google Meet*: Google Meet has a taskbar at the bottom of the page that allow video or audio settings to be enabled or disenabled during meetings.	All three platforms allow easy access of both audio and video functionality for the convenience of the participants.
9.	Allows participants to view the host and other participants while content is shared.	*Microsoft Teams*: Yes *Zoom*: Yes, allows the participants and host to change their view based on their convenience. *Google Meet*: Yes	Zoom appears to be the more effective platform to use to view the content, participants, and host simultaneously
10.	Platform's ability to present YouTube videos with audio.	*Microsoft Teams*: The host has to select 'share content', then click on the specific page that needs to be shared. Thereafter, the host has to select the audio settings to be shared under the 'more function' on the top taskbar. *Zoom*: The host selects the share content, then clicks on the page that needs to be shared and when sharing selects the option on the share page to share audio. *Google Meet*: The host selects share content, share video and the audio is automatically shared.	Even though Google Meet appears more user friendly when sharing content, Zoom allows greater functionality when sharing videos with audio.
11.	Platform's ability to present a PowerPoint presentation.	*Microsoft Teams*: Yes, host selects 'share content' and selects page to be shared. *Zoom*: Yes, host selects 'share content' and selects page to be shared. *Google Meet*: Yes, host selects 'share content' and selects page to be shared.	All three platforms allow for sharing of PowerPoint presentations.
12.	Platform's ability to present an integrated collaborative Whiteboard which both the host and participants can access.	*Microsoft Teams*: No, Microsoft Whiteboards need to be downloaded and is then integrated into the platform. This function allows both the host and participants to collaborate on the white board only if both the host and participants have Microsoft accounts. *Zoom*: Yes, has an integrated Whiteboard, however, only the host can collaborate on the Whiteboard with the free account. When the host has a professional account both the host and participant can collaborate on the Whiteboard function. *Google Meet*: No, Google Meet does not have an integrated Whiteboard function. A separate tab needs to be opened on the web browser, for example, Jamboard. Jamboard allows collaboration, however, increases confusion for the participants as they do not know whether they are viewing the Jamboard on which they can collaborate or the Jam board is being presented by the host which they cannot collaborate on. For the participants to access the Whiteboard, the link to the Whiteboard needs to be shared either in an email or in the chat function of the platform.	It appears that Zoom allows more Whiteboard functionality if the host has a professional account.
13.	To determine the platform's ability to create multiple Whiteboards and ease of accessing the multiple Whiteboards during the session.	*Microsoft Teams*: No, only one Whiteboard can be created during a meeting. *Zoom*: The host can easily access a maximum of three Whiteboards with a free account. *Google Meet*: With Google Jamboard, the host can create as many Whiteboards as required, however, a separate tab is needed during the meeting to access the Whiteboards	Zoom appeared to be the most user-friendly platform to create multiple Whiteboards and to access them.

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Nr	Aim	Findings	Recommendations
		which increase confusion when switching from one board to the other.	
14.	To determine the utility and user-friendliness of the Whiteboard (e.g., adding sticky notes, writing, text, or images).	*Microsoft Teams*: A taskbar appears at the top of the page including the features of the Whiteboard. However, only the host can see this taskbar if the participant does not have a Microsoft account. *Zoom*: In the free account, a taskbar appears at the top of the page that only the host can access. The only way that the participant can add to the Whiteboard is when the host shares the mouse selection. A paid account is required for the participant and the host to collaborate. When the host has a paid account, the taskbar will appear in the middle on the left side of the page. *Google Meet*: Google Jamboard has a taskbar on the left side of the page that includes Whiteboard functionality.	Only Zoom allows the participant and host to easily access the taskbar for collaborating on the Whiteboard.
15.	To determine the availability of the collaborative Whiteboard after the meeting has ended and the ease of accessing this stored Whiteboard.	*Microsoft Teams*: During the meeting the host needs to save the Whiteboard as a PDF in an easily accessible folder as the Whiteboard is not available after the session. *Zoom*: The Whiteboard can be downloaded to share the content with the participants. The host can also download the content of the Whiteboard as Zoom saves the boards in a separate Zoom document on the host's computer. Additionally, the Whiteboards are saved under the Whiteboard heading in the host's account. *Google Meet*: The host and participant have access on Jamboards to the Whiteboards after the session.	Zoom appears to be the most user-friendly platform to access Whiteboards after the session as it is saved in two places and allows the participants to also have access to it.
16.	To determine whether participants have access to the "chat function" and to the reactions (e.g., thumbs up or raise hand).	*Microsoft Teams*: The host and participants only have access to the chat function if they have paid Microsoft accounts. However, the participants can access the reactions without an account. *Zoom*: Both the host and participant have access to the chat and reaction function with the free account. *Google Meet*: Both the host and participant have access to the chat and reaction function with the hosts free Gmail account.	Both Zoom and Google Meet allow the host and participant access to the chat function and reactions during the meeting.
17.	To ensure the platform features are available for the full duration of the meeting.	*Microsoft Teams:* With the host's paid Microsoft account, the platform features are available for the full session for the host, however, limited options are available for participants without a Microsoft account. *Zoom*: With the free account most features are available for only 40 minutes. *Google Meet:* Limited features available for both the host and participants for the full session.	Zoom appears to be the platform with the most features available, however, a paid account is required to ensure functionality for the full duration of the meeting.
18.	Allowing recording of both the meeting video as well as the collaboration on the Whiteboard.	*Microsoft Teams*: Allows recording of both the audio and video, however, the recording does not include visual footage on the Whiteboard collaboration. *Zoom*: Allows both video and audio recording and includes the Whiteboard collaboration. *Google Meet*: Does not allow recording. Recording can only be obtained by downloading a plugin called screen recorder, however, a separate tab needs to be open on the browser and this plugin complicates the process during screen recording as the host needs to constantly switch between screens. Additionally, an administrator account is required to allow recording.	Zoom appears to be the platform that allows audio and video recording more readily with visual footage of the Whiteboard collaboration.
19.	To determine the platform's ability to provide full and accurate verbatim transcriptions of the meeting audio.	*Microsoft Teams*: An audio transcript is made during the session and is easy to access on the scheduled meeting of the host's account.	A paid Zoom account appears to be preferred due to increased accuracy of verbatim

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Nr	Aim	Findings	Recommendations
		Zoom: Provides a separate audio file and an accurate verbatim transcription when the host has a paid account. This feature is not available in the free account. *Google Meet*: Google Meet allows verbatim transcription that can be viewed in the host's Google drive. These transcriptions are often not 100% accurate and requires the host to review the transcript, however, with difficulty due to no video or audio accessibility within the programme. In addition, audio recorders on external devices are required for audio files.	transcriptions and availability of separate audio file.
20.	To determine the ease of accessing the recording and transcript function in the platform as well as after the meeting is concluded.	*Microsoft Teams*: The transcription and video file can be obtained from the hosts Microsoft Teams platform in the scheduled meeting. *Zoom*: Zoom creates a separate Zoom document folder on the hosts computer where the host can access the transcript and recording and additionally saves the recording and transcript on the host's Zoom account. *Google Meet:* The transcript can be accessed in the host's Google Drive, however, no video or audio file is available.	Zoom appears to be the more user-friendly programme that assists the host in obtaining both the original files and back-ups.
21.	Cost-effectiveness of platform	*Microsoft Teams*: Paid account (R1299) *Zoom*: Free with limited access to features. There are two options available for a paid account, a monthly (R323) and an annual (R2533) subscription with additional Whiteboard functionality (monthly—- R44,37). This account can easily be cancelled. *Google Meet*: Free	Even though the Google Account is free, the Zoom account for a once-off monthly subscription appears more cost-effective as the host and participants have access to more features (One month subscription costs R323).
Nominal group technique methodology			
23.	To determine the applicability of the questions in addressing the concepts mentioned in the second aim of Phase 3.	The pilot study participant mentioned that the content of the questions was applicable and addressed the concepts identified in the sub-aims.	The questions could therefore remain as designed by the researcher.
24.	To determine the applicability of the wording to ensure ease of understanding of participants.	The participant mentioned that the wording of the questions was simple and that participants would understand exactly what was expected of them. Additionally, she mentioned that probing questions be reduced to ensure that the process does not become more complex and longer in duration than necessary.	The wording and content of the questions were appropriate and could remain the same. Probing questions were reduced.
25.	Trialling the nominal group technique namely: i) an opening statement (brief introduction to topic, purpose of the session and value of participant contributions); ii) generating concepts (one open-ended question is provided to discuss); iii) sharing and recording concepts (each person is afforded one answer at a time for the question); iv) group discussion of concepts (once all the concepts are recorded, the participants are invited to ask for clarification or elaboration); v) voting and ranking of concepts (the participants first rank the concepts privately with a Likert scale based on criteria provided by the facilitator and second, vote publicly on their	The participant mentioned that the Zoom platform allows for all the steps of the nominal group technique to be implemented without difficulty. The participant mentioned that host write the initials of the participants on the Whiteboard and create a block for each participant's response. Additionally, the participant suggested that the host should write participant responses to ensure that all participants contribute equally.	Zoom platform is preferable to conduct six steps of nominal group technique without difficulty.

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Nr	Aim	Findings	Recommendations
	preferences); and last vi) data analysis (thematic analysis) (Hugé & Mukherjee, 2018).		
26.	To determine ethical considerations of the platform and to maintain confidentiality.	The participant mentioned that pseudonyms can be used to label the participants videos when joining the meeting. Additionally, participants could select whether their video was visible to others and could therefore remain unseen based on their preference. The host should also only use the names of participants to address them to ensure that other participants do not know their surnames or additional identifying information.	These recommendations were added to the nominal group script to increase the ethical principles of the group session related to confidentiality.
27.	To determine the time required for the main study nominal group technique.	Based on the participants' experience, at least 60 minutes is required to conduct the session and complete all the questions.	This recommendation was added to the nominal group script as well as the informed consent letter.

As indicated in Table 5.5, a synchronous online methodology can effectively be implemented to conduct a nominal group technique. Additionally, based on the recommendations of the pilot study, a paid Zoom account would allow to access the features required for this specific technique (Whiteboard application, PowerPoint, and video share as well as multiple users contributing at once). The pilot study also indicated that the nominal group technique as described in literature would need to be modified. In the literature it is suggested that a nominal group technique uses only one to two questions, however, six questions were used in the current study to match the six constructs of clinical utility suggested by Smart (2006). Additionally, the nominal group technique is usually conducted in person, however, in the present study it was conducted online via a platform. An online platform allowed for a PowerPoint presentation and YouTube video to be added, to provide a background on the programme and then apply the nominal group focus on each of the six constructs.

5.6.3.5. Conclusion from pilot study and recommendations for main study

After careful consideration and based on the results of the pilot study, the Zoom platform with a paid account was selected to host the online nominal group technique (Stewart & Shamdasani, 2017). This platform provided for a degree of customisation and was relatively easy to use for both the facilitator and participants (Stewart & Shamdasani, 2017). More importantly, this platform can be designed to assure participants' confidentiality and between-participant-anonymity also allows the easy capturing of the content of the discussion (Stewart & Shamdasani, 2017).

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5.6.3.6. Data collection nominal group technique

Prior to any data collection, ethics approval was obtained from the Research Ethics Committee of the Humanities Faculty at the University of Pretoria (Appendix A). Potential participants were contacted via email to request their participation in the phase (Appendices N1–N2). Once the clinicians indicated their interest, an informed consent letter as well as the biographical questionnaire (Appendix K3) was emailed to them (Harvey & Holmes, 2012). A Zoom link was sent the day before the meeting to individual participants who had provided consent. The Zoom meeting was scheduled on a date and at a time convenient to all participants (31 May 2022; 19:00). None of the participants experienced any difficulty in joining the Zoom platform. The session was video and audio recorded by the Zoom platform and allowed the researcher access to the recording post the session. As a precaution, a backup audio recording was also made with the platform software to increase the validity of the data obtained (Gregory & Radovinsky, 2012). The meeting commenced with the researcher introducing herself after which she explained the aim of the phase and the proposed procedure (Harvey & Holmes, 2012). In addition, general comments regarding the meeting were made such as the expected length of the meeting, as well as ground rules (Harvey & Holmes, 2012) before the ethical principles that would be upheld during the session were reiterated. A PowerPoint presentation (Appendix L) was then presented to ensure that all participants had the same general information on the background, design, and content of the original CPT programme as well as the suggested adaptations. The PowerPoint presentation concluded with an opportunity for the participants to ask questions.

An explanation was then given to participants of the Zoom platform applications such as the Whiteboard that would be utilised during the session as well as how these features work. The nominal group technique was then introduced. This technique consists of five steps and these steps were repeated for each of the six questions.

i) Silent generation of concepts

Participants silently generated answers on sticky notes without the knowledge and contribution of others (Boddy, 2012; Harvey & Holmes, 2012; Hugé & Mukherjee, 2018; McMillan et al., 2014). The participants were asked to mute their microphones and switch their videos off and write down answers to the respective questions on their personal sticky notes. They received three minutes to generate and create answers for a specific question. This amount of time seemed appropriate as participants were done writing within the allocated time (Harvey

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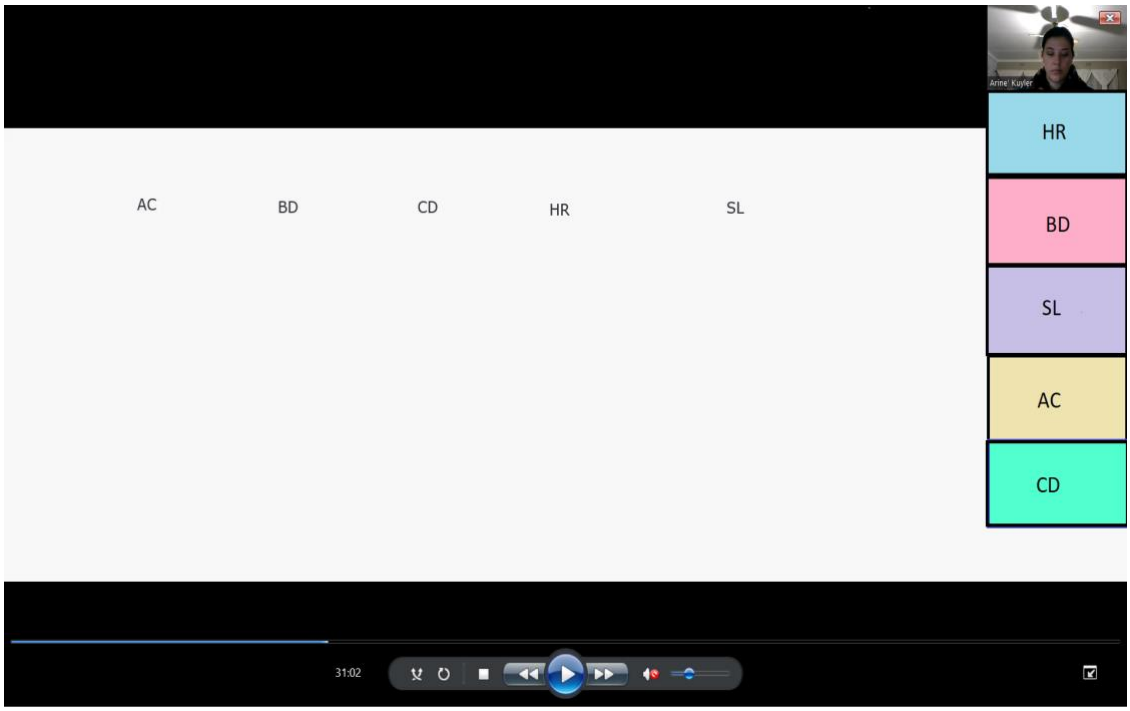
& Holmes, 2012). Hereafter they were asked to unmute their microphones and turn their videos back on again. To prevent researcher bias, the researcher was not allowed to contribute to the answers and the findings and was therefore dependent on participant contributions only (McMillan et al., 2014). Figure 5.2 illustrates the Zoom screen during silent generation of ideas.

Figure 5.2

Silent generation of ideas



ii) Sharing and recording ideas

Next the participants shared the answers that they wrote down by means of a round robin technique (one participant shared one answer at a time) (Boddy, 2012; Harvey & Holmes, 2012; Hugé & Mukherjee, 2018; McMillan et al., 2014). The researcher used the Whiteboard functionality to create five separate columns (one column for each participant, with their initials at the top of the column as a heading). Each participant was then asked to give one answer at a time. The researcher listened to the answer and then typed one keyword per sticky note in the column dedicated to the participant. Hereafter, the researcher asked the participants whether the keyword was aligned with the answer they wanted to contribute. The researcher selected the participants randomly to ensure that all participants contributed equally to the discussion. The round robin was repeated until all the participants shared all their answers in this manner. The answers on the sticky notes were visible to all the participants via the Zoom platform's

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Whiteboard function and the researcher continuously asked participants whether they were able to view the content. Figure 5.3 illustrates the recording of ideas.

Figure 5.3

Sharing and recording of ideas

iii) Group discussion

Once all the sticky note answers were generated and posted on the Whiteboard, the participants were invited to request clarification or elaboration, or to comment on each other's contributions (Boddy, 2012; Harvey & Holmes, 2012; Hugé & Mukherjee, 2018; McMillan et al., 2014). This process allowed the participants to make informed decisions in the ranking step (McMillan et al., 2014). During this step duplicate answers were removed, similar answers were grouped together, and some answers were eliminated. Participants were encouraged to ask questions and comment on answers that were unclear to them. Emphasis was placed on the fact that no answer was irrelevant to the discussion and that all answers should be shared by participants. Additionally, participants were selected in a random order to ensure that everyone contributed to the discussion and that no person dominated the discussion (McMillan et al.,

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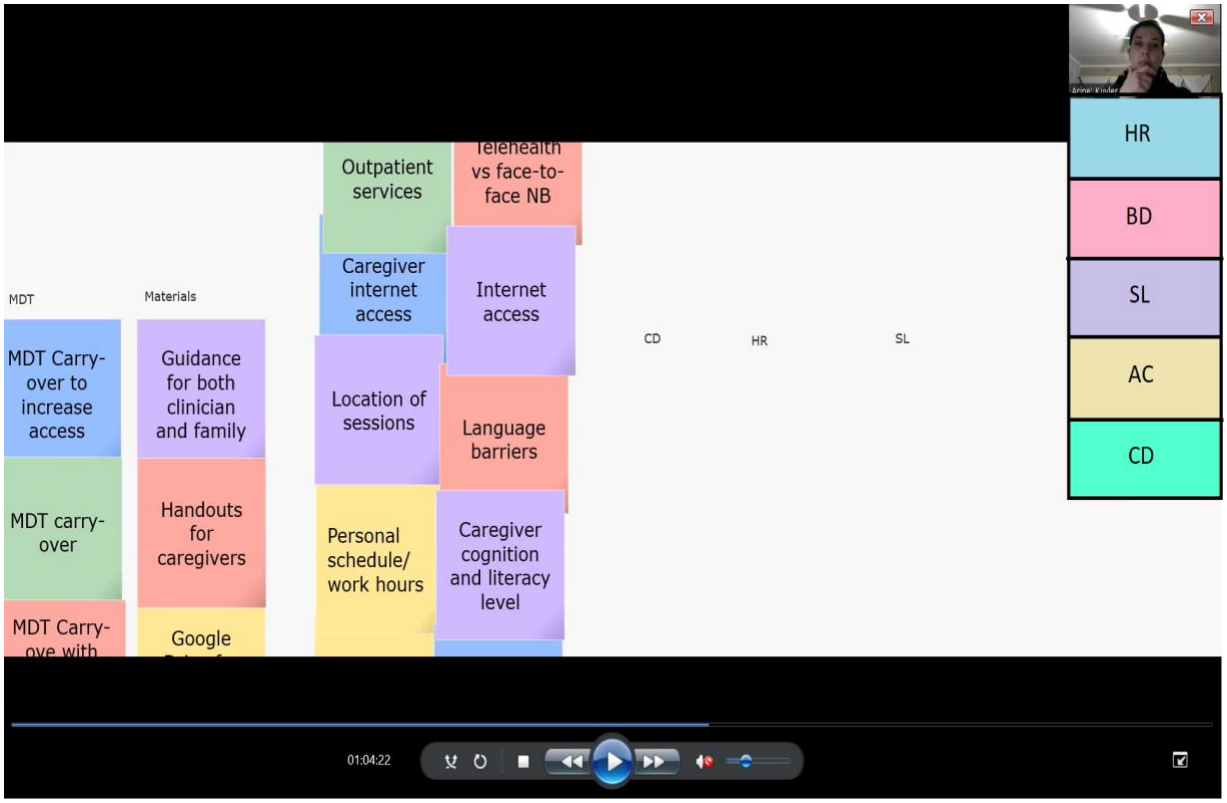
2014). Upon completion of the discussions, the next step in the process was initiated. Figure 5.4 illustrates the group discussion.

Figure 5.4

Group discussion



iv) Ranking and voting

Participants were asked to collaborate and to prioritise the top five answers during a consensus negotiation procedure (Boddy, 2012; Harvey & Holmes, 2012; Hugé & Mukherjee, 2018; McMillan et al., 2014). The researcher asked one of the participants to assist her, by taking the responsibility to move the sticky notes to one of the three categories suggested, namely most important, important, and less important. The researcher randomly selected a participant, asking the participant to rank the specific answer displayed on the sticky note based on the three suggested categories. This was then discussed among all the group members. If any discrepancies occurred, the group discussed the discrepancy and a consensus was obtained between the participants. Figure 5.5 illustrates the ranking of the concepts.

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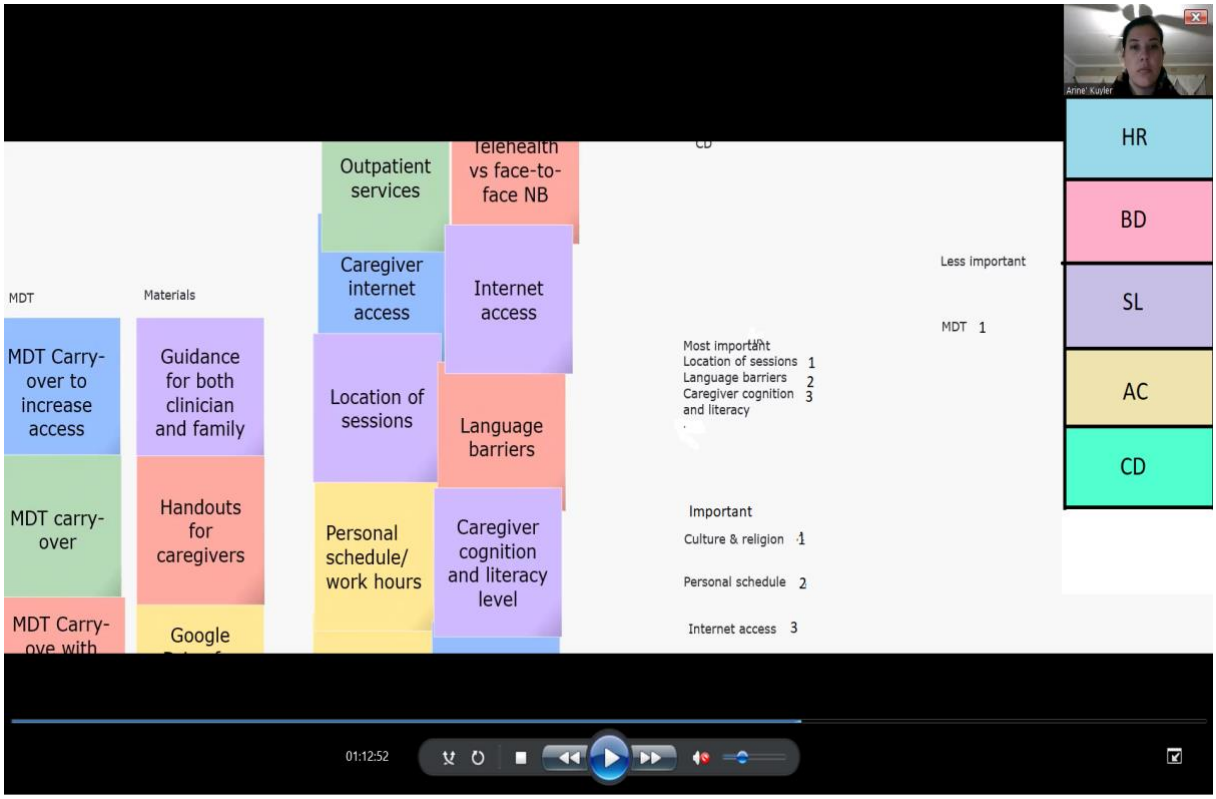
Figure 5.5

Ranking and voting



v) Data analysis

The nominal group technique resulted in answers that were ranked into one of the three categories in terms of importance (Boddy, 2012; Harvey & Holmes, 2012; Hugé & Mukherjee, 2018; McMillan et al., 2014). Qualitative content analysis principles were used to further analyse the qualitative foundations of the identified concepts by reviewing the data generated in/from/by of the nominal group technique. The data was sent to the participants as part of member checking, however, also for them to add any comments which they deemed appropriate or relevant. This assisted in streamlining the data and identifying supportive quotes for the concepts identified in the previous steps of the nominal group technique.

5.6.3.7. Findings

The findings of this phase are discussed according to the six constructs of clinical utility proposed by Smart (2006). Findings from the nominal group technique regarding the perspectives of SLTs on the aspects of clinical utility are shown in Table 5.6.

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Table 5.6

Findings of nominal group technique

Category	Importance Ranking	Code		Supportive Quotes (The initials at the end of the quote refer to the participants who mentioned the quote)
Accessibility				
	Most important			
Communication partner factors	1	Location of sessions		"Sometimes it is better to conduct communication partner training in the place where the person lives. You can also consider doing communication partner training where the person has other appointments to make it easier for the communication partner." (HR)
	2	Language barriers		"We also need to consider if the patient and their communication partner cannot speak English, what accommodations would we make to ensure that they understand and benefit from the programme." (HR, SL)
	3	Communication partner cognition and literacy		"You need to consider the level of cognition and literacy of the communication partner as this will impact the comprehension of the content in the programme." (SL)
	4	Culture and spirituality		"Culture is also important as they may perceive things differently, to what they actually are or interpret information differently. This may impact their access to services." (AC)
	5	Personal schedule		"We need to consider the schedule and responsibilities of the communication partner as to determine if they may prefer after work sessions in the evenings rather than sessions during working hours." (HR, SL)
	6	Internet access		"Something that I was thinking about is that if online resources are used, some of the communication partners may not have internet access." (BD)
	Important			
Materials	1	Preference of presentation	Face-to-face Online Multiple modules in one session	"Sometimes it may be preferable if communication partners don't have internet access to have face-to-face communication partner training." (BD) "If participants are situated at home, it may be easier for them to receive online training than in person training." (HR) "Something that we see in South-Africa is the socio-economic status as well, if the communication partner has a higher income, they may receive therapy more frequently than someone who cannot afford sessions. Therefore, we need to consider if the communication partner is not able to afford sessions can multiple sessions be conducted in one session?" (SL) "If you purchase the programme, can you use it with multiple people especially in South Africa this is something that needs to be considered." (SL)
	2	Guidance for both communication partner and SLT		"The resources that are available provide nice guidance. I think it is really great to have something to review and go back to after a session with this type of patient." (AC)
	3	Communication partner handouts		"If the patient is in the government setting, printed handouts can be made available to communication partners." (CD)

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Category	Importance Ranking	Code	Supportive Quotes (The initials at the end of the quote refer to the participants who mentioned the quote)
	4	Access to Google Drive	"I would suggest a Google Drive folder where information handouts have been sorted for communication partners and they can access the drive to provide them with the necessary information." (CD)
	5	Accessible YouTube channel	"I think this programme is very accessible and something that I wrote down at the beginning was the YouTube channel that provides guidance for the therapist and communication partner." (AC)
	Less important		
Multidisciplinary team	1	Multidisciplinary carry-over Role release Communication between healthcare practitioners	"It would be great if this programme could be adapted into some sort of multidisciplinary team programme as to ensure that patients receive holistic care." (AC) "I often see these patients with the OT and PT and it would be great if they can reinforce communication within their separate sessions as well." (AC) "Carry-over between healthcare workers is important especially when the person is in the hospital. The therapist therefore needs to provide training to other healthcare workers (e.g., nurses) because they look after the patient the whole day." (AC, CD)
Practicability Barriers			
	Most important		
Clinician factors	1	Time	"I think it is important to consider the time of the therapist as well as the communication partner and their other responsibilities. Time of intervention is also important for example does the patient respond better in the morning or in the afternoon." (CD) "If different communication partners are present, will you have enough time to train the communication partners on separate days." (AC, BD) "You need to consider whether you will have enough time to train communication partners in between your other patients as well." (AC)
	2	Patient Priority	"You need to consider is this a high priority patient compared to a new referral." (HR, AC)
	3	Therapist competence (experienced versus unexperienced)	"Something to consider is the therapist competence in administering the programme. Especially, comparing a more experienced therapist to a younger therapist such as myself." (AC)
Factors affecting both the clinician and communication partner	4	Location of services including travel time and transport	"You need to consider whether you will be able to provide services at home or will you need or the communication partner need to travel for example if a communication partner is living in a rural area and need to travel to the hospital, what are the logistics around that." (CD)
	5	Internet access	"If the communication partner is in a rural area, telehealth may also not be an option as they do not have internet access." (CD) "Due to loadshedding, South African therapists also don't always have internet access." (SL)
	6	Language barriers	"You need to consider the language, for example, how practical it is to present this programme in Zulu." (CD, AC, BD)
	Important		

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Category	Importance Ranking	Code	Supportive Quotes (The initials at the end of the quote refer to the participants who mentioned the quote)
Communication partner factors	1	Communication partner responsibilities and schedule	"You need to consider the communication partners schedule as they also need to go to work every day and manage other responsibilities." (BD, SL)
	2	Communication partner coping and psychosocial wellbeing	"Caregiving can be stressful for communication partners and therefore you need to consider how much information you are giving the communication partner as to not increase their burden." (HR, BD)
	3	Cultural aspects	"Cultural barriers should also be considered when implementing the programme as communication partners might perceive things differently." (SL)
	4	Variation in communication partners (different communication partners on different days)	"Another thing especially in the African context that we need to consider is that the person has different communication partners on different days and the problem then comes in to consider which communication partners to train." (AC, SL)
	5	Context Private versus public National versus international	"I was thinking that we need to consider whether we can directly implement something that is developed in the Western world into the South African context (CD)." Careful consideration should be given to the South African context and its barriers." (CD)
Facilitators			
	Less important		
Programme	1	Options for materials	"A facilitator that I thought about was the different options for materials which could assist various patient. So different ways of people accessing the same information that might work better for their learning needs or literacy needs." (HR)
	2	One license for multiple users	"It would be great if there is one license for multiple users." (CD)
Training and Qualification			
	Most important		
Communication partner factors	1	Knowledge and acceptance of persons diagnosis	"I think you might at least have some knowledge of disorders of consciousness. When you implement the programme, it will be easier for you to identify whether the person is in a minimally conscious state or whether the person is emerging from that state." (HR)
	2	Settled in mental health	"Conceptually it would be great if the communication partner had accepted the diagnoses of the person." (AC, HR, CD, BD, SL) "Additionally, it would be great if they are okay and settled in their mental state." (HR).
	3	Time	"Taking some time to identify the needs of the communication partner." (HR)
Clinician factors	4	Baseline knowledge of patient Case history Communication assessment	"You need a thorough case history of the patient as well as doing your normal language and communication assessment so that you can establish a baseline of the patient." (AC, CD, BD)
	Important		
	1	Experience in disorders of consciousness	"Even if you are a young and inexperienced therapist, the resource of this programme is easy to follow." (AC, HR)

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Category	Importance Ranking	Code	Supportive Quotes (The initials at the end of the quote refer to the participants who mentioned the quote)
	2	Degree in speech-language therapy	"I would hope that the therapist does at least have a degree in speech therapy." (CD, SL, BD)
	Less Important		
	1	Familiarisation with the programme	"If I understand correctly the therapist does not need training to implement the programme, but it will benefit the therapist if they familiarise themselves with the programme prior to implementing it with communication partners." (AC, BD, SL)
Acceptability			
	Most important		
Methods and means to increase acceptability	1	Goal-setting templates	"There should be templates for families to use especially for goal-setting." (AC, CD, HR, BD, SL) "This also helps to give them an achievement summary to motivate them and see the success that they as communication partners have achieved." (AC, CD, HR, BD, SL)
	2	Information handouts	"The process may be very overwhelming for families and giving them information handouts to fall back on can be advantageous." (AC, CD, HR, BD, SL)
	3	Communication book	"' don't know if it's in the programme or it could be in the programme, but some sort of communication book that explains the strategies. Additionally, explaining the context. This may provide a means to optimise intentional communication and to inform unfamiliar communication partners on the likes and dislikes of the person. This may provide some contingency as when someone else is communicating with them, then other people have got those strategies that the main communication partner got from the training." (HR)
Professional Utility			
	Most important		
Clinician factors	1	Contextual relevance	"I would go back to contextual relevance to the South African population, and to sort of resolve that direct application might not be applicable. Adaptations might be required after trialling it in different contexts with our population." (AC, HR)
	2	Confidence	"If you are a young and inexperienced therapist you may lack confidence when implementing the programme. This may be due to the communication partner asking questions that you might not know the answer to." (AC)
Support	3	Adaptation of programme post-implementation	"An important component may be to trial and error the programme with the population as only then will you be able to identify the changes required." (AC)
	4	Clinical supervision	"Having experienced colleagues to assist you may also give you more confidence when implementing the programme." (AC, HR, CD, BD, SL)
	5	Time to familiarise with the programme	"Familiarising yourself with the programme can assist you in better implementing the programme." (AC, CD, HR, BD, SL)
Appropriateness			
	Most important		
Usefulness of information	1	Information on patient diagnosis and condition	"It is very important that communication partners know the diagnosis of the patient as well as their condition and progress trajectory." (AC, CD, HR, BD, SL)

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Category	Importance Ranking	Code	Supportive Quotes (The initials at the end of the quote refer to the participants who mentioned the quote)
	2	Specific advice for loved ones instead of generic advice	"It is nice that the programme provides information that is specific to loved one and not only generic advice that do not address communication partners specific needs." (AC, CD, HR, BD, SL)
	3	Better equipped to identify intentional motor movement to indicate awareness and wakefulness	"Being better equipped to identify voluntary movements to indicates awareness." (AC, CD, BD, HR, SL)

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In summary, the SLTs mentioned that to improve the clinical utility of CPT interventions, accessibility and communication partner components were the most important considerations. While materials were also important, multidisciplinary teamwork was the least important. Participants also mentioned that components such as where services were located, the daily schedule of the communication partners, language barriers, the SLTs, partners and persons culture and spirituality, internet access as well as the cognitive level and literacy skills of the communication partners were important considerations when reviewing the accessibility and the affordability of the CPT programme.

Additionally, the SLTs recommended that when reviewing the practicability construct related to the CPT training programme, greater emphasis should be placed on clinician factors as well as factors that affect both the clinician and communication partner, rather than focusing on factors that only pertain to the communication partner. Both the SLT and communication partner should receive training, as therapists starting in clinical practice may not have sufficient knowledge to assess and manage these persons' communication. These clinician factors include time, patient priority, SLT competence, location of services, language barriers, and internet access. For training and qualification, SLTs mentioned that the clinician requires a degree in SLT and some knowledge of disorders of consciousness. They further explained that communication partners also require knowledge regarding the diagnosis and condition of the person regardless of their qualification or literacy levels. To ensure that the programme is acceptable to communication partners, SLTs mentioned that sufficient handouts should be given as well as achievement summaries and goal-setting templates.

Most SLTs mentioned that the professional utility of the programme was largely dependent on clinician factors and support which were equally important. They also explained that the presenter of the CPT programme (preferably a SLT), needed to be confident and should also ensure that the programme is contextually relevant to the South African population. Furthermore, the SLTs mentioned that the programme should be acceptable to the South African population as it provides information on the patient diagnosis and condition, specific information to meet the needs of the communication partner and ensures that they are better equipped to identify intentional forms of communication than when they initially started caring for the person.

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5.6.3.8. Discussion

From the findings of the nominal group technique, the inclusion of both paid and unpaid communication partners are important factors that have an impact on the implementation of CPT interventions. The findings are reiterated by the work of Cruice et al. (2018); and O'Halloran et al. (2012) who suggest that communication partner's perspectives provide important insights into factors that may influence the successful application of CPT programmes within the clinical contexts as well as the persons in an MCS+'s experience of their communication challenges. More so, the SLTs (paid communication partner) should communicate effectively with both the partner and person as it influences the quality of care that they provide (Van Rijssen et al., 2021). Van Rijssen et al. (2021) also suggest that SLTs respect patient autonomy and want to facilitate successful communication with persons with communication difficulties, however, due to challenges such as time constraints, there is often difficulty implementing facilitative communication strategies and rather train the partner to implement these strategies. Even though, Van Rijssen et al. (2021) mention that optimally, SLTs and the partners should implement facilitative communication strategies, especially for persons in an MCS+. Therefore, this phase aimed to include factors that influence both the paid (SLT) and unpaid communication partner when implementing a CPT programme through the SLT's perspectives and experience working with persons in an MCS+ and their communication partners. SLTs specifically mentioned the clinical utility as influencing the implementation of the CPT (Connect^{+}) and these constructs are discussed in the paragraphs that follow.

The SLTs mentioned that accessibility was influenced by communication partner factors, materials, and the multidisciplinary team. Communication partner factors were seen as the most important construct affecting accessibility, specifically the location of services (travelling distance between care facility or home and the clinicians main office), the daily schedule of the unpaid communication partners (which includes both the person's schedule and the other responsibilities of the partner), language barriers (language of communication relating to the partner, person in an MCS+ and the SLT which may be different), culture and spirituality (partner, person and SLTs may have different backgrounds, cultures and spirituality which may impact service provision and how the person's condition is understood and perceived), internet access (partner and person may be situated in rural or low-resourced settings where they do not have internet access), and the communication partner's cognitive abilities and literacy skills (communication partners may have low literacy levels and limited health literacy proficiency which may impact their interaction with SLTs and their understanding of concepts discussed

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in the CPT programme). The majority of the South African population consists of persons who need to provide quality care within resource limited areas (Siedner et al., 2020; Winchester & King, 2018). These factors affect the South African population in both private and public healthcare settings. Therefore, careful consideration of the communication partner's literacy levels and health literacy proficiency is needed, since SLTs often provide (written) information as a form of care and this information should be comprehensible and on the literacy level of all communication partners. SLTs mentioned that the Connect^{+} CPT provides information on an easy-to-understand level enabling communication partners with limited literacy skills as well as those who do not necessarily have a background in communication training, to access and benefit from the training programme. Additionally, the various added materials such as handouts and instructional YouTube videos further increase the applicability of the programme. The applicability of the materials can be enhanced further by adding face-to-face or in-person preferences for communication partners. O' Rourke et al. (2018) suggest that by providing these materials and preferences, communication partners are allowed to support communication as they have improved understanding of the impact of the person's condition on communication. These materials can also increase the acceptability of the Connect^{+} CPT as the SLT receives a manual for implementation that both the inexperienced and experienced therapist can understand (Rietdijk, Power, Brunner, Attard et al., 2019). This manual provides specific goal-setting templates for communication partners (Rietdijk, Power, Brunner, Attard et al., 2019).

According to the SLTs, practicability was influenced by individual and combined barriers affecting the SLTs and communication partner. Specific barriers that may impact both the SLT and communication partner is the language in which the programme is presented, the culture and spirituality. These factors are specifically relevant when providing SLT services in the multilingual, multicultural, and multireligious South Africa population (Mophosho, 2018). The core beliefs of a person and their communication partner influence their behaviour and expectations of SLTs, their understanding of the condition, spiritual influences, and resources (Mathisen et al., 2015). From the findings of this phase, the Connect^{+} CPT addresses the behaviours, expectations, and understanding of the person's condition and their communication partners prior to the implementation of the programme (Rietdijk, Power, Brunner, Attard et al., 2019,).

Although, the intervention does not directly address the spirituality and culture of the person, SLT, or communication partner, it carefully considers the factors that may impact

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communication between the person and their communication partner. This is achieved during the initial interview when communication partners are allowed to set goals after each session based on their needs (Rietdijk, Power, Brunner, Attard et al., 2019).

Professional utility was largely impacted by SLT factors such as the confidence of the SLT in implementing the programme and whether the SLTs found the Connect+ CPT to be contextually relevant. The findings also showed that SLTs did identify the Connect+ CPT as contextually relevant and that they would implement it with confidence without training. SLTs also verbalised that they wanted to familiarise themselves with the programme prior to the first session with the person-partner dyad. Verheul (2005) suggests that prior familiarisation to implementation can strengthen the clinical utility of an intervention. Additionally, the programme provides instructional videos on YouTube for both the communication partner and SLT which added to their perceptions of support (Rietdijk, Power, Brunner, Attard et al., 2019).

Appropriateness, according to the SLTs, was influenced by the information on patient diagnosis and the condition, specific advice for loved ones and better equipping the SLT to identify intentional motor movements indicating self- and environmental awareness. The Connect+ CPT addresses these factors of appropriateness specifically through the provision of background information on the condition and providing support to specifically target communication. According to Verheul (2005), improving appropriateness of the intervention for both paid and unpaid communication partners assists in ensuring the potential benefits of the intervention are transmitted to the target population. These aspects allow the SLT to perform best practice clinically and improves their confidence when implementing intervention with this population (Roberts & Greenwood, 2019). Additionally, improving the clinical utility of the CPT programme may assist the SLT in providing guidance and improve the knowledge of the multidisciplinary team when communicating with persons in an MCS+ (Finch et al., 2017; Van Rijssen et al., 2021).

5.6.3.9. Conclusion of Phase 3

From the findings of Phase 3, it appears as if the SLTs identified the Connect+ CPT as having clinical utility within the South African context as it successfully addressed all dimensions of clinical utility, namely accessibility, practicability, training and qualification, acceptability, professional utility, and appropriateness. The findings of this phase also caution SLTs to consider the travelling distance of both the partner and SLT as well as literacy levels of the partner. Additionally, careful consideration should be given to the specific context in

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which the CPT programme is to be implemented (rural or urban), the access to digital platforms by communication partners and person in an MCS+ as well as the culture and spirituality of both the person in the MCS+ and communication partner. These factors were considered of cardinal importance for the successful implementation of the Connect+ CPT programme. As a next step, the Connect+ CPT programme should be piloted with communication partners of persons in an MCS+.

5.7. Summary of Chapter 5

This chapter discussed the clinical utility of the adapted intervention, namely the Connect+ CPT programme, by first focusing on Smart's (2006) six constructs that underly clinical utility, namely appropriateness, accessibility, practicability, training and qualification, acceptability, and professional utility. The findings from the pilot study identified the Zoom paid account as being the most suitable, user-friendly platform to host the online nominal group technique. SLTs included in this phase were in agreement that the Connect+ CPT is an intervention with clinical utility.

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CHAPTER 6
CONCLUSION

6.1. Introduction

The final chapter (Chapter 6) of the present study commences with a brief review of the whole study, highlighting the most important findings as well as the clinical implications. Next a critical reflection of the study is provided, specifically exploring the strengths and weaknesses, followed by a discussion of the contribution that the study makes to the field of AAC and how it pertains to persons in an MCS+. The chapter concludes with recommendations for future research based on the findings of the study.

6.2. Study review

The main aim of the present research study is to identify and adapt an intervention in the form of a communication partner training programme to facilitate interaction between communication partners and persons in an MCS+. This is done by empowering communication partners to observe, assess, interpret, and respond to the communication behaviours displayed by these individuals. Previous research in the field of DOC that pertains to communication partners focused mostly on the communication partners' experiences of caregiving, identifying their support needs, and reducing the burden of care (Fins, 2013; Giovannetti et al., 2013). Regarding communication of persons in an MCS+ , the literature mostly focuses on aided communication such as brain-computer interfaces or microswitch adapted assistive devices (Lancioni et al., 2021; Lugo et al., 2014). In most low-middle income countries, including South Africa, these options for person-partner communication are, however, not viable for the majority of the population due to limited resources, high costs of aided communication devices, and limited HCPs who have individualised knowledge on aided communication. It is therefore preferable that communication partners are empowered to strengthen and expand naturally occurring human interaction which does not require extensive resources to facilitate communication with persons in an MCS+ such as multimodal communication which includes various aided and unaided forms of interaction persons in an MCS+. However, limited research is available to assist communication partners in identifying communication behaviours of persons in an MCS+ and especially, unaided forms of communication as well as what multimodal communication strategies communication partners can use to effectively facilitate interaction (Rasmus et al., 2019; Sautet et al., 2022). This scarcity of research is especially identified when the person in an MCS+ is discharged from the hospital and placed into the care

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of the communication partner either at home or at a care facility. Therefore, this study added to the current body of evidence (Chapter 2) by not only providing information on the challenges that both the persons in an MCS+ and their communication partners experience, but also on how these challenges may impact communication and communication competence of both parties.

Chapter 3 comprises Phase 1 including a scoping review (Step 1.1) and synchronous online interviews with communication partners of persons in an MCS+ (Steps 1.2–1.3). The scoping review was conducted to identify the unaided communication behaviours displayed by persons in an MCS+, to assist their communication partners in gaining a better understanding of the communication means and functions used by these individuals. It included 18 full-text studies and showed that persons in an MCS+ displayed unaided communication behaviour ranging from unintentional to intentional communication. When categorising these behaviours according to the seven levels described in the Communication Matrix (Rowland, 2011), findings showed that persons in an MCS+ mostly used gestures, facial expressions, reflexive behaviours, eye movements, and vocalisations. Moreover, these behaviours were used to access 31 different communication functions. The findings also highlighted that the communication partners of persons in an MCS+ were typically trained communication partners (e.g., HCPs such as nurses) with a small number of untrained communication partners (e.g., family members, relatives, or paid caregivers). This is in contrast to the work of Covelli et al. (2016); Giovannetti et al. (2015); and Pagani et al. (2014) who suggest that in practice, the majority of persons in an MCS+ are cared for by untrained communication partners, who could be paid or unpaid. They reported that untrained communication partners such as family members, relatives, or paid caregivers are often the only communication partner of persons in an MCS+ since they spend the majority of their time with the person. This results in these partners becoming invested in the long-term. The findings of the scoping review also highlighted a gap in the literature regarding the perspectives of untrained communication partners (e.g., family members, relatives, or paid caregivers). Hence, the next step in the study focused on obtaining the untrained communication partners' perspective on the communication strategies that they utilised to communicate with persons in an MCS+.

Synchronous semi-structured online interviews were conducted with untrained communication partners of persons in an MCS+ to identify the communication methods and strategies they currently used as well as the functions thereof. Additionally, their support needs were explored and the impact on communication was identified. The synchronous online

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interviews (Steps 1.2 and 1.3) with seven untrained communication partners of persons in an MCS+ (or who were in an MCS+) indicated that the partners used multimodal communication strategies, comprising of both verbal communication such as short, simple sentences (language form) that mostly revolved around familiar topics (language content) as well as non-verbal communication. The latter included using kinesics such as facial expressions to convey positive affect, positioning oneself facing the person, using body language such as nodding to indicate engagement, and maintaining eye contact. Additionally, active listening behaviour and proxemics such as the physical presence of a familiar person and positioning the person upright were mentioned. Vocalics that were mentioned included increased responsiveness to familiar voices as well as haptics such as using affectionate-comforting touch as well as massaging to prevent contractures. Chronemics such as active engagement during interaction with the person as well as acknowledgement of their humanity and respecting their human dignity were mentioned. Lastly, communication partners mentioned artefacts such as physical objects; an iPad to act as a communication aid and environmental objects (television).

The same findings on unaided or non-verbal communication behaviours and functions, which were identified in the scoping review, were confirmed in the interviews with communication partners. However, 36 different communication functions were identified during the interviews, as opposed to the 31 delineated in the scoping review. Communication partners of persons in an MCS+ stated that they used naturally occurring communication, yet often felt unsure whether they were providing appropriate support. This uncertainty may be as communication partners perceived themselves as guessing and relying on intuition when observing, assessing, interpreting, and responding to unaided communication behaviours of the person in an MCS+. The communication partners also mentioned that the inconsistency of the person's unaided communication behaviours contributed to them feeling unsure about their attempts at eliciting interaction. Despite being unsure, communication partners remained motivated to communicate with the person in an MCS+ and respected their human dignity and human right to communicate. These findings indicated that communication partners require support from HCPs to facilitate communication with persons in an MCS+, which prompted a further analysis of the synchronous online interviews with untrained communication partners.

Bronfenbrenner's bioecological systems theory (Bronfenbrenner, 1992) was used to categorise the information obtained from communication partner interviews. The communication partner's needs were described according to the micro-, meso-, macro-, exo- and chronosystem, adding in a more nuanced understanding of their support needs. This in turn

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creates opportunities for HCPs to assist these communication partners in a more targeted manner. Subsequently, a positive impact can also be expected on the functioning of the person in an MCS+ as these persons are dependent on the communication partners to meet their needs in activities of daily living.

Chapter 4 comprises Phase 2, which was initiated with an umbrella review that clustered the existing 11 systematic reviews on this topic in order to aggregate the findings from the current evidence-based CPT programmes. This type of review imposes an overall coherence by lumping previous reviews together and the findings identified the TBI Express as being the most suited programme in terms of its focus on employing the principles of adult learning to optimally engage communication partners in training. From the TBI Express, the TBI Connect was created which is specifically focused on a single person-partner dyad and consists of the same evidence and principles as the TBI Express (Rietdijk, Power, Brunner, Attard et al., 2019).

The TBI Connect focuses on communication partners of persons with TBI who have regained (some) verbal communication. Therefore, adaptation to the TBI Connect was necessary to meet the needs of communication partners of persons in an MCS+ who present with limited verbal responses. The Intervention Mapping approach was used to ensure that the Connect^{+} (adapted TBI Connect) meets the needs of the target population of the current study (communication partners of persons in an MCS+) and is anchored in the E^{3}BP principles. This approach initiated synchronous online interviews with clinicians with a special interest in neurorehabilitation as a first step in adapting the TBI Connect to the Connect^{+}. These clinicians suggested that the content of the Connect^{+} target unaided communication behaviours, multimodal communication strategies, multisensory stimulation, and environmental adaptations to improve both environmental- and self-awareness and also to facilitate wakefulness and responsiveness of persons in an MCS+. Additionally, it was recommended that focus should be placed on providing communication partner support through a multidisciplinary teamwork as well as providing information on how the partner can access this support. These recommendations of clinicians were instrumental in the adaptation of the TBI Connect programme.

Phase 3 (Chapter 5) focused on the clinical utility of the Connect^{+}. A nominal group technique was used to determine the clinical utility by focusing on Smart's (2006) constructs, namely appropriateness, accessibility, practicability, acceptability and training or qualification

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requirements, acceptability, and professional utility. Overall, SLTs mentioned that they thought the content and design of the Connect^{+} were appropriate. Various aspects that could influence the implementation of the programme in a clinical setting such as culture, religion, financial resources, time, and transport, were also highlighted. By adapting the original CPT programme, this study assists in guiding communication partners on how persons in an MCS+ communicate and to facilitate early intervention. The Connect^{+} also promotes the use of multimodal communication strategies by communication partners to ensure that persons in an MCS+ receive optimal support to prevent sensory deprivation. Communication partners are especially targeted in this study due to the dependence of persons in an MCS+ on their partners during activities of daily living as well as to facilitate interaction with them.

6.3. Clinical implications of the study

The main clinical contribution of this study is the adaptation of a CPT (which resulted in the Connect^{+}) which is intended for communication partners of persons in an MCS+. To the knowledge of the researcher, there is currently no similar programme available in literature that provides in-depth information on the specific communication modes and functions that both the communication partner and the person in an MCS+ use (or could use) and how these modes and functions can be harnessed to facilitate interaction based on their specific communication needs.

The Connect^{+} was formulated based on E^{3}BP principles. The first principle of E^{3}BP is to review the current evidence available. This was done by first, conducting a scoping review (Phase 1) to obtain a detailed and expansive description of the communication modes and functions displayed by persons in an MCS+. This information assists communication partners of persons in an MCS+ to better understand the communication behaviours of these persons which in turn, could lead to less misunderstandings, misinterpretations, or ignorance of communication attempts. Second, a deeper understanding of the adult learning principles and trainee engagement targeted by CPT characteristics was obtained from the umbrella review in Phase 2. This review assisted in identifying a CPT with a solid E^{3}BP foundation. Thirdly, the identified programme was adapted in a scientific manner using the theoretical constructs related to intervention mapping which also highlighted the importance of determining the clinical utility of the Connect^{+}.

The second principle of E^{3}BP is to include the perspectives of the patient/family. In this study, the perspectives of the person in an MCS+ could not be obtained due to the person's

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level of consciousness and limited verbal communication. However, as these persons are dependent on their communication partners to perform activities of daily living, the communication partners were targeted as proxies. During Phase 1 the specific perspectives of unpaid communication partners were obtained to identify which multimodal communication strategies they use to communicate with the person as well as to describe which unaided communication behaviours they had noticed in persons in an MCS+. They were also asked to comment on what communication functions they thought the person was trying to communicate through the specific behaviours. The communication partners' perspectives did not vary greatly from the literature; however, they required support through training to optimise their knowledge and improve their confidence when interacting with the person. Additionally, their specific support needs were identified to ensure that the adaption of the proposed CPT programme was based on their needs and communication strategies.

The third and final E^3BP principle that was addressed was focused on clinical practice. To address this principle, the study included paid communication partners' perspectives (clinicians and SLTs) based on their interest in neurorehabilitation and clinical practice with persons in an MCS+. From the clinicians' perspectives, important clinical information was obtained to identify the specific adaptation requirements of the proposed CPT programme. This ensured that the Connect$^+$ targets the needs of both the communication partner and the person in an MCS+. Additionally, the perspectives of SLTs were obtained regarding the clinical utility of the Connect$^+$. Their perspectives confirmed that the Connect$^+$ has adequate clinical utility to be implemented in the South African context and that it also has potential for international clinical contexts.

The Connect$^+$ CPT programme thus, has specific clinical implications for both paid and unpaid communication partners:

Unpaid communication partners

The Connect$^+$ can provide a means of social support to the unpaid communication partner such as life partners, siblings, and other family members, as they often feel socially isolated and withdrawn due to their care responsibilities. As communication is a social activity, the Connect$^+$ may support these communication partners to facilitate interaction with persons in an MCS+. This may empower them to experience the communication with these persons to be more gratifying. The Connect$^+$ can also assist the communication partners to scaffold their communication with persons in an MCS+ and to build on these persons' current level of

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communication by strengthening and expanding their existing communication. Furthermore, it can also teach communication partners to participate in self-directed learning and to create their own communication targets which will allow the programme to generalise to real-life contexts.

The information provided through the Connect+ can also empower unpaid communication partners to advocate for their needs and the person's needs. This can be achieved by making the communication partners aware of the services available to them but by guiding them on how to access these services. This empowers communication partners as it increases their autonomy and allows them to be active members of the multidisciplinary team.

The format of the Connect+ can also vary between face-to-face and online training, which caters for the needs, preferences, and convenience of the communication partners. This will allow communication partners to exert further autonomy based on their schedules and will allow them to benefit fully from the programme. The Connect+ could also increase the perceptions of communication partners of the importance of individualised social support by allowing them to not feel overwhelmed with irrelevant generic information. The Connect+ includes discussions on the specific communication goals and objectives in all the modules.

Paid communication partners

The Connect+ may assist HCPs to improve the quality of care they provide to persons in an MCS+. This programme can increase clinicians' awareness on the important role that communication partners play in the assessment and management of persons in an MCS+. The inclusion of communication partners in the multidisciplinary team could assist HCPs to obtain important information related to the persons' unaided communication behaviours. Additionally, the unpaid communication partners could provide the paid partners (e.g., the HCPs) important autobiographical information that the person responds to which can positively impact communication.

The Connect+ may specifically be of relevance to HCPs during behavioural assessment which is the gold standard for the assessment of DOC (Seel et al., 2010). This study creates awareness amongst HCPs of the communication content of the clinical tools that are currently used. As communication is an integral part of this assessment, the findings of the present study can add to an elaboration of these components to ensure early identification of the emergence of one of the disorders of consciousness. It is suggested that the section on communication in tools such as the Glasgow Coma Scale, the Sensory Modality Assessment and Rehabilitation Technique, and the Coma Recovery Scale- Revised be expanded to include the various unaided

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forms of communication ranging from non-linguistic to linguistic (Seel et al., 2010). These components may provide valuable clinical information for HCPs to assess and treat persons in an MCS+.

A further clinical implication of the present study is that the newly developed Connect^{+} can be seen as a CPT programme that includes the facilitation of multisensory therapeutic environments to increase person-partner interaction. This multisensory stimulation is often based on using stimuli that is familiar to the person and that is emotionally laden. Research suggests that when these two factors are incorporated in multisensory stimulation, the person is often more prone to respond to environmental stimuli, albeit inconsistently (Lancioni et al., 2021). Additionally, providing multisensory stimulation may prevent sensory deprivation for the person in an MCS+ and provide them with the opportunity to respond to the environment.

Finally, through the implementation of the Connect^{+}, HCPs are made aware of the important role they play in providing multisensory stimulation and guiding all communication partners (both paid and unpaid) on these aspects. As such, the Connect^{+} specifically creates awareness of the important role that SLTs play in providing communication support and training for communication partners. As communication specialists, SLTs can provide unique perspectives on unaided communication behaviours and multimodal communication strategies for communication partners of persons in an MCS+. The provision of the Connect^{+} may improve person-partner communication as the content of the programme is relevant to the current needs of communication partners of persons in an MCS+. The content of the Connect+ could also be used as training materials for undergraduate SLT students as part of their training regarding neurological conditions. This may improve the knowledge of SLT students and have a positive impact on their perceived readiness to treat persons with DOC within multiple settings.

6.4. Evaluation of the study

In this section, both the strengths and limitations of the qualitative exploratory collective case study design with three sequential phases each comprising of distinct steps are examined to provide a comprehensive view of the research conducted.

6.4.1. Strengths of the study

An important strength of the present study was the adaptation of an existing CPT, namely the Connect^{+}. The adaptation mostly centred around a new target population

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specifically persons in an MCS+ and their communication partners as well as ensuring relevance to the South African context. The Connect^{+} can be regarded as a strength as it is based on E^{3}BP principles and also includes stakeholder perspectives to ensure that it is based on the needs of the target population.

The specific research design allowed the researcher to identify and adapt a CPT based on E^{3}BP principles. Employing a qualitative exploratory collective case study design comprising of three sequential phases with different data sources allowed for the collection of descriptive data. The data of the three sequential phases was obtained from multiple sources (e.g., literature, face-to-face interviews, synchronous online interviews, nominal group technique) and comprising of multiple perspectives (e.g., literature, caregivers, clinicians, and SLTs) which facilitated data crystallisation and added to the trustworthiness of the study's findings.

During data collection procedures, all ethical considerations were adhered to specifically conducting online interviews during the COVID-19 pandemic as well as following COVID-19 safety protocols for face-to-face interviews. Additionally, permission and consent were obtained from all the relevant parties prior to any data collection. The researcher was sensitive to the needs of the caregivers, given the fact that the content was often emotionally laden, and if participants became emotional during the interviews, they were given a break after which the procedures continued. Confidentiality of participants was maintained by using participant codes to de-identify all data.

Unpaid communication partners who were interviewed in the study were optimistic regarding their participation and reacted positively to the research procedures and expressed that it provided them with an opportunity to find meaning in their care-giving role. In the case of caregivers who had cared for persons in an MCS+ who had passed away, they stated that they received closure of the passing of their loved ones. This was achieved through participation in the research study when asking the participant to mention what they have learned during the caring process. These perspectives allowed unique insights into the caring process, the communication of persons in an MCS+ as well the strategies that they themselves employed. The untrained communication partners had heterogenous work contexts as some cared for the person at home, while some provided care in a care facility. They often had other competing responsibilities (e.g., caring for children and spouses, work, and social obligations) which added to the richness of the data obtained. The richness of the data was increased due to

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the competing responsibilities of the communication partners data which included experiences from real-life contexts.

The participants in the trained communication partner groups such as the clinicians and SLTs, were equally motivated to participate in the study, albeit for different reasons. Their interest mostly sprung from wanting to gain more knowledge and insight on the topic at hand and wanting to contribute to the field. These clinicians added unique perspectives on the assessment and treatment of persons in an MCS+ which ensured that an existing CPT programme could be adapted to address the needs of communication partners. This also ensured that the CPT programme is applicable to this unique and often overlooked target population.

The Intervention Mapping approach (guiding the adaptation of the CPT) ensured that the fidelity of the TBI Connect programme remained intact and that the findings were trustworthy. The Connect^{+} incorporated six andragogical principles for adult learning and trainee engagement, which was appropriate for the study, given the fact that all communication partners were adults. In addition, the Intervention Mapping approach could facilitate self-directed learning of communication partners. Furthermore, the Connect^{+} utilises the social model of experiential learning that could encourage communication partners' accountability for their learning and could enhance problem-solving through shared experiences. Learning of communication partners could be facilitated through the communication activities, case studies, role play and discussions.

The study concluded by focusing on clinical utility – a step often overlooked when adapting training programmes. The inclusion of clinical utility ensured that both the barriers and facilitators to person-partner communication were identified prior to the implementation of the training and it also assisted in obtaining the perspectives of SLTs on the Connect^{+}. Determining the clinical utility assisted in identifying opportunities for maintenance of skills acquired during the training and increases SLTs awareness of the tools available to them.

6.4.2. Limitations of the study

Even though this study has made various contributions to the field of DOC, specific limitations are present that need to be mentioned.

Firstly, although the qualitative exploratory collective case study design that was used allowed for rich descriptions of phenomena, the data collection and analysis procedures were

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extremely lengthy and time consuming. The COVID-19 pandemic also resulted in access restrictions to participants and changes in data collection procedures.

Another limitation was that prior to the commencement of data collection, the owner of the private practice from where most of the potential participants were recruited, passed away. This resulted in the practice dissolving and as a result, these participants could not be contacted which could have potentially excluded valuable data. Alternative sources had to be used and both the clinical networks of the researcher and that of her supervisors had to be employed for the purposes of this study, to obtain a heterogenous sample which met the participant selection criteria. This might have resulted in selection bias and may not be representative of all the potential participants and hence, findings did not allow for generalisation of findings.

The scoping review focused only on patients with a CVA as a narrow aetiology scope provided a more homogenous population and stronger premise for the review. This resulted in an exclusion of participants with various other aetiologies such as neurodegenerative diseases and TBI, even though these are considered as potential causes of DOC.

When conducting the online interviews with untrained communication partners of persons in an MCS+, it was noted that not all communication partners could access the platform easily, which resulted in the change of platforms during the interview that increased the duration of some interviews. Due to the widespread effects of the different waves of the global COVID-19 pandemic at the time of data collection; alternative forms of data collection were not possible.

Throughout the study, a relatively small sample size was used, which negatively affects the generalisation of findings. Some SLTs were excluded due to personal emergencies at the time when data collection was scheduled. High caseloads further prevented some SLTs from participating, despite their interest in- and clinical expertise related to the topic.

Another limitation to this study included limited heterogeneity with the linguistic background of the participants in the three phases of this study. Additionally, the study did not include participants from public institutions. This limits the application of the findings to the larger South African context.

6.5. Recommendations for future research

The following recommendations are suggested for future research based on the findings of this study:

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- As this study concluded with determining the clinical utility of a CPT programme, it is suggested that this proposed programme (Connect^{+}) be piloted with the target population by implementing a single subject multiple baselines between subject designs. Piloting and implementing the Connect^{+} could assist both trained and untrained communication partners to facilitate communication with persons in an MCS+ and could support and guide them to observe, assess, interpret, and respond to persons in an MCS+ to the unaided communication behaviours of persons in an MCS+.
- Alternatively, an experimental group design (comprising of a treatment group and control group) could be used to evaluate the effectiveness of the Connect+ with communication partners of persons in an MCS+. Such a quantitative experimental design could assist in providing information on the generalisability of the Connect+ with larger populations.
- The Connect+ could also be implemented in comparative studies which evaluate to what extent the outcome of the implementation method differed (e.g., telehealth versus face-to face), if the context differed (e.g., international versus national or hospice/care facility versus a home context), or if the communication partners differed (e.g., trained/untrained familiar partners such as relatives, friends, or neighbours versus trained/untrained unfamiliar partners such as care workers, nurses, or allied HCPs). Evaluating the different implementation methods, contexts, and communication partners may assist in targeting larger samples of the target population and may address other needs of the communication partners or persons that are not targeted in this study.
- The possibility also exists to implement the Connect^{+} with the paediatric population of children in an MCS+ (e.g., children following near-drowning incidents). Due to the acquired neurological injury (near-drowning incident), these children may remain in an MCS+ for an extended period of time with minimal changes in their level of wakefulness and awareness. The Connect^{+} may therefore be beneficial for the communication partners of children in an MCS+ as it includes the provision of multisensory stimulation which decreases sensory deprivation. Additionally, it may assist communication partners to facilitate communication with the child based on their means and method of communication.
- Further research should also include retrospective interviews of persons who have recovered from an MCS+. This may provide insights into the MCS+ state from the person's perspective and experience and further elaboration can be achieved on the specific

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communication behaviours that these persons use as well as the function of these behaviours.

6.6. Conclusion

The main aim of this study is to identify and adapt a CPT programme to facilitate interaction between communication partners and persons in an MCS+, by empowering communication partners to observe, assess, interpret, and respond to the communication behaviours displayed by these individuals. The concluding chapter of the present study started with a summary of the most important findings of the qualitative exploratory collective case study design. Next the clinical implications of this study were discussed, after which the strengths and limitations were critically evaluated. This chapter concluded with recommendations for future research.

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Appendices

Appendix A: Ethics Permission

UNIVERSITEIT VAN PRETORIA
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YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100. Since 1919

5 August 2020

Dear Miss A Kuyler

Project Title:	Communication partners of minimally conscious persons: Developing and implementing a training programme focused on strengthening unaided communication
Researcher:	Miss A Kuyler
Supervisor(s):	Prof JJ Bornman Dr E Johnson
Department:	CAAC
Reference number:	12043193 (HUM029/0720)
Degree:	Doctoral

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 30 July 2020. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely,

Prof Innocent Pikirayi
Deputy Dean: Postgraduate Studies and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: PGHumanities@up.ac.za

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Research Ethics Committee Members: Prof I Pikirayi (Deputy Dean); Prof KL Harris; Mr A Bizos; Dr A-M de Beer; Dr A dos Santos; Ms KT Govinder Andrew; Dr P Gutura; Dr E Johnson; Prof D Maree; Mr A Mohamed; Dr I Noomè; Dr C Puttergill; Prof D Reyburn; Prof M Soer; Prof E Taljard; Prof V Thebe; Ms B Tsebe; Ms D Mokalapa

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Appendix B: Practice Permission Letter

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Centre for Augmentative and Alternative Communication

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Private practice: Permission letter and reply slip

To the Practice Manager

Name of Practice _____

Date _____

Dear _____

Permission to recruit participants for a research study using your practice's database

My name is Ariné Kuyler and I am a PhD student at the Centre for Augmentative and Alternative Communication at the University of Pretoria. In partial fulfilment for the requirements of this degree; I am requested to conduct a research project. Herewith I request your permission to recruit participants for my study through your practice. We request your permission for the recruitment of healthcare practitioners working at your practice as well as caregivers of minimally conscious patients affiliated with your practice and who have been discharged home.

Research Topic: *Communication partners of minimally conscious persons: Developing and implementing a training program focussed on strengthening unaided communication*

Rationale for the study: Informal caregivers of minimally conscious persons often experience challenges when providing long term patient care. These challenges can be due to financial constraints, decreased socialization with neighbours, friends and family and ineffective caregiver-person communication. Ineffective communication between caregivers and minimally conscious persons can be influenced by the caregiver's inability to recognise unaided communication behaviours of minimally conscious persons. Caregivers mostly misinterpret or judge minimally conscious persons' attempts to communicate as incomprehensible. This may cause decreased duration of caregiver contact and reduced motivation of minimally conscious persons to communicate. Caregivers would therefore benefit from communication-partner training as it may improve their communication with minimally conscious persons.

Objectives of the study: The main aim is to determine the effect of a communication-partner training programme on the frequency and type of unaided communication cues used by caregivers of minimally conscious persons and the duration of caregivers' conversational turns.

Participants of the study: The participants of the study will include three groups: (i) healthcare practitioners from your practice who will provide input during the development of the communication-partner training programme; (ii) informal caregivers of minimally conscious persons who have been discharged home who will be involved in online interviews, and (iii) informal caregivers of minimally conscious persons who will receive training on the communication-partner programme. The focus of this study will NOT be on the patients but on the informal caregivers when caring for the minimally conscious persons.

Page 1 of 4

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Email: saak@up.ac.za | Web address: www.caac.up.ac.za

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What will be expected from your practice? We request your permission that potential participants from your practice; specifically, healthcare practitioners currently working with minimally conscious persons and home-based informal caregivers of minimally conscious persons affiliated with your practice could be recruited for this study. Upon ethics approval obtained from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria and permission from you, you will be requested to identify potential participants affiliated with your practice based on the following criteria: (i) The healthcare practitioners should have completed their degree in their relevant field, have at least 3 years' experience with minimally conscious persons, have specialised training (diploma of Master's degree in neuro-rehabilitation or Augmentative and Alternative Communication), be registered with the HPCSA and be proficient in English; (ii) The participants included in the two caregiver groups should be adults older than 18 years, they should have given or give care to minimally conscious persons for at least 3 months, they should be literate and proficient in English. As practice manager it would be appreciated if you could inform the identified potential participants about the study and once they have indicated their interest to participate in the study, to provide their details to the researcher. The researcher will then contact the potential participants and provide them with letters of informed consent as well as a biographical questionnaire which they will have to complete upon consent.

What will be expected from the participants?
The first group of informal caregivers will have to participate in an online interview of a 60- to 90-minute session that will take place on Zoom, Skype or Google Hangouts. During this session the informal caregivers will be asked questions relating to their challenges, barriers and facilitators of caregiving and communication with minimally conscious persons. It is estimated that these interviews will take place in October to November 2020 and will be conducted at a time convenient to the participant. Should the participant be unable to complete the full session due to responsibilities related to the care of the minimally conscious person, shorter sessions will be scheduled to cover all the questions. These online interviews will be audio-recorded.

For the second group of informal caregivers, caregivers who were not involved in the online interviews will be required to participate in a 12-week communication-partner training programme. Participants will have to attend one weekly session of 60-90 minutes at a location specified by them. The communication-partner training programme will entail training on the frequency and type of unaided communication cues as well as determining the duration of caregiver conversational turns to improve caregiver communication. It is estimated that this data collection will take place during 2022 as the communication-partner training programme still needs to be developed. The training sessions will be audio- and video-recorded.

The healthcare practitioner participant group will be involved in the development of the communication-partner training programme. Upon consent, these professionals will receive a preliminary copy of the communication-partner training programme to determine the applicability and relevance of the items included. Participants will also have to provide suggestions on items that can be included. This process will entail email correspondence at a time and location convenient to the participants. Repetition of data collection procedures may occur until changes made are satisfactory to the healthcare practitioners. Participation will be done in participants' private time and will not influence their work at your practice. It is estimated that this data collection will occur during 2021.

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Ethical considerations

Risks and possible disadvantages to participants: There are no anticipated risks related to this research.

Participants' rights: The participant's participation in this research is completely voluntary and participants may withdraw without negative consequences to them or the practice. The caregivers will not receive incentives to participate but the healthcare practitioners or your practice will receive the completed communication-partner training programme upon request.

Confidentiality: There will be no identifying information of either the practice or participants in any publications or presentations resulting from this study. The information provided during the interviews or questionnaires will be kept safely, and the information will only be viewed by the PhD student and her supervisors. The data obtained will be securely stored for a period of 15 years on an online data storage platform regulated by the University of Pretoria.

Research results: The results from this study will be reported in general terms in the content of speech and writing that may be presented in a PhD thesis, manuscripts submitted for publication in scientific journals or oral and/or poster presentations at scientific meetings, seminars, and/or conferences. If you wish to receive a copy of the results of the study, you may contact the principal researcher at the telephone number given below. My supervisors and I would also be willing to give feedback to representatives and staff from your practice.

It would be greatly appreciated if you would consider this request favourably. If you agree, kindly submit a signed letter of permission, acknowledging your permission for me to conduct this study with the support of your practice. Thank you for your time and consideration of this request. Should you need any further information on the study, you are welcome to contact me or my supervisors on the contact details below. I look forward to receiving your response.

Kind Regards

Ms Ariné Kuyler
(Researcher)
Email: [redacted]
Tel: [redacted]

Prof Juan Bornman
(Supervisor)
Email: [redacted]
Tel: [redacted]

Dr Ensa Johnson
(Co-supervisor)
Email: [redacted]
Tel: [redacted]

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Centre for Augmentative and Alternative Communication

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Permission Letter: Practice Manager Reply Slip

Practice nr:

Name of participating practice:					
Name of practice manager:					
Project title:	*Communication partners of minimally conscious persons: Developing and implementing a training program focussed on strengthening unaided communication*				
Researcher:	Ariné Kuyler [redacted]	**Supervisor:**	Prof Juan Bornman [redacted]	**Co-supervisor:**	Dr Ensa Johnson [redacted]

I, _____, (full names and surname) hereby:

- Agree that participants (healthcare practitioners; informal caregivers of minimally conscious persons) may be recruited from this practice.
- Understand that participants will at no stage during the research process be exposed to any harmful situations.
- Understand that participants will be audio and video recorded after consent.
- Understand that the practice may withdraw at any time from this study, without negative consequences.
- Understand that confidentiality of the practice, and participants will be guaranteed in the research PhD thesis and any publications or conference proceedings that may arise from it.
- Agree that the data may be analysed further in future.
- Understand that the data will be stored for a period of 15 years on an online data storage platform regulated by the University of Pretoria.

(Please tick appropriate block)

I give permission		I do not give permission	

_____ _____

Signature of Practice Manager Date

Practice
Official Stamp

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Centre for Augmentative and
Alternative Communication

00/00/2021

Dear Communication Partner

Thank you for your willingness to participate in this research study. Your input will aid in the adaptation or development of a communication-partner training programme for communication partners of persons in a minimally conscious state (MCS+). This informed consent letter consists of 2 sections, namely a reply slip and a biographical questionnaire. If you are willing to participate in the research, kindly complete both and email them back to me before the interview.

Letter of informed consent and reply slip

Invitation to participate in an online interview

My name is Ariné Kuyler and I am a PhD student at the Centre for Augmentative and Alternative Communication at the University of Pretoria. In partial fulfilment for the requirements of this degree, I am requested to conduct a research project. The practice manager, of the practice where the person in an MCS+ you are caring for receives or has received therapy, provided us with your details. Herewith, I request your consent to participate as a communication partner of a person in an MCS+ in an online interview.

Research Topic: Communication partner training programme to support persons in a minimally conscious state: Identifying and adapting an intervention programme

Why is this study important? Communication partners of persons in an MCS+ often experience challenges when providing long term patient care. These challenges can be due to financial constraints, decreased socialisation with neighbours, friends and family and ineffective communication partner-person communication. Ineffective communication between communication partners and persons in an MCS+ can be influenced by the communication partner's inability to recognise unaided communication behaviours of persons in an MCS+. Communication partners mostly misinterpret or judge persons in an MCS+ to communicate as incomprehensible. This may cause decreased duration of communication partner contact and reduced motivation of persons in an MCS+ to communicate. Communication partners would therefore benefit from communication-partner training as it may improve their communication with persons in an MCS+.

What are the aims of the study? This study aims to identify and adapt an evidence-based intervention in the form of a communication partner training programme to facilitate interaction between communication partners and persons in an MCS+. This is done by empowering communication partners to observe, assess, interpret and respond to the communication behaviours displayed by these individuals.

What will be expected of you when you participate? You will be requested to complete the attached consent form and biographical questionnaire, which is expected to take approximately 10 minutes to complete. Upon your consent, I will arrange a time and date convenient to you to participate in an online interview. This interview will be a once-off session of approximately 60- to 90-minutes using an online platform such as Zoom, Skype or Google Hangouts, depending on your choice. A link to this platform will be sent to you once the details have been confirmed with you. During this session you will be asked questions relating to your

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experiences (both positive and negative) when caring and communicating with persons in an MCS+. The estimated time frame for this interview to be conducted will be during March 2021. Should you be unable to complete the full interview in one session due to responsibilities related to the care of the person in an MCS+, shorter sessions can be arranged to cover all the questions. These online interviews will be audio-recorded. Please note that the recording will be transcribed and sent back to you a week after the interview. You will be expected to review this transcript to ensure that your opinion is reflected in the data. Based on your preference you will be able to review the transcript independently or with the researcher present.

Ethical considerations

Are there risks and possible disadvantages to participation? There are no anticipated risks related to this research.

What are your rights? Your participation in this research is completely voluntary and you may withdraw at any time during the interview without negative consequences to you or the person in your care. You will not receive any incentives to motivate you to participate however the outcome of the research may improve communication between you and the person in an MCS+ in your care.

Will your information be kept confidential? Your information will be kept confidential as no identifying information will be reported in any publications or presentations resulting from this study. The information provided during the interviews will be kept safely, and the information will only be viewed by myself and my PhD supervisors. The data obtained will be securely stored for a period of 15 years on an online data storage platform regulated by the University of Pretoria.

Will you see the results*?* If you wish to receive a copy of the results of the study, you may contact me directly. The results from this study will be reported in general terms in the PhD thesis, in manuscripts submitted for publication in scientific journals related to the thesis, and in oral and/or poster presentations at scientific meetings, seminars, and/or conferences. If the need arises, data may be used for future research.

It would be greatly appreciated if you would consider this request favourably. If you agree, kindly submit the signed reply slip to indicate your willingness to participate. Thank you for your time and consideration of this request. Should you need any further information on the study, you are welcome to contact me or my supervisors. I look forward to receiving your response.

Kind Regards

Ms Ariné Kuyler
(Researcher)
Email: [redacted]
Tel: [redacted]

Prof Juan Bornman
(Supervisor)
Email: [redacted]
Tel: [redacted]

Dr Ensa Johnson
(Co-supervisor)
Email: [redacted]

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Name of participant:					
Project title:	**Communication partner training programme to support persons in a minimally conscious state: Identifying and adapting an intervention programme**				
Researcher:	Ariné Kuyler [redacted]	**Supervisor:**	Prof Juan Bornman [redacted]	**Co-supervisor:**	Dr Ensa Johnson [redacted]

I, _____, (full names and surname) hereby acknowledge that:

- My participation in the online interview is completely voluntary.
- I may withdraw from the study at any time, without negative consequences.
- I will not be exposed to harmful situations during the stages of the study.
- I acknowledge that the online interview sessions will be audio recorded.
- The information I supply for the PhD study will be kept confidential and confidentiality will be maintained if any publications or conference proceeding arise.
- The data may be analysed further or used in future research, but that confidentiality of personal information will be maintained.
- I understand that the data will be securely stored for a period of 15 years on an online data storage platform regulated by the University of Pretoria.

(Please tick appropriate block)

I give consent		**I do not give consent**	

_____ _____

Signature of participant Date

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Appendix C3: Biographical Questionnaire-Phase 1

Communication partner nr:

Biographical information

Please complete all the following questions by filling in the empty spaces supplied for the answers or alternatively where multiple options are given, please mark your answer with an X.

Background information of the person that you care for:				
1. How old is he/she	_____ years			
2. What is his/her gender of the person?	Male	Female		Other
3. What is his/her first language?				
4. What is the person's highest qualification?	Matric	Diploma		Bachelor's Degree
	Master's Degree	PhD	Don't know	Other:
Incident information				
5. What was their occupation?				
6. What happened to the person or what caused the incident?				
7. When did this happen?				
8. How long was the person in the hospital?				
9. When was the person discharged?				
10. When was the person diagnosed as being in a minimally conscious state?				
11. How long has the person been in this minimally conscious state?				
12. What type of medication is the person currently taking?	Sleep medication	Anti-convulsant	Anti-depressant	Don't know
	Diabetes medication	Hypertension medication		Anxiety medication
	Other: _____ (Please state)			
Therapeutic information				
13. How do you know if the person is awake and not sleeping?				
14. Is the person currently receiving therapy?	Yes		No	
15. What therapy does the person receive?	Speech therapy	Physiotherapy		Occupational therapy
	Hydrotherapy	Other: _____ (Please state)		
16. Does the person receive individual or group therapy?	No therapy	Individual therapy		Group therapy
17. State the frequency of therapy for the different therapies that the person receives (e.g., speech therapy-weekly/monthly)?				
18. How long has the person been receiving therapy?				

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Appendix D: Journal Agreement to Include Manuscript in Study

From: Ariné Kuyler <[redacted]>
Sent: 15 October 2022 19:54
To: ijlcd.office <[redacted]>
Subject: Re: International Journal of Language & Communication Disorders TLCD-2020-0279.R3

This is an external email.

Dear Dr. Rosu

I hope that you are well. My co-authors and I would like to request your permission to include this manuscript in my PhD thesis. Please let me know if this aligns with the copyright agreement of the journal and whether this has your approval. Thank you again for publishing our work in your journal we look forward to hearing from you.

Kind regards
Arine Kuyler

ijlcd.office 18 Oct 2022, 16:28 (3 days ago)
to me

Dear Ariné,

Please note that you can use the manuscript for your PhD thesis.

Thank you.

Best Regards,
[redacted]

[redacted]
Editorial Assistant
International Journal of Language and Communication Disorders
[redacted]

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Appendix E: Manuscript Unaided Communication Behaviours

Received: 30 December 2020 | Revised: 15 November 2021 | Accepted: 18 November 2021
DOI: 10.1111/1460-6984.12691

International Journal of Language & Communication Disorders

REVIEW

Unaided communication behaviours displayed by adults with severe cerebrovascular accidents and little or no functional speech: A scoping review

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Abstract

Background: Unaided communication behaviours may provide communication support for persons with severe cerebrovascular accidents (CVA), as these individuals often experience severe communication difficulties, regardless of the aetiology. Though often subtle, these behaviours are present during all stages of recovery, and therefore communication partners need to know not only which unaided strategies are used as communication attempts, but also what their function is (i.e., what the person aims to achieve with the communication).

Aim: To identify the unaided communication behaviours that adults with severe CVA and little or no functional speech use to communicate, and to determine the communication functions addressed by these behaviours.

Methods & Procedures: The study used a scoping review methodology and included articles on communication partners of persons with CVA published between 1986 and 2020. Initially the searches yielded 732 studies from which 211 duplicates were identified. The remaining studies (n = 531) were then screened on title, abstract and full-text level resulting in a final inclusion of 18 studies. Of the 18 studies, five were qualitative and 13 consisted of quantitative methodologies.

Main contribution: The subtle communication behaviours used by persons with CVA (and resultant severe communication difficulties) are often misinterpreted or overlooked by their partners. If partners are trained to recognise such subtle or unaided communication behaviours, they can provide adequate support to access a range of communication functions. The unaided communication behaviours, which include 13 primary behaviours ranging from non-linguistic to linguistic, were utilised to convey 31 communication functions classified into four main communication categories.

Conclusions & Implications: Although unaided communication behaviours often appear as limiting, they can be utilised to communicate various communication functions. The findings of this review support the training of partners to identify these behaviours and improve person-partner communication.

KEYWORDS
cerebrovascular accidents, communication functions, unaided communication behaviours

What is known?

Unaided communication has been widely researched. However, a summary is needed of the various unaided communication behaviours and of the different communication functions addressed by these behaviours.

What the paper adds…

This paper emphasises that unaided communication behaviours range from non-linguistic to linguistic, and they can support unintentional, pre-intentional and intentional communication functions.

Clinical implications

- Even though aided communication is preferred, unaided communication behaviours are generally used in contexts with limited resources, as well as among culturally and linguistically diverse populations.

This study advocates the identification of unaided communication behaviours by partners as well as the support and provision of access to communication strategies for persons with severe CVA.

- Future research should include more untrained communication partners.

INTRODUCTION

Adults with severe cerebrovascular accidents (CVA) and little or no functional speech experience communication difficulties due to various factors (Beukelman & Light, 2020). These difficulties manifest as challenges in persons exchanging thoughts and expressing needs and wants appropriately and effectively (Teachmen & Gibson, 2014). Communication challenges are attributed to cognitive, emotional, sensory, motor, speech, language and voicing difficulties that may prohibit affected individuals from responding to environmental stimuli (Lancioni et al., 2016). These challenges, which are typically described with clinical diagnoses such as apraxia, aphasia and/or dysarthria, are chronic in nature. According to Beukelman et al. (2015) 40- 60% of persons with CVA experience chronic, severe communication difficulties. This may impact both the individual with the condition and the communication partner, and typically result in participation restrictions in various settings (Simmons-Mackie, 2018). Since the publication of the first case studies pointing to the use of augmentative and alternative communication (AAC) as a potential communication solution for persons with severe CVA who present with little or no functional speech in the late 1980's, there has been significant developments in the field (Dietz et al., 2020; Geise Arroyo et al., 2012). Following extensive research, Simmons-Mackie et al.'s (2017) suggest the so-called "top 10: best practice recommendations for aphasia" of which the fourth one specifically refers to AAC:

> "No one with aphasia should be discharged from services without some means of communicating his or her needs and wishes (e.g. using AAC, supports, trained partners) or a documented plan for how and when this will be achieved (Level: Good Practice Point)". (p. 139)

Loncke (2014) describes AAC as evidence of the resilience of humans' communication capabilities and their ability to adapt when typical forms of communication are ineffective. AAC may assist adults with severe CVA and little or no functional speech to become competent communicators again, as it is the most fundamental of human capacities and basic human right (International Communication Project (ICP) n.d.). By providing alternative strategies that result in functional communication

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and participation, AAC could support and supplement natural speech production (Beukelman & Light, 2020). AAC also provides adults with severe CVA and little or no functional speech a means to perform a vast array of communication functions, such as obtaining information, communicating thoughts and feelings, and re-establishing relationships with partners (Hogrefe et al., 2012).

According to the AAC symbol taxonomy suggested by Lloyd and Fuller (1986), there are different classifications of AAC. The most common classification involves unaided (relying only on the body) and aided (relying on external aids or supports) communication strategies. The current scoping review focused on unaided communication, which can be defined as conveying one's thoughts, feelings and messages through natural nonverbal communication (Beukelman & Light, 2020). Unaided communication can be portrayed on a continuum with non-linguistic and linguistic systems being the two anchors (Beukelman & Light, 2020; Bornman & Tönsing, 2019). Non-linguistic unaided communication includes vocalisations and natural gestures (e.g. pointing, idiosyncratic gestures, eye movement and/or deliberate blinking, lip reading, head nodding and shaking, whistles and facial expressions), while linguistic unaided communication includes natural speech, sign language and alphabet signs such as finger spelling (Bornman & Tönsing, 2019; Loncke, 2014; Radkte et al., 2011; Ten Hoorn et al., 2016). Unaided communication is typically used more frequently than aided forms and can be used to communicate specific communication functions. For instance, agreement ("yes") can be indicated by head nodding or eye blinking, while disagreement ("no") can be indicated with head shaking or prolonged eye closure (Fleischer et al., 2009). However, Ten Hoorn et al. (2016) warn that unaided communication can be frustrating for both communication partners, as it does not meet all the communication needs of the individual (e.g. conversational topics regarding spiritual beliefs).

Unaided communication is present during all phases of recovery for individuals with severe CVA and little or no functional speech, with eye movements often being one of the first signs to indicate that a person is aware and alert (Bareham et al., 2018). Nonetheless, these unaided communication behaviours are typically subtle, and therefore communication partners need to know which unaided strategies are used as communication attempts, as well as what their function is (in other words, what the person aims to achieve with the communication) (Fleischer et al., 2009). Unfortunately, in cases where the communication partners are untrained or not familiar with the affected person, these subtle communication attempts can easily be ignored, misinterpreted or judged as incomprehensible (Ellis & Astell, 2017; Radtke et al., 2011). Moreover, unaided communication attempts may be overlooked by communication partners due to time constraints and limited contact opportunities during activities of daily living (Radkte et al., 2011).

Another component adding to this dilemma may be limited knowledge and negative attitudes of communication partners regarding the identification of subtle intentional unaided communication behaviours, as they may mistakenly perceive verbal communication as the only means to emotionally connect with people (Holt et al., 2012). This may result in reduced motivation, decreased initiation of interaction and limited participation attempts on the side of the individual with severe CVA and little or no functional speech (Finkel et al., 2018).

Training may alter the perspectives of communication partners, as it may encourage them to focus on observable behaviours during interaction and interpret them as communication attempts. Training should also improve the participation of persons with severe CVA and little or no functional speech and reduce their activity limitations (Simmons-Mackie, 2018). Communication partners furthermore require training to observe and interpret different forms of unaided communication behaviour. It may empower them to intervene during the earliest possible stages of the condition, and to assist in assessment, establishment of the prognosis and planning of appropriate treatment (Bareham et al., 2018). Training partners to recognise unaided communication behaviours may also result in improving the emotional state of communication partners and increasing the duration of partner contact (Watson et al., 2012). Finally, communication-partner training can assist with the carry-over of therapeutic skills in real-life contexts (Simmons-Mackie et al., 2010) and often leads to a positive change in the communication skills of the person with a severe CVA and improved person outcomes (Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016 and 2017).

The aim of the scoping review in hand was to identify the range of different unaided communication behaviours used by adults with severe CVA and little or no functional speech, as well as the function of these behaviours. This knowledge can be used when communication partners are trained to be sensitive and to observe subtle unaided forms of communication used by this often-neglected group of individuals. The specific research question posed was: What unaided communication behaviours do adults with severe CVA and little or no functional speech use during communication, and what functions do they serve?

METHODOLOGY

Since it provides a broader overview of the state of evidence within a field (O'Brien et al., 2016), a scoping review

based on an approach suggested by Tricco et al. (2018) was selected to address the aim of the study and guide the research process. This review evaluated studies relevant to the topic (unaided communication behaviours displayed by adults with severe CVA and little or no functional speech) and suggested recommendations related to unaided communication, based on evidence. It also allowed for flexibility regarding the type of literature (both published and grey literature, such as handouts) and the variety of study designs (both qualitative and quantitative studies) that were included (O'Brien et al., 2016; Tricco et al., 2018). A scoping review was essential in this specific study due to the limited information available on the topic (O'Brien et al., 2016).

To ensure that the review included information relevant to the main aim, the population, exposure and outcome (PEO) approach was utilised. This included a systematic search of literature that focuses on the unaided communication (outcomes) of persons with severe CVA and little or no functional speech (population) and in specific communication settings (exposure) (see Table 1). Due to the pervasive impact of severe CVA on communication, the search was narrowed to focus specifically on unaided communication.

Search strategy and study selection

The three-part search strategy that was applied, started with a limited cross-database search through interfaces to identify relevant keywords from studies relating to the topic (Khalil et al., 2016). Next, relevant interfaces such as Ebscohost, Scopus, Proquest and Cochrane were used, through which databases such as Medline, CINAHL, Pubmed, Psycharticles, Academic Search Complete, Health Source: Nursing/Academic Edition, Taylor & Francis, and PsychInfo were searched individually by using the identified keywords (Khalil et al., 2016). The final component of the search included the screening of reference lists of studies relevant to the topic, as well as the hand-searching of paper-based journals (Khalil et al., 2016; Tricco et al., 2018). The selected keywords included thesaurus and synonym recommendations made by these databases (Table 1). Keywords included general AAC nomenclature obtained from the AAC profile code set (Rowland, 2011) and the AAC symbol taxonomy classification (Lloyd & Fuller, 1986). The keywords included Boolean operators and truncation, and were used in all fields – including title, abstract, subject terms and mesh terms.

The following inclusion criteria were applied in the searches:

- Studies on human participants, specifically adults (18+ years old).
- Material published between 1986 and March 2020 to coincide with the publication of the AAC symbol taxonomy that coined the aided/unaided symbol dichotomy (Lloyd & Fuller, 1986).
- Qualitative and quantitative studies as well as mixed-method research designs.
- Studies published in English.
- Grey literature (Peer-reviewed grey literature such as reports, fact sheets, theses, conference proceedings and chapters of academic textbooks were included, while websites, newspapers and policy documents were excluded as searches yielded limited information relevant to the pre-determined inclusion criteria of the scoping review (Godin et al., 2015)).

Two librarians assisted the first author in refining search terms, identifying studies and eliminating the duplicates. Initially, the searches yielded 732 studies and 10 additional searches as shown in the PRISMA diagram in Figure 1 (Blanco et al., 2019). A total of 211 duplicates were identified and removed (n = 531 remained) and 438 studies were excluded on title level as they did not focus on the topic of the current scoping review. It should be noted that a small proportion of studies (n = 20) in the initial search were also excluded due to access restrictions. The 93 remaining studies were uploaded onto Rayyan, an online platform where researchers can perform collaborative systematic reviews (Ouzzani et al., 2016). Rayyan proved beneficial as it increased the objectivity of study selection and aided in improving the inter-rater agreement (Ouzzani et al., 2016). The first author screened all the abstracts, while the studies were divided equally between the second and third authors. This process ensured that all the abstracts were reviewed by at least two authors (Blanco et al., 2019). The abstracts were divided into three groups: undecided, included and excluded. The initial inter-rater agreement on abstract level was 75%. The remaining 25% (undecided abstracts as well as disagreements) were discussed until 100% consensus was reached (Blanco et al., 2019). Studies were excluded on abstract level due to the wrong population, wrong outcome or wrong focus of the study.

The same process was followed to select the full text selection and the abstract. Initial inter-rater agreement was 75%, which is regarded as acceptable according to Graham et al. (2012). Disagreements were again discussed until 100% consensus was reached. Altogether 17 studies were selected for full-text inclusion, based on the criteria in Table 1. The preferred reporting items for systematic reviews and meta-analysis (PRISMA) diagram are shown in Figure 1.

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TABLE 1 Inclusion criteria and keyword selection for partner-assisted communication programmes

Content	Keywords	Inclusion	Exclusion	Justification
Population: Adults with CVA (18 years and older)	Cerebrovascular incidents/accidents/stroke-impair*/difficulties/aphasia/dysarthria, apraxia of speech dis*-neurological Acquire neurological injury/accident/disorder	Only studies that focused on adults with cerebrovascular accidents were included.	Studies focusing on acquired neurological disorders such traumatic brain injury, neurodegenerative diseases (e.g., Dementia/Alzheimer's disease and Parkinsons disease) will be excluded. Other studies targeting congenital neurological disorders such as cerebral palsy (CP), autism spectrum disorders (ASD), pragmatic disorders, syndromes, developmental delays, learning disorders, congenital hearing, cognitive and visual impairments, paediatric DOC (Disorders of Consciousness) and cancer (except head and neck cancer) were excluded. Studies focusing on children were excluded.	Various individuals with cerebrovascular accidents experience communication difficulties – from initial admission to the critical care unit until they are discharged to go home (Ten Hoorn et al., 2016). Adults were classified as individuals who are 18 years old and older. This population is often affected by acquired neurological disorders (Beukelman & Light, 2020)
Exposure: Communication activities, procedures, contexts or interventions	Support-assist*, aid, support, help, guid* Intervention- therap*, manag*, interven*, rehab*, strategies Programme-program*, train*, caregiver education, patient discharge instruct*, communicat*, part*, train*	Studies focused on the communication activities, procedures, contexts and interventions that include unaided communication.	Studies focusing on general support, emotional burden, physiotherapy, acupuncture, pharmacological and medical interventions such as transcranial direct current stimulation, brain computer interface, FMRI (Functional Magnetic Resonance Imaging), EEG (Electroencephalogram), were excluded.	Identifying these components may provide a form of environmental stimulation that may elicit increased responses from adults with acquired neurological disorders (Lancioni et al., 2016). This may assist in the identification of daily familiar stimuli that promote access to and experience of communication and that motivate participation (Lancioni et al., 2016).
Outcome: Unaided communication	Communicat*- nonverbal, non tech, intentional, volitional, augmentative and alternative, aids, devices, unaided, kinesic, non-speech, functional, expres* strategies, multimodal, motor, pain, gestures, patient-nurse, behaviours, interaction	Studies focused on identifying the unaided communication behaviours used by persons with acquired neurological disorders to support interaction with communication partners.	Studies focusing on low-high technology AAC systems were excluded. Another component that was excluded was nonverbal communication with typical adults (related to psychology), as well as nonverbal movements that were not related to communication.	Identifying unaided communication behaviours may assist partners in identifying the communicative intent of adults with acquired neurological disorders messages and provide the appropriate intervention (Beukelman & Light, 2020).

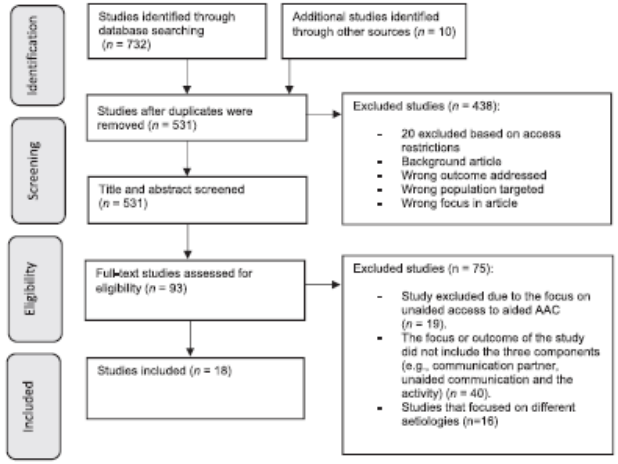

FIGURE 1 Prisma diagram for scoping review process (Blanco et al., 2019)

Data extraction, analysis and reporting

A data extraction tool was developed to assist the authors in compiling consistent and independent data reports. The data extraction instrument included the date, authors, research design, outcomes, outcome measures, unaided communication behaviours, communication content and communication activity/context or intervention. All the data was extracted independently by at least two authors. The first author extracted 100% of the studies while the second and third author each extracted 50% of the studies. Only 10% discrepancies occurred for which a third opinion was sought to act as an arbitrator. Upon full consensus the extracted data was recorded on a data extraction form and transferred to an Excel spreadsheet.

Following data extraction the quality of the included studies was appraised using the mixed methods appraisal tool (MMAT) (Hong et al., 2018). This tool assisted the authors in critically appraising the methodologies of the included studies and the scores are shown in Table 2. However, the focus of this appraisal was on description rather than on exclusion, and therefore no studies were excluded based on their MMAT score (Hong et al., 2018). The first author critiqued 100% of the studies and the other two authors independently appraised 20% of the studies. The MMAT overall quality score used descriptors such as numbers ranging from 1 (indicating 20% quality criteria) to 5 (indicating 100% quality criteria met).

Thematic analysis was used to analyse the data, as this process allows for the systematic and insightful identification and organisation of data into themes in order to address the aim of the research (Nowell et al., 2017). The six-step approach suggested by Braun and Clarke (2012) was followed: 1) The authors familiarised themselves with the data and focused on data reduction through triangulation; 2) the data was then hand coded by the authors; 3) themes were determined by means of inductive coding (i.e. a bottom-up approach that uses the data content to determine codes); 4) the identified themes were reviewed; 5) themes were defined and named; and 6) the thematic analysis process was concluded with the production of a report.

RESULTS

The results of the scoping review are presented as descriptive information related to the 34 included studies (authors, country, research design) and the study population (adults with CVA and little or no functional speech and their communication partners) (see Table 2). This is followed by an analysis of the unaided forms of communication (Table 3 and Figure 2), as well as the various

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TABLE 2 Description of included studies (alphabetical according to authors)

	Descriptive information: Study					Population: Participants			Population: Partners
No	Author	Country	Research design	MMAT rating (Score out of 5)	Progressive/ Non-progressive	Participants	Aetiology	Context/setting	Communication partner
Person-centred communication									
Quantitative design									
1	Blonder et al. (1993)	USA*	Experimental comparison with control group	5	Non-Progressive	N = 22	7 CVA** (Right) 7 CVA (Left) 8 Normal	Home	Life partner
2	Blonder et al. (1995)	USA	Experimental comparison with control group	5	Non-Progressive	N = 21	7 CVA (Right) 7 CVA (Left) 7 Normal	Home	Life partner
3	Bond et al. (1989)	USA	Descriptive, correlational	4	Non-Progressive	N = 41	35 CVA (Left)	Therapy	SLT#; Nurse; Researcher
4	Daumüller et al. (2010)	Germany	Experimental comparison with control group	3	Non-Progressive	N = 35	35 CVA (Left)	Hospital	Researcher
5	Dipper et al. (2015)	UK**; Australia	Experimental comparison with control group	5	Non-Progressive	N = 58	29 CVA (Left) 29 Normal	Therapy; support groups; community	Researcher
6	Finkel et al. (2018)	Germany; USA; Austria	Experimental comparison with control group	4	Non-Progressive	N = 117	67 CVA (Left) 50 Normal	Hospital	Researcher
7	Hanlon et al. (1990)	USA	Single subject design	5	Non-Progressive	N = 24	24 CVA (Left)	Support groups; Therapy	Researcher
8	Marangolo et al. (2010)	Italy	Single subject design	4	Non-Progressive	N = 6	5 CVA (Left) 1 TBI****	Therapy	Researcher
9	Preisig et al. (2018)	Netherlands; Switzerland	Single subject design	5	Non-Progressive	N = 36	20 CVA (Left) 16 Normal	Therapy	Researcher
10	Rautakoski (2011)	Finland	Experimental-baseline and intervention	5	Non-Progressive	N = 38	38 CVA (Left)	Therapy	Life partner
11	Sekine and Rose (2013)	UK Australia; Japan	Experimental comparison with control group	5	Non-Progressive	N = 162	98 CVA (Left) 64 Normal	Therapy	SLT

(Continues)

TABLE 2 (Continued)

	Descriptive information: Study					Population: Participants			Population: Partners
No	Author	Country	Research design	MMAT rating (Score out of 5)	Progressive/ Non-progressive	Participants	Aetiology	Context/setting	Communication partner
Qualitative design									
12	Cocks et al. (2007)	UK & Australia	Multiple single-case study design	5	Non-Progressive	N = 24	19 Normal 5 CVA (Right)	Community; support groups; hospital	Researcher
13	García et al. (2000)	USA	Opinion piece	0	Both	N = 4	3 CVA (Left) 1 ALS*****	Not specified	Researcher
14	Herrmann et al. (1988)	Germany	Interviews	5	Non-Progressive	N = 7	7 CVA (Left)	Therapy	Relative or close friend
15	Lanyon and Rose (2009)	Australia	Naturalistic observation	5	Non-Progressive	N = 18	18 CVA (Left)	Therapy	Researcher
16	Rhys (2005)	UK	Single case study	5	Non-Progressive	N = 1	1 CVA (Left)	Therapy	Student
17	Uruma et al. (2007)	Japan	Case study	5	Non-Progressive	N = 1	1 CVA (Left)	Hospital	Researcher
Partner-centred communication									
18	Rose et al. (2017)	Australia; UK	Observation	5	Non-Progressive	N = 67 students	11 CVA (Left)	Therapy	Researcher

Note: *USA = United States of America.
**UK = United Kingdom.
***CVA = Cerebrovascular Accident.
****TBI = Traumatic Brain Injury, *****ALS = Amyotrophic Lateral Sclerosis.
#SLT = Speech-Language Therapist.

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TABLE 3 Types of unaided communication behaviour

Type of unaided communication behaviour	Meaning	Characteristics or examples	Studies
Non-linguistic unaided communication			
Eye movements	Using eye movement to communicate.	Eye blinking; eye gaze; prolonged eye closure; referential gaze to person's face, object or elsewhere; weeping eyes; closing eyes tightly; opening/slight opening of eyes; visual pursuit; gaze withdrawn; gaze returned	4, 10, 14, 16
Facial expressions	Using the face to communicate/ to indicate a thought or an emotion.	*Positive* – smile; blowing a kiss; winking; lip puckering *Neutral* – eyebrow raise, posed or spontaneous; licking lips; scratching chin; scratching nose; relaxed face; open mouth; chewing; finger in mouth; chewing thumb *Negative* – crying; frowning; levator contraction or cheek tightening; poking out tongue; not opening mouth for feeding; biting lower lip; clenching teeth; wincing; grimacing	1, 10, 12, 13, 14, 15, 18
Gestures			2, 3, 4, 5, 6, 7, 8, 9, 11, 12, 14, 15, 16, 17, 18
Head and neck movement	Moving the head and neck to communicate.	Nodding head; shaking head; lifting head of bed; slow turn; moving head side to side; rubbing head on bed; turning head to one side (left or right)	
Pantomime gestures (miming)	Actions of a complex concrete, sequential nature that are used to describe a construct and can be interpretated in isolation – substituting verbal utterances. These gestures include body parts that can be used as objects.	Walking that refers to forward movement of hand with alternating extension and flexion of index and middle finger Drawing a vertical rectangle to indicate air or holding an imaginary remote	
Metaphoric gesture	Presenting an image of an abstract concept, such as knowledge or justice.	Two fists bouncing against each other can refer to "clashing arguments" in a heated discussion Tilting the horizontal hand from side to side to indicate equivocation	
Pointing	Deictic	Pointing to self, a location on the body or pointing to a referent in physical environment.	Pointing to referents, to their arm or to something on the table Pointing to distant referents, for instance, to the wall to indicate the neighbours or something outside Pointing to abstract referents, for instance to the sky to refer to "heaven"

(Continues)

TABLE 3 (Continued)

Type of unaided communication behaviour	Meaning	Characteristics or examples	Studies
Referential gesture	Assigning an entity of referents, such as objects, places or characters in the story.		
Beat gestures	Movements that do not present a discernible meaning are recognised by prototypical repetitive movements and following speech intonation patterns.	Touching nose during conversation	
Emblem gestures	Hand movements that go simultaneously with the rhythm of speech, used for emphasis and to accentuate syllables or words.	Thumbs-up gesture in the Dutch and English culture Thumb and pointer finger making a circle shape for "OK"	
Non-communicative gestures	These gestures do not indicate communication intent but the motor execution of activities.	Fidgeting: repetitive movements involving self-touch but not grooming of body Grooming: grooming the body and changing the body's position	
Reflexive behaviour	These behaviours are automatic and reflexive motor movements of the body.	Muscle tension or compliance; rising temperature; sweating; heartbeat; heart rate; flexing and deflating muscles; absence of movement; restlessness; flexion;, flushing; tactile and olfactory response; opening mouth;, removes feeding tube; squeezing hand; shrugging shoulders; shaking body; leaning forward; clasping/shaking hands; leaning on partner; feeling collar; slow cautious movement; repetitive movement; attempting to reach pain site; touching pain site; guarding oneself from the caregiver; massaging pain site; pulling tube; defensive grabbing; cooperative movement; attempting to return to supine; clenching fist; slapping nurse's hand away; rubbing knees	9, 10, 12, 13
Vocalisations	These vocalisations are voiced or voiceless utterances that are not considered as words.	Laughing; yawning; clearing throat; heavy breathing; producing high-pitch sound; growling; clicking tongue; sighing; singing; tutting; moaning; intonation (pitch and prosody); coughing; mouthing (voiceless vocalisation)	9, 12, 13, 18

(Continues)

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TABLE 3 (Continued)

Type of unaided communication behaviour	Meaning	Characteristics or examples	Studies
Linguistic unaided communication			
Gestures			
Iconic gestures (symbolic, meaning-laden, speech focused and codified)	These are hand gestures that have semantic content closely related to speech production. The gestures can be used for word retrieval. They are context specific and support speech production. They are combined with natural speech and cannot be interpreted in isolation.	The iconic gesture of pretending to drink is similar to the real activity of drinking Swinging arms back and forth could indicate running Tracing index finger in the frontal space from left to right to indicate running Imitating the action of throwing a ball Pointing index finger upwards and making a circular movement upwards to indicate going up the stairs Moving lips without producing sound and moving hand back and forth in front of mouth to indicate one cannot speak	In above mentioned studies
Finger spelling	Time	Spatial indication to denote a time, such as past or future.	Indicating the past (back of the body) or the future (front of the body)
Letter	Movements associated with writing letters.	Writing letters in the air or on the desk/thigh with an empty hand or fingers	
Number	Using one's fingers to display numbers.	Displaying numbers by showing the fingers	

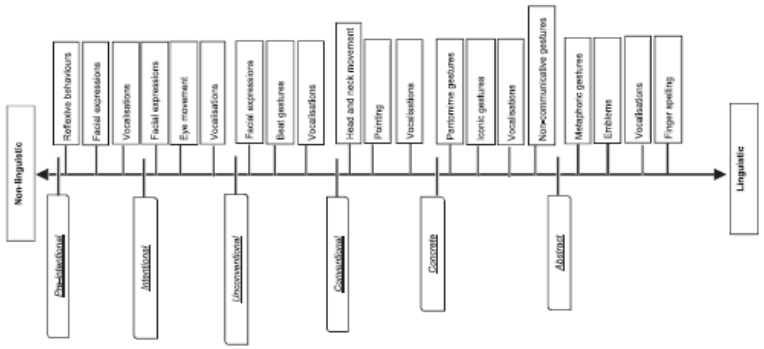

FIGURE 2 Continuum of unaided communication behaviours

communication functions served by these behaviours (see Table 4).

Descriptive information on the studies that were included

The methodologies used in the 18 studies included 13 quantitative (72%) and five qualitative (28%) studies. Most of the quantitative designs comprised experimental comparisons with a control group (n = 7), while the qualitative designs were case studies (n = 3). Geographically, 6 of the studies (33%) were conducted solely by or in collaboration with researchers from the USA, 28% (n = 5) were situated in Australia, 17% (n = 3) in Germany, 28% (n = 5) in the UK and 28% (n = 5) were carried out in collaboration with or solely in other countries. The descriptive quality met in the studies ranged from 0 to 5. Most studies (n = 18; 13-quantitative and 5-qualitative) obtained a 5 which indicated 100% descriptive quality, with 3 studies obtaining a score of 80%, 1 study obtaining a score of 60% and 1 study obtained a score of 0 due to the nature of the study (i.e. literature review).

Population: adults with CVA and little or no functional speech

In total, 18 studies reported on patients diagnosed with CVA and little or no functional speech.

Most participants were recruited from therapeutic and research settings (e.g. community or support groups) (n = 11). The therapy context was followed by studies in a hospital setting (n = 4) and at the participant's home (n = 2), and the remaining studies were not specified (n = 1). All 18 studies targeted communication during activities of daily living such as feeding or natural communication.

Population: communication partners

In 11 (n = 61%) of the person-centred communication studies (i.e. studies that focused on the person with a CVA and little or no functional speech and their communication partner) the researchers acted as communication partners. The researchers were mostly healthcare practitioners from various disciplines (e.g. speech-language therapists (SLTs), nurses, psychologists or medical specialists. In three studies, trained partners (17%) acted as the communication partners (e.g. nurses, SLTs, students and others). Only four studies included untrained partners, and these were life partners/spouses and relatives (22%). Partner-centred communication studies referred to those studies in which the focus was on the partner relaying information regarding the unaided communication of persons with CVA and little or no functional speech (n = 1).

Unaided communication behaviours

Figure 2 illustrates that unaided communication behaviours were plotted onto a continuum with non-linguistic and linguistic systems as the two anchor points (Beukelman & Light, 2020; Bornman & Tönsing, 2019). The different types of unaided communication behaviour were further delineated according to the seven levels of communication described in the communication matrix of Rowland (2011). Table 3 shows that different types of gestures (n = 15) were described most frequently, followed by facial expressions (n = 7), reflexive behaviours (n = 4), eye movements (n = 4) and vocalisations (n = 4). The gestures mostly involved use of the upper limbs – specifically the hands, arms and shoulders – followed by the head and the lower limbs, specifically the leg and foot.

Communication functions

Communication functions refer to the vocal, verbal and gestural intent or purpose of an individual's message (Austin, 2013; Beukelman & Light, 2020). For the purpose of this paper, communication functions were classified according to the communication function categories in Rowland's (2011) communication matrix. This Matrix indicates how the four basic communication functions, namely refusal (declining the options), obtaining (acquiring what is desired), social engagement (engaging in social interaction) and information (providing and seeking information) are linked to the seven levels of communication functions (Rowland, 2011).

In the 18 studies included, a total of 31 different communication functions were identified that were conveyed using unaided forms of communication. Level 1 (pre-intentional communication) included three communication functions classified according to three communication function categories – specifically social engagement (n = 1), obtain (n = 1) and refuse (n = 1). The second level (intentional behaviour) included two communication function categories, namely social engagement (n = 1) and obtain (n = 1). For instance, the ability to convey affect or emotions was mentioned in seven studies. Communication functions in Level 3 (unconventional communication) focused on expressing wants and needs (n = 3), using unaided communication for basic or beginning communication support (n = 4) and for comprehending messages (n = 3).

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TABLE 4 Communication functions

Communication level according to communication matrix	Communication function according to communication matrix	Nr	Label	Definition	Studies
Level 1: Pre-intentional behaviour	Social	1	Searching behaviour	Searching for a person or object in the environment.	15
	Obtain	2	Expressing components related to physical functioning	Communication regarding the physical functioning of the person.	10, 15
	Refuse	3	Expressing pain/discomfort	Physiological expression of pain.	10, 13, 15
Level 2: Intentional behaviour	Social	4	Drawing attention	Focusing the communication partner's attention on a specific object, person or event.	3
	Obtain	5	Expressing affect	This refers to the individual's ability to communicate positive or negative emotions and feelings (e.g., happy, sad, anger, fear)	1, 2, 3, 9, 15, 18
Level 3: Unconventional communication	Obtain	6	Comprehending messages (basic)	Understanding the intent of a message produced by a communication partner.	11, 12, 14
		7	Choice making	Conveying personal preferences to the communication partner.	5, 11
		8	Expressing wants and needs (basic)	Expressing wants and needs.	4, 12, 15
		9	Basic or beginning communication support	Using unaided communication to represent basic messages.	4, 5, 12, 15
Level 4: Conventional communication	Social	10	Greeting	Following social etiquette rules such as saying "hello" or "goodbye".	1, 3, 15
		11	Engagement in interaction	Attending to the communication partner through active listening and body engagement.	1, 5
		12	Turn taking	Reciprocity of turns with communication partners.	1, 10, 16
	Information	13	Functional use of objects	Knowing the function of an object e.g., using a comb.	5, 7, 15
	Obtain	14	Requesting information by asking questions	Requiring the communication partner to provide more information.	1, 4, 15
		15	Responding (basic)	This refers to a voluntary response to a communication partner's initiation to communicate.	1, 2, 3, 4, 5, 8, 10, 12, 14, 15

(Continues)

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TABLE 4 (Continued)

Communication level according to communication matrix	Communication function according to communication matrix	Nr	Label	Definition	Studies
Level 5: Concrete communication	Social	16	Imitation	Imitating an action, object or person.	5, 11
	Information	17	Naming	Labelling an object, person or event in the person's environment.	7, 16
		18	Commenting	Providing comments during the conversation.	1
		19	Answering questions	Responding to the communication partner's questions (yes/no or general).	1, 2, 3
	Obtain	20	Requesting a turn	When the person with an acquired neurological injury initiates the interaction or requests to take part in the conversation.	16
		21	Requesting participation	When the person with an acquired neurological injury is requesting reciprocal interaction from a communication partner.	3, 15, 16
Level 6: Abstract communication	Information	22	Providing clarification	Elaborating or providing more information based on the communication partner's request.	1, 4
		23	Describing	Describing an object, event or person to the communication partner.	5
	Social	24	Modelling	Demonstrating what is required of the communication partner.	3, 5
Level 7: Linguistic	Information	25	Narrative	Telling a story.	1, 2, 3, 6, 11, 14, 17
	Refuse	26	Arguing	Debating the point of view of the person with an acquired neurological injury.	1
	Social	27	Leading the conversation	Leading the conversation by discussing topics related to the concerns or interests of the person with an acquired neurological injury.	3, 16
		28	Observing social etiquette	Using words that are socially appropriate or inappropriate.	1

(Continues)

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TABLE 4 (Continued)

Communication level according to communication matrix	Communication function according to communication matrix	Nr	Label	Definition	Studies
		29	Termination	When the person with an acquired neurological injury withdraws from the conversation.	16
		30	Interrupting	The person with an acquired neurological injury interrupts the conversation to provide their point of view.	1
	Obtain	31	Conversational pause	The speaker takes a rest, hesitates, or temporarily stops.	16

Level 4 (conventional communication) included six communication functions categorised according to three communication function categories, namely social engagement (n = 3), obtain (n = 2) and information (n = 1). The conventional communication function mentioned in the majority of the studies was responding (n = 10). Communication function categories included in Level 5 (concrete communication) referred to social engagement (n = 1), information (n = 3) and obtain (n = 2). The second-last level (Level 6 – abstract communication) included the information (n = 2) and social engagement categories (n = 1). Lastly, Level 7 (linguistic communication) was the only level that included all four categories of communication functions – social engagement (n = 4), information (n = 1), refuse (n = 1) and obtain (n = 1). The communication function mentioned most in Level 7 was narratives (n = 7).

DISCUSSION

Research shows that persons with severe CVA often experience communication difficulties during interaction (Beukelman et al., 2015). Typically, a functional means of communication is recovered within the first year after the incident but severe communication difficulties remain longer for some persons with CVA (Godecke et al., 2021). Due to the pervasiveness of a severe communication disorder, a person's autonomy, engagement, satisfaction, safety and overall communicative effectiveness are affected, which in turn results in limited participation in activities of daily living within their communities (Baylor et al., 2019).

These communication challenges can also extend to the communication partner. Communication partners are often aware of the person-partner/ sender-receiver communication challenges and recognise that persons with severe CVA require an effective means of communication (Baylor et al., 2019). Alas, partners often misinterpret the person's communication intent or fail to respond appropriately to communication attempts, due to the subtle nature of these behaviours (Ellis & Astell, 2017). Moreover, for effective communication to transpire, mutual engagement is required. Partners should also identify the intent, motivation and willingness of the person with a severe CVA to participate in communication, in other words to identify the functions of communication.

In the current study, most of the communication functions that were identified focused on the social category of the Communication Matrix (Rowland, 2011). This included components such as producing narratives, leading the conversation and using communication intent. The other communication category that contained numerous communication functions was the obtain category, which included expressing affect or emotions, using unaided communication behaviours to aid the comprehension of

messages or instructions, and providing a communication support for verbal interaction. These findings are supported by Beukelman and Light (2020) who suggest that communication has a social purpose and is used to regulate the behaviour of a partner or to obtain something desired from them.

However, regulating the behaviour of a partner may be challenging if they have limited knowledge or skills and struggle to identify subtle communication attempts made by the persons with severe CVA and little or no functional speech (Hogrefe et al., 2012). This shortcoming can be addressed by training communication partners to be sensitive to subtle communication attempts and by allowing them to reinforce such behaviours (Rowland, 2011). If the partners can be trained to identify the means and functions of communication, they can engage with the person with a severe CVA in an attempt to co-construct meaning (Glize et al., 2017; Simmons-Mackie et al., 2010 and 2016).

This training may create opportunities for persons with severe CVA to also be active partners during interaction (Finkel et al., 2018). Thus, it should include not only well-known unaided communication behaviours such as eye movement, facial expressions (Blonder et al., 1993) and gestures (for instance sign language), but also less common unaided communication behaviours identified through this study (such as reflexive behaviour). This scoping review supports the notion that unaided communication behaviours occur on a continuum and the acquisition thereof is a process that occurs at various stages (e.g. waking up from a coma and expressing needs and wants) (Rasmus et al., 2019; Rowland, 2011). This suggests that when a developmental approach is followed, the acquisition of unaided communication behaviours occurs prior to verbal communication. However, the person with a severe CVA and little or no functional speech may still access a range of unaided communication behaviours after some verbal communication has been attained (Rasmus et al., 2019; Rowland, 2011).

Accessing a range of unaided communication behaviours may be utilised to successfully influence the social environment (Rowland, 2011). To achieve this, the individual's communication behaviour may include unintentional, pre-intentional and intentional communication functions (see Table 4) (Austin, 2013; Rowland, 2011). However, the progression from unintentional to intentional communication functions can only occur during interaction with and reinforcement of behaviour by communication partners (Austin, 2013; Rasmus et al., 2019; Rowland, 2011). Therefore, for persons with severe CVA and little or no functional speech to progress to intentional communication, partners need to understand and identify the various communication functions that can be accessed through unaided communication behaviours. Unaided communication behaviours may appear limiting at first glance (Ten Hoorn et al., 2016), but this review emphasises the fact that they can be used to access a range of communication functions – from indicating responsiveness to playing an active role during communication.

To access various communication functions, partners should be alerted to the fact that unaided behaviour is often ambiguous and complex (Holt et al., 2012; Lin et al., 2010; Rasmus et al., 2019). Due to the mind-body connection, behaviour does not occur randomly but may instead be determined by thoughts, feelings and experiences (Holt et al., 2012). Therefore, the interpretation of these behaviours cannot rely solely on the personal perspective, knowledge and beliefs of communication partners (Lin et al., 2010). Interpreting unaided communication behaviours requires attention, motivation and time if it is to occur effortlessly and accurately (Lin et al., 2010). Partners need to be trained to identify and reinforce the communication behaviours of persons with severe CVA, as these may influence partner expectations and thoughts and may also bring about positive partner behaviour modification (Holt et al., 2012).

Positive behaviour modification of partners can only occur when the partners are willing to accommodate persons with severe CVA and little or no functional speech. If this accommodation occurs, partners will have greater knowledge of communication strategies that may facilitate the building of mutual trust and the creation of reciprocal understanding during person-partner communication (Watson et al., 2012).

The training of partners on unaided communication behaviour holds benefit for the partner as well as for the person with a severe CVA, as both members of the person-partner dyad may experience enhanced perceptions of personhood and quality of life (Watson et al., 2012). Furthermore, persons with severe CVA may experience greater success during interaction with a trained partner, which may lead to increased communication autonomy, engagement and quality of interaction. This may ultimately also have a positive impact on the quality of life of both partners (Hogrefe et al., 2012).

LIMITATIONS OF THE SCOPING REVIEW

This review did not include studies on aided AAC (e.g. speech-generating devices or communication boards) or on unaided access to high-tech AAC (e.g. brain/computer interfaces). It focused solely on the use of unaided communication. Studies on unaided communication used by partners were also excluded, as the main focus was on the person with a severe CVA and little or no functional

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speech and did not include persons with other aetiologies using unaided forms of communication. The only partner studies that were included focused on partners relaying information regarding the affected person's use of unaided communication behaviours. Moreover, these studies typically included researchers or healthcare practitioners rather than informal or natural partners in the communication partner role, which may negatively impact clinical practice.

Another limitation may be that the review was confined to studies published in English and also did not include studies conducted prior to 1986. This date was selected because the first taxonomy of unaided and aided AAC had been suggested by Lloyd and Fuller in 1986. Studies that were included focused on the adult population (18 years and older) with specific medical diagnoses related to severe CVA. The review did not include studies on adults with developmental disabilities (e.g. cerebral palsy or autism spectrum disorder). Since its aim was to provide descriptive information on the various unaided communication methods, the review included grey literature, and hence quality appraisal of studies was not performed for inclusion and exclusion purposes but rather to describe the studies. This focus was decided on due to the limited availability of relevant research and the specific communication functions addressed by unaided communication behaviours.

CONCLUSION

The scoping review attempted to summarise the various unaided communication behaviours available in the literature and emphasised the importance of partner awareness of these behaviours. Since unaided communication behaviours could be subtle and easily be overlooked or misinterpreted, partner training was required to improve the quality of person-partner communication. Furthermore, unaided communication strategies were used to target a wide range of communication functions – from indicating an initial awareness and alertness to being an active participant in communication. For both communication partners to act as equal and active participants during interaction, partners should reinforce unaided communication behaviours to access a range of communication functions. This study also emphasises the role of the SLT's as previously limited focus was placed on this population with severe communication difficulties due to their limited lifespan. However, persons affected by severe CVA's have an increased lifespan due to medical advances and therefore their quality of life should be considered. Due to the effect of communication on quality of life the role of the SLT's has expanded to include not only improving their own knowledge of communication in severe CVA but also training communication partners on these strategies. SLT's make a critical difference to this population – without access to key services, persons with severe CVA are at a lifelong disadvantage for meeting their basic communication needs and rights (International Communication Project, n.d.).

RECOMMENDATIONS

Studies identified in this review mostly targeted researchers and healthcare practitioners as communication partners, with the result that the primary partners were often overlooked. Future research should include these partners (both paid and unpaid). Even though various aided methods of communication are available, many countries still have limited access to these communication supports and struggle with additional contextual, linguistic and cultural barriers. Future research should therefore target all of these partner populations (researchers, healthcare practitioners and primary partners) as suitable training could enhance their knowledge of unaided communication. It may also enhance partners' insight into the different communication functions addressed by these behaviours, resulting in the increased communication competence of persons with severe CVA and little or no functional speech.

ACKNOWLEDGEMENTS

We would like to thank Isabel Claassen for providing the language editing for this article.

ROLE OF THE FUNDING SOURCE

The authors have no sources of funding to declare.

CONFLICT OF INTEREST

There is no conflict of interest to report.

AVAILABILITY

No data is available.

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How to cite this article: Kuyler, A., Johnson, E. & Bornman, J. (2021) Unaided communication behaviours displayed by adults with severe cerebrovascular accidents and little or no functional speech: A scoping review. *International Journal of Language & Communication Disorders*, 1–19. https://doi.org/10.1111/1460-6984.12691

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ARTICE DOI:	10.1080/17549507.2022.2096926
AUTHOR(S):	Arine' Kuyler, Ensa Johnson, Juan Bornman
JOURNAL TITLE ('Journal'):	International Journal of Speech-Language Pathology
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International Journal of Speech-Language Pathology

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Multimodal communication reported by familiar caregivers to build communication capacity in persons who are minimally conscious

Ariné Kuyler, Ensa Johnson & Juan Bornman

To cite this article: Ariné Kuyler, Ensa Johnson & Juan Bornman (2022): Multimodal communication reported by familiar caregivers to build communication capacity in persons who are minimally conscious, International Journal of Speech-Language Pathology, DOI: 10.1080/17549507.2022.2096926

To link to this article: https://doi.org/10.1080/17549507.2022.2096926

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Multimodal communication reported by familiar caregivers to build communication capacity in persons who are minimally conscious

ARINÉ KUYLER, ENSA JOHNSON AND JUAN BORNMAN

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Abstract

Purpose: Limited clinical and research evidence is available to support healthcare practitioners in the communication assessment and intervention of persons who are minimally conscious. This study placed a specific focus on the multimodal communication strategies familiar caregivers of persons who are minimally conscious observed, as well as the verbal and the nonverbal communication strategies they employed to build communication capacity. This may inform clinical practice as it provides valuable autobiographical information as well as familiar stimuli that may elicit responses from persons in a minimally conscious state.
Method: A descriptive qualitative design employing in-depth semi-structured interviews with familiar caregivers was utilised to address the purpose of the study.
Result: Familiar caregivers reported that they used both nonverbal and verbal communication strategies to obtain a response from persons who are minimally conscious. These caregivers also reported that these persons appeared to rely on nonverbal communication strategies to express 36 different communication functions.
Conclusion: Based on the findings of this study, it is clear that caregivers can be beneficial to persons who are minimally conscious, if they are able to observe and capitalise on naturally occurring multimodal communication strategies and functions. This study emphasises that familiar caregivers respect and value the dignity of persons who are minimally conscious and want to improve their communication capacity, but often lack confidence in their own communication skills.

Keywords: *caregiver; familiar caregiver; minimally conscious; non-verbal communication strategies; multimodal communication*

Introduction

Disorders of consciousness (DOC) progress on a continuum from a coma to an unresponsive wakefulness syndrome and finally to a minimally conscious state (MCS), before being regarded as wakeful and alert (Martens, Bodien, Sheau, Christoforou, & Giacino, 2020). Persons with MCS present with fluctuating but reproducible signs of awareness and communication, including inconsistent following of commands and expressing limited intelligible speech (Lancioni, Singh, O'Reilly, Sigafoos, & Desideri, 2021). Such individuals can be divided into two groups, namely persons with MCS+ (those who present with steady behavioural responses and who can follow simple directions and answer yes/no questions) and persons with MCS- (those who present with low level behavioural responses, who give emotional responses to affective stimuli and can locate stimuli) (Rasmus, Góral-Półrola, Orłowska, Wilkość-Dębczyńska, & Grzywniak, 2019).

Behavioural assessment and stimulation are widely regarded as the gold standard to assess the level of consciousness (such as wakefulness, self- and environmental awareness) in these persons. Assessment and stimulation can include behavioural (multi-sensory stimulation, environmental stimulation, and music) and non-behavioural (pharmacological agents [amantadine], transcranial direct current stimulation, repetitive transcranial magnetic stimulation, and brain computer interfaces) strategies to support optimal arousal (wakefulness, self- and environmental awareness) (Lancioni et al., 2021).

Despite the valuable information that healthcare practitioners could obtain regarding a person's level of consciousness through the evaluation of communication during behavioural assessment, a paucity of research evidence on nonverbal communication skills

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DOI: 10.1080/17549507.2022.2096926

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in these behavioural scales exists (Rasmus et al., 2019). Typically only eye contact, yes/no responses, and vocalisations are addressed, thus highlighting the necessity for a more comprehensive understanding of the different forms of nonverbal communication and its characteristics. Often, nonverbal communication can be subtle as well as ideosyncratic, and therefore healthcare practionioners who spend limited amounts of time with the person in a MCS might overlook these signs or misinterpret them. Familiar caregivers who spend extended amounts of time with these individuals might therefore be better positioned to observe and interpret nonverbal communication behaviours. This places familiar caregivers in a solid position to assist healthcare practitioners with the interpretation of nonverbal communciation

The word "communication" stems from the Latin word "*communicare*" and is defined as "to share" or "to impact" with the purpose of creating a shared meaning between the sender and the receiver of a message. To share meaning, language is typically required as it facilitates mutual understanding allowing communication to occur (Owens, 2016). The classic language model developed by Bloom and Lahey (1978) is effective for differentiating language form (i.e. the structure of language and includes phonology [sound units], morphology [prefixes and suffixes], and syntax [sentence structure], although this paper only focusses on the latter); language content (i.e. semantics, which refers to the meaning of messages), and language use (i.e. pragmatics, which refers to the social use of language). Pundole and Crawford (2018) reiterate that adjustments to language are often required when conducting a behavioural assessment to accurately determine the person's communication capacity. For example, adaptations could include simplifying the language stimuli that is used by reverting to less complex syntax and semantics. Research has shown that one of the signs of being in a minimally concious state (as opposed to being in a coma) is that these individuals are able to respond to verbal demands, despite the fact that they are unable to communicate functionally (Rasmus et al., 2019). During the MCS, these persons may also respond better to verbal instructions, and show a variety of emotional expression (signs of pain, anger, as well as smiling and even some vocalisations) when stimuli is presented by familiar caregivers (Van Erp et al., 2014). As a result, diagnostic accuracy (regarding both verbal and nonverbal communciation) is increased when healthcare practitioners involve familiar caregivers, who have spent extended periods of time with the person in a MCS, during assessment (Bruno et al., 2011).

However, when caregivers are first expected to interact with persons in a MCS, they might feel overwhelmed as familiar communication is now altered, placing new demands on them. For this reason, caregivers should be trained to not only listen for verbal communication attempts (i.e. which would more closely resemble their communication style prior to the person being in a MCS), but to also observe the smallest reactions of the person to environmental stimuli, as these could be indications of nonverbal communciation attempts (Pundole & Crawford, 2018). Creating this type of awareness of nonverbal communication attempts could also reduce the caregiver's initial anxiety around the loss of communication. Nonverbal communication could include using artefacts (physical objects in the environment familiar to the person), chronemics (increasing awareness and perception of time), haptics (using touch or reflexive behaviour such as fidgeting), kinesics (using eye movement, head, neck and body movement, gestures and sign language), proxemics (using space and distance to position the person), and vocalics (using vocalisations, which includes laughter, humming, singing as well as word approximations) (Keutchafo, Kerr, & Jarvis, 2020). Figure 1 includes a graphic representation of nonverbal and verbal communication.

Familiar caregivers should therefore preferably employ both verbal and nonverbal behaviour to support persons who are minimally conscious by eliciting communication as a form of enacting their human

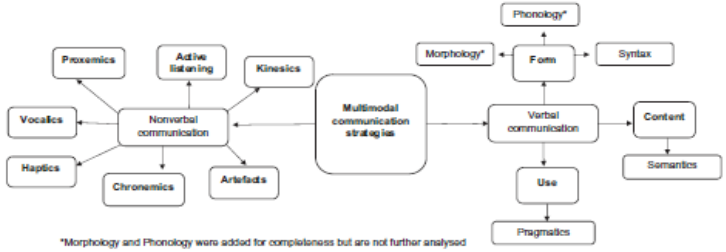

Figure 1. Classification of multimodal communication strategies conceptualised from Keutchafo et al., (2020) and Van Manen et al. (2021). *Morphology and phonology were added for completeness but are not further analysed.

rights and their need to communicate in order to have a voice in issues that affect them. However, these familiar caregivers can either be a facilitator or a barrier to participations as caregivers may lack knowledge, confidence, and skills to augment verbal communication with nonverbal communication to facilitate communication capacity in persons who are minimally conscious. The familiar caregiver may attempt interaction, but due to inconsistent responses from the person and missed subtle communication attempts, familiar caregivers may feel uncomfortable around persons who are minimally conscious (Cruice, Blom Johansson, Isaksen, & Horton, 2018). This may result in missed opportunities regarding interaction or for facilitating consistent responses in persons who are minimally conscious but who are starting to demonstrate environmental awareness (Pundole & Crawford, 2018).

Currently, there are limited data available that analyse the communication attempts of individuals in a minimally consious state as well as the strategies employed by their caregivers to elicit interaction. Therefore, this study aims to:

i. Identify the multimodal communication behaviours used by familiar caregivers of persons who are minimally conscious to facilitate interaction.
ii. Identify partner observations of the nonverbal responses that were noticed in persons who are minimally conscious.
iii. Include partner reports regarding perceived communication functions conveyed though the nonverbal communication responses of persons who are minimally conscious.

Method

Research design

A descriptive qualitative design employing in-depth, semi-structured interviews is used to address the main aim of this study while also allowing flexibility for participants to report on aspects which are important to them (Creswell & Creswell, 2018). As a result, participants felt that their voices were heard, which led them to have a sense of empowerment (Creswell & Creswell, 2018). The semi-structured interviews thus regarded the participants as the experts which allowed the development of a comprehensive picture of their communication with persons who are minimally conscious (Creswell & Creswell, 2018). The Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist was used to guide the reporting of the study methodology (Tong, Sainsbury, & Craig, 2007).

Participants

Recruitment and selection

Ethics approval was obtained from the research ethics committee of the relevant institution (HUM029/0720). Thereafter, the author (first author) contacted the practice manager of a private medical practice telephonically to request their participation in the study. The manager provided written permission and identified a nurse to assist with the identification and recruitment of participants, based on the specific selection criteria. Once potential participants had been identified, the nurse contacted them and informed them about the nature of the study and requested verbal consent to provide their contact details to the first author. Once written consent was given, a convenient time and date was arranged to conduct the interview (Janghorban, Roudsari, & Taghipour, 2014).

Sampling

Purposive sampling was used to identify potential participants from a private medical facility situated in the Gauteng province in South Africa which treats persons in a MCS due to diverse acquired neurological conditions. These conditions include diagnoses such as Dementia, severe Traumatic Brain Injury (TBI) and severe Cerebrovascular Accidents (CVA). Specific selection criteria were used to identify potential participants (Creswell & Creswell, 2018). All familiar caregivers had to: (1) be/have been actively involved in the care of the person who is/was minimally conscious for at least two months; (2) be older than 18 years themselves; (3) (have) fulfil(led) their caregiving role for at least two consecutive hours a day; and (4) be literate and proficient in English. Furthermore, a criterion was set that the person with the acquired neurological injury should have been in a MCS for at least two to six months prior to the interview. Familiar caregivers of both living and deceased persons who are or were minimally conscious were included in this study. This allowed the participants to self-reflect on the process, accessing their extensive knowledge and skills as well as give valuable advice to other familiar caregivers in similar situations, while not having the time pressure of still actively participating in caregiving activities. The familiar caregivers and persons in their care who were minimally conscious are described in Table I.

Table I illustrates that the familiar caregivers were all female whose ages ranged from 40- to 63 years old with an average age of 53.6 years. The familiar caregivers were all related to the persons with acquired neurological conditions and included four daughters, two wives and one mother.

Five participants were working full-time while also caring for the persons who were minimally conscious, while two participants were retired. Three of the familiar caregivers cared for relatives residing in advanced home care facilities and four of the familiar caregivers cared for the person at home. All seven caregivers cared for these minimally conscious persons daily, between 2 to 24 hours (daily average of 8.3 hours). As some of the caregivers had full-time jobs and had other responsibilities at home (caring

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Table I. Demographic information of participants (n = 7).

Familiar caregiver							Person who is minimally conscious				
Participant number	Age in years	Sex	Relationship to person	Home language	Additional language	Qualification	Duration of care (hours per day) received	Age in years	Sex	Reason for minimally conscious state	Duration of minimally conscious state
P1	63	F	Wife	E	A	Diploma	2	66	M	Abscesses on the brain	7.7 years
P2*	40	F	Daughter	E	A	Master's degree	2	69	F	CVA	2 years
P3	62	F	Mother	E	A	Diploma	24	31	M	TBI	5 years
P4*	54	F	Daughter	A	E	Diploma	2	80	M	Alzheimer's Disease	6 months
P5*	57	F	Daughter	E	A	Diploma	2	76	F	Alzheimer's Disease	4.5 years
P6*	54	F	Daughter	A	E	Diploma	2	83	M	Alzheimer's Disease	71 days
P7	45	F	Wife	A	E	Bachelor's Degree	24	41	M	TBI	1 year

F: female; E: English; A: Afrikaans; TBI: traumatic brain injury; CVA: cerebrovascular accident.
*Indicates that person who was minimally conscious was deceased.

for children, cooking etc.) this impacted the amount of time they had available daily to care for and visit their relative at the care facility. While other caregivers caring for the person at home spent more time caring for the person on a daily basis.

The diagnoses of MCS of the persons were diverse and included three with Dementia, two with severe TBI, one with a severe CVA and one with abscesses in the brain due to septicaemia.

Material

An interview script was developed based on information obtained from an earlier scoping review that focussed on the communication strategies used by persons with CVA with little to no functional speech (Kuyler, Johnson & Bornman, 2022). Both open- and closed-ended content-driven questions were used to obtain answers of a factual nature, but also include the participant's opinions, beliefs and judgements (Creswell & Creswell, 2018). Probing techniques as well as recasting questions were used to obtain additional information or to accommodate for the misunderstanding of questions (Josselson, 2013).

Ethical considerations

This study aimed to respect the autonomy of the participants through voluntary participation (Ketefian, 2015). Additionally, beneficence and non-maleficence were upheld as all procedures aimed to ensure that no harm came from participation in the study (Ketefian, 2015). Due to the nature of the information conveyed during the interviews, participants at times became emotional. The researcher used supportive responses and gave participants time to recollect themselves before continuing with the interview questions. Justice was also upheld as an interview protocol was used to ensure that all participants were treated fairly and equally (Ketefian, 2015).

Procedures

Data collection procedures. Seven semi-structured in-depth interviews were conducted with familiar partners of persons who were minimally conscious (Creswell & Creswell, 2018). An interview script was used to guide the process. Interviews were specifically selected as opposed to alternative measures such as observations, as literature indicates that familiar caregivers who spend extensive periods of time with persons in a MCS are able to offer in-depth information of their behaviour as opposed to healthcare practitioners who typically spend shorter periods of time during assessment. Furthermore, clinical data has shown that a greater variety of behaviours are seen in the presence of familiar caregivers (Lancioni et al., 2013). Four interviews were conducted virtually using Google Meet and three were conducted face-to-face. This was done depending on participant preference, as data were collected during different levels

of lockdown during the Covid-19 pandemic. Google Meet was selected as it is a free platform suited to conduct synchronous online interviews, allowing the reach of a wider sample not precluded by time, locations and social barriers in a feasible and convenient manner.

The Google Meet online application allowed for audio recordings and the face-to-face interviews were also audio recorded. The duration of the semistructured interviews ranged from 29 to 90 minutes with a mean time of 54 minutes. Although the author confirmed with the participants that they were correctly understood throughout the online interview to ensure that the findings are trustworthy, formal member checking was done with each of the participants once the recorded interviews had been transcribed by the first author (Josselson, 2013). All participants confirmed the correctness of the transcripts.

Data analysis. Upon receiving feedback from the participants, a qualitative content analysis consisting of three phases, namely: immersion; reduction; and interpretation was used to analyse the data (Braun & Clarke, 2021). During immersion, the authors independently engaged with data in order to obtain a holistic view. The immersion phase served as a motivation for the author to reread the transcripts and relisten the audio-recordings to gain a deeper understanding of the participants perspectives (Braun & Clarke, 2021). This phase concluded with the authors identifying preliminary codes (Forman & Damschroder, 2007) and was followed by the reduction phase which included a systematic approach that was initiated by reducing the amount of raw data to only include relevant information which addressed the aim of the research. Thereafter, the data were fragmented into manageable codes (e.g. facial expressions), then reorganised into themes (e.g. nonverbal communication) and sub-themes (e.g. kinesics) to address the aims of the research (Forman & Damschroder, 2007). Codes provided a means to exhaustively identify and retrieve data from the transcripts (Forman & Damschroder, 2007). The first and second author coded information independently during the first two phases, after which a meeting was scheduled to compare codes and to collectively complete phase 3. During this meeting the first two authors collaborated and developed inductive codes (to address sub-aim i and ii).

To address sub-aim iii, the first two authors met and used deductive coding based on a pre-existing codebook which was developed from an earlier scoping review (Kuyler, Johnson, & Bornman, 2022) and included definitions for codes such as the recovery of consciousness, intent to communicate and initiate interaction. The communication functions were analysed according to the seven levels and categories mentioned in the Communication Matrix (Rowland, 2011).

The final data analysis phase focussed on interpretation and included the reorganisation and re-assembly of the codes into themes and sub-themes to promote a coherent and revised understanding or explanation (Forman & Damschroder, 2007). The findings thus provide evidence of the identified themes by reporting compelling examples and relating these themes to the aims of the research.

Trustworthiness

The trustworthiness of the studies was sought to be enhanced in several ways. Credibility (i.e. data that truthfully represents the study population) (Sarvimaki, 2018) was increased through member checking to ensure that the findings were accurate and reflective of the participant's experiences (Josselson, 2013). Minimal clarification or additions were needed as participants agreed that the transcripts reflected their answers. Furthermore, an interview script was used to ensure consistency. The second and third author provided peer debriefing to the first author in order to give an external review of the research process and to increase referential adequacy (Nowell, Norris, White, & Moules, 2017). Transferability (i.e. applicability of information representative of a larger population) (Sarvimaki, 2018) was enhanced by thick and rich descriptions provided by the heterogenous participants who described different settings (e.g. home care and care facilities). Conformability (i.e. clarity of data collection procedures and documentation) (Sarvimaki, 2018) was addressed by employing field notes, audio-recordings and an interview script, small group discussions and author consensus during coding to ensure that personal bias and possible assumptions were addressed as to not influence findings.

Result

Findings are set out in three sections according to the sub-aims of the study.

Communication strategies used by familiar caregivers

Familiar caregivers used multimodal communication (including both verbal and nonverbal strategies) when communicating with persons who are minimally conscious, as shown in Table II.

Nonverbal communication strategies

Nonverbal communication strategies included modalities such as kinesics, active listening, proxemics, vocalics, haptics, chronemics, and artefacts, as was unpacked in Figure 1 (Keutchafo et al., 2020). Kinesics was mentioned by three participants and included facial expressions (*"We used to smile at my dad" [P6]*), expressing positive affect and using body language to facilitate conversation. Facilitative body language included the caregivers facing the person,

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Table II. Multimodal communication strategies used by familiar caregivers.

Theme	Sub-theme	Codes	Examples of verbatim quotations from participants with participant numbers
Nonverbal Communication	Kinesics (i.e. body movement)	Facial expressions	We used to smile at my dad. (*My dad couldn't speak but he would try to joke with gestures*)(P6)
		Body language	Body language is important when you communicate with them (P7).
	Active listening (silences)	Using expectant delay	If you couldn't understand what she said you would observe her to try and understand what she wanted (P2).
	Proxemics (i.e. distance and space)	Presence of familiar persons	We would sit around her bed/wheelchair and talk to her (P2). If she didn't respond we would talk around her (P2, P6). We used to organise family functions at our home to ensure that they interact with the family (P4, P5, P6). The whole family would go and visit him at the care facility (P7). We used to organise outings with the family to a tea garden and take him with us (P3).
		Fellow persons in the facility	He would share a room with someone else and they would not talk to each other (P6). The other people would lay across from my husband and make a lot of noise (P1). The place where my mom was had a large room with many beds and so the other people at the care facility would often talk to my mom (P5).
		Positioning	They would often put her in the wheelchair or in an upright position in bed (P6). This made her respond better during interaction (P6). I would say that she/he responded better when she/he was upright as was more awake (P2, P3, P4, P5, P6, P7). It didn't really matter in which position we had him he was minimally conscious (P1).
	Vocalics (i.e. prosody)	Familiar voice	He recognised my voice. (*He would move his eyes and his eyes would light up* (P1)). I could see that he recognised my voice. (*You could see in his eyes that he was happy to see me* (P3)).
		Singing	My dad would sing to my mom (*She would smile at him*) (P2). I would sing to him to get his attention (P1). My daughter used to sing hymns to him and you could see that he relaxed (P4). I used to sing to my mom as she used to love singing. (*Later on as the disease progressed it was easy for her as it became automatic and she didn't have to remember the words)* (P5).
	Haptics (i.e. touch)	Orientation to touch	I kissed him to regain his attention (P1)…. and I pulled his ear to irritate him (P1).
		Affectionate touch	I held his hand to comfort him (P1). I touched him to let him know I am there (P1, P4).I used to hold his hand and then start to talk to him about my day (P4). I used to touch him to let him know I wanted to communicate with him (P3). I also touched him to reassure him (P1).
		Massage	I used to massage him from top to toe (P3). When I used to visit her, I would put cream on her skin while stretching her (P5). I used to put cream on her hands and she used to smell her hands afterwards (P5)
	Chronemics (i.e. time and communication behaviour)	Active engagement	I always engaged with him even though he didn't respond (P4). I would hold her/his hand and try to engage with her/him. (*My mom/dad would lay with her/his eyes closed*) (P1, P2, P6). I really wanted to engage with my son and I used to do my own speech therapy (P3). You have to talk to him even if you just tell them about your day even though they don't respond. (*Months after he finally regained his consciousness, he would mention things that I told him while he was in a minimally conscious state*) (P7).
		Personhood	I wanted to treat him as a person as he would do this for me if I was in the situation (P4). I was patient with her (P2, P5).

(*Continued*)

Table II. (*Continued*).

Theme	Sub-theme	Codes	Examples of verbatim quotations from participants with participant numbers
		Familiar activities	I used to let him assist in activities of daily living such as peeling potatoes to help him regain his independence (P6). It was about my husband and not me and I wanted to do my best for him (P1, P3). My mom really enjoyed eating and my dad really just wanted to please her and therefore gave her some treats (P2). My dad used to love to eat fruit and we always gave him some fruit (P6). I really wanted to do things for him that he enjoyed (P3, P4, P5).
		Activities of daily living	I used to help feed her, comb her hair and help her to drink tea (P5). I used to help my dad by washing his feet, cutting his toenails and putting cream on him (P4, P6).
		Communication opportunities	You need to create time to communicate with the person because there are various other things that take up your time during daily life (P7). You need to make time to spend with her (P2).
	Artefacts (i.e. physical and environmental objects)	*Physical objects (person specific):*	Communication aid I used a book to show photos or a picture of family and friends (P1, P2, P3). Phone (WhatsApp) I showed him videos and photos of where I went and I who I was talking to (P1) and I played voice messages of friends and his brother (P3). We would also do video calls on WhatsApp with familiar people such as relatives and friends (P2).
		Familiar environmental objects that facilitate responsiveness:	Television There was a television in the room to see if we could get a response from my son. (*He used to hate the television and got such a fright because of the light)* (P3). My husband was in a minimally conscious state and I used to put the television on as he used to love watching sports (e.g. rugby, cricket and Formula 1 racing) and I thought he would enjoy it (P1). My mom used to put on the television for my dad as it calmed him down. It was also something that he used to do with my mom while he was able to walk (P4). They would put the TV on to provide environmental stimulation to the patients. (*Nobody would be watching as everyone would just stare at each other)* (P5, P6). My mom wasn't interested in watching television she preferred interaction with people (P2). Music on radio Music was provided as a means of providing familiar environmental stimulation based on the preference of the person to facilitate responsiveness: (*My mom used to love the music of Vera*

(*Continued*)

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Table II. (*Continued*).

Theme	Sub-theme	Codes	Examples of verbatim quotations from participants with participant numbers
			Lynn) (P5). *(My dad loved country music and he would become very nostalgic when he heard Don Williams music)* (P4). *(My dad didn't really have a great appreciation for music)* (P6).
		Entertainment groups	Once a month there was a group of people who came to do activities with them for example playing music, holding birthday parties or just playing games with them (P5).
Verbal communication	Language content Semantics)	Discussion topics *Naturalistic everyday conversations*	I used to talk about what happened at home (P1, P3, P6) I told him/her about his/her friends that came to visit (P1, P3, P4) We used to talk about someone who is worried about him/her (P1–P7) The responsibility fell on me to tell him that his mother and my mother and father passed away (P1) I reassured him/her that I loved him/her and enjoyed being there (P1–P7) I also used to talk about everyday things (P1–P7) When talking to my mom I used to also mention the other people at the care facility (e.g. Did you see that lady's hair and did you notice that lady shouting? (P6)) I talked to my mom/dad about my children (P4, P5, P6, P7) Sharing familiar positive memories was very important to me (e.g. Do you still remember this and that ….? (P1–P7)).
		Environment	I explained to him what happened and how he ended up in the hospital (P7) I used to tell him his name and age, where he is, the time, day of the week and date. (P7) I would name all his body parts while massaging him (P3). I would tell him about the trees, flowers and how the lawn has gone green (P1). I used to talk to him about things in his environment that were familiar to him (P4). I would comment on her physical appearance (P5). I would talk about the terrace and the home where he obtained care (P6).
		Passing on	I know you are tired; we will be ok if you leave (P4). You don't need to hold on anymore (P4). I want you to rest (P4).
	Language form (Syntax)	Using simple subject-object-verb sentences	I used to use simple sentences to communicate with him for example I saw your brother today (P1–P7). I used to comment on how she looked e.g. Your hands are so dry today (P5). I used to inform him on how my week was, e.g. Yesterday, I went to the shop and I saw this person (P1). The language of communication was either English ($n = 4$) and Afrikaans ($n = 3$) when familiar caregivers spoke to the persons with acquired neurological disorders. Familiar caregivers used sound structure characteristics of these languages.
	Language use (pragmatics)	Anticipating communication	I used to guess what he wanted to say (P1). I used to guess what she wanted to say and only got it right half of the time (P2). She would get so frustrated when I couldn't guess what she wanted (P6). Sometimes I couldn't understand what he wanted and we would go around talking in circles (P4, P5, P7).
		Including person in interaction	I would always include him in conversations and prepare unfamiliar partners on communicating with him (P1). I used to include him in normal daily activities (e.g. taking him outside to eat lunch with us at home) (P3). I would invite my parents-in-law over for dinner to include my mom in family life (P2). We would braai at our home and he would be present during the interaction even though he didn't contribute we wanted to include him (P6).

(*Continued*)

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Table II. (*Continued*).

Theme	Sub-theme	Codes	Examples of verbatim quotations from participants with participant numbers
		Taking communication turns	I provided opportunities for him to communicate (P3). I just responded to what my dad was talking about at the time even when it didn't make sense (P4).
		Maintaining conversational topics	When my mom used to think I was her sister I used to just go with it (P5). Because you can't reason with her (P5).
	Communication functions	Social	• When I came into the room I used to greet him (P7) • I asked him/her yes/no questions (e.g. is your name … …) (P1–P7)
		Obtain	• I used to ask her/him about her/his basic needs and wants (e.g. what did you eat today) (P1–P7) • When I spoke to him/her I always provided choices (e.g. would you like to wear the red of blue shirt) (P1–P7)
		Information	• I always waited for him/her to confirm his/her answer (P1–P7) • I asked him if what he wanted to communicate is more important than the task I am busy with (P7). • I used to explain the procedure to him (e.g. I am going to change you, bath you, comb your hair etc.) (P7) • Asking easy everyday questions(P1–P7)

Note: Phonology and morphology are not included in this table as caregivers did not mention altering their spoken language in this way.

maintaining eye contact and nodding to indicate active listening and engagement (*"Body language is important when you communicate with them" [P7]*). Active listening was also mentioned by two participants who used expectant delay to actively facilitate listening behaviour.

All seven participants mentioned proxemics, which included being physically present, the physical presence of other familiar people in the persons care facility as well as positioning both persons in the dyad in such a way that it would facilitate communication (*"We used to organise outings with the family to a tea garden and take him with us" [P3]*). Moreover, all of the participants explained that positioning the person in an upright sitting position tended to increase their responsiveness during interaction.

The specific vocalics mentioned by participants were that upon hearing familiar voices the person would show increased responsiveness or attempt to locate the source of the voice. Another component associated with vocalics included the participant singing to the person who is minimally conscious (*"I would sing to him to get his attention" [P1]*).

Haptics (touch) was used to gain the persons attention (Orientation Touch), to provide comfort (Affectionate Touch) (*"I held his hand to comfort him" [P1]*) and also using massaging to prevent contractures through stretching.

Chronemics were mentioned by all seven of the participants and included showing an active interest or engagement when interacting with the person and acknowledgement of the person's personhood (*"I always engaged with him even though he didn't respond" [P4]*). Furthermore, all participants mentioned that they felt that treating the person with human dignity and valuing their livelihood was important. Five participants mentioned that they assisted the person in activities of daily living such as feeding, bathing, and grooming. Two participants mentioned that they wanted to perform familiar activities which increased the person's attentiveness or responsiveness (*"I used to help feed her, comb her hair and help her to drink tea" [P5]*). These experiences, however, required the two participants to create a specific time in their daily schedules to perform these activities.

Two types of artefacts, namely physical objects and environmental objects were mentioned by the participants. The physical objects were specific and familiar to the person who is minimally conscious and included a communication aid such as a book with photos of family and friends. Three participants mentioned using their mobile phones to show the person pictures or photos of loved ones, playing voice messages of familiar people and performing video calls on WhatsApp (*"We would also do video calls on WhatsApp with familiar people such as relatives and friends" [P2]*). However, although these three participants use these activities such as communication books and showing digital photos to the person, they

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mentioned that they lacked confidence when implementing these components as the person could not initially recall the people in the photo.

Six participants reported that familiar environmental objects such as a television increased responsiveness in persons who are minimally conscious. However, these participants reported that the persons had varying reactions to the television with one showing increased awareness, four remaining lethargic and one displaying a negative reaction (*"He became anxious due to the light of the television" [P3]*). One participant mentioned entertainment arranged for the person by outside volunteers. Two participants specifically referred to familiar music on the radio leading to increased responses in one person (*"My mom used to love the music of Vera Lynn" [P5]*), while the other person showed no interest in the music.

Verbal communication

Verbal communication (spoken language) was divided into language form, content and use as per the classification by Owens (2016). The linguistic form used by participants portrayed the first language of the participants, namely Afrikaans ($n = 3$) and English ($n = 4$). All of the participants used simple subject-object-verb sentences (e.g. syntax) and simple vocabulary which were scaffolded according to the perceived linguistic and cognitive level of the person who is minimally conscious. These simple sentences were used to convey familiar discussion topics (*"I told him/her about his/her friends that came to visit" [P1, P3, P4]*), with four of them attempting to create awareness of the person's environment by either conversing about the person's physical appearance or about familiar objects, such as a phone.

Due to the complex communication needs of the person who is minimally conscious, all seven participants mentioned that they wished they knew what the person wanted to communicate about. According to caregiver perceptions they often lacked confidence in their own communication attempts as they did not understand the person. They perceived themselves to anticipate what the person wanted with only 50% accuracy which led to increased frustration for both the person and the participant. Four participants mentioned that even though the person showed minimal responses in conversation, they still attempted to include them in the interaction (*"I would always include him in conversations and prepare unfamiliar caregivers on communicating with him" [P1]*). Only two participants mentioned that they attempted to create opportunities for the person to communicate and maintained the topic of conversation which they perceived the person had initiated. Five participants continued conversing with the person while performing stretching exercises or massaging the person.

Four participants felt that their questions remained unanswered – specifically whether the person was in pain, why the person did not laugh anymore or why they did not appear to have a desire to communicate. All seven participants assumed certain things they thought the person would want to communicate about. For example, that the person might want to tell them that they are doing okay, that they love them, that they miss their family and that they understood what was being said but that they did not know how to respond. One participant mentioned that she thinks the person would want to tell his family that he was mad at them for putting him in the care facility and that he wanted to put an end to his life. Another participant thought the person wanted to speak to the family and tell them that he did not have any news, whilst another participant mentioned that she thought that her husband wanted to know what happened to him, to ask her questions about the incident, to mention that nobody understands him, to understand why he is in the specific facility, and why he cannot talk as well as certain practical aspects such as what he had for breakfast.

Communication strategies used by persons who are minimally conscious

This section focusses on the information pertaining to the caregiver's perception of the nonverbal communication behaviours that the person who is minimally conscious displayed. Figure 2 includes a layout of the communication behaviours of persons who are minimally conscious as perceived by their caregivers.

The perceived communication behaviours of the persons who were minimally conscious were classified according to the communication strategies previously mentioned in Figure 1 (Keutchafo et al., 2020).

The kinesics category most commonly mentioned by all seven participants, included eye movement as a means to communicate. For example, participant 7 mentioned that her husband would use eye blinking to answer yes/no questions. The most prevalent eye movements observed by participants were prolonged gaze (*"My father would stare at me for a long time as if he wanted to ask for something"* [P6]) and prolonged eye closure (*"My son would close his eyes to tell me he wanted to be alone"* [P3]). These eye movements were followed by head, neck, and shoulder movements which consisted of nodding and shaking the head (*"My mom would nod her head to answer affirmative to questions"* [P2]). Gestures used by persons who are minimally conscious included using mostly the upper limbs (hand, arm, and shoulder) to point and tap (*"My dad would tap his finger to follow the rhythm of the music he liked"* [P4]) with the index finger and to squeeze the caregiver's hand. One participant also mentioned the use of sign language (*"My husband and I would use sign language to gossip about people"* [P7]). Facial expression as a component of kinesics was the least mentioned means of communications by participants, with only two participants mentioning that facial expression were used to express either positive or negative affect (e.g. crying) (*"My dad would get very emotional and cry when we played country music for him"* [P4]).

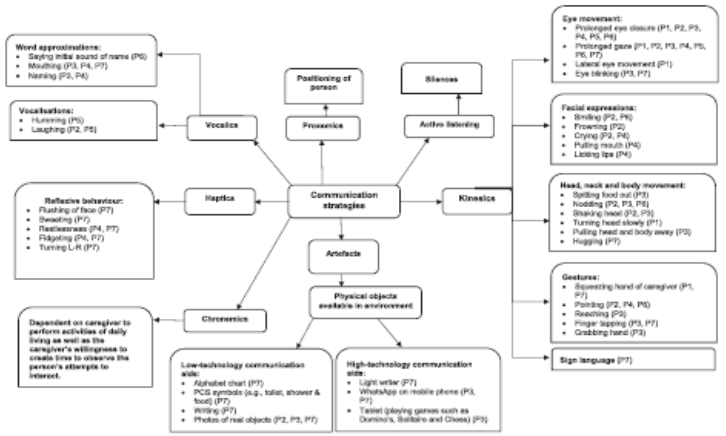

Figure 2. Communication strategies displayed by persons who are minimally conscious as reported by participants (Participant 1 (P1)–Participant 7 (P7)).

For both proxemics and chronemics, the persons who are minimally conscious were totally dependent on the participants in all seven cases to position them and to perform activities of daily living for them. For example, participant 5 mentioned that she had to help her mother to wash her hair and so forth.

The vocalics observed by participants included both vocalisations such as laughing (*"My mom would laugh at my dad when he started singing"* [P2]) and humming (*"My mom loved singing and would hum to the music"* [P5]), as well as word approximations such as mouthing and attempts at naming or labelling people and objects (*"My mom couldn't remember my name in the late stages of her disease and would only say the first letter of my name"* [P5]).

Haptics mostly comprised of reflexive behaviour such as fidgeting and restlessness (*"My dad used to get very restless and then my daughter would sing hymns to him as it would help him relax* [P4]), while the artefacts mentioned by participants included physical objects. These physical objects were categorised according to low- and high-technology communication aids. The low-technology communication aids included alphabet charts, Picture Communication Symbols, writing and real photos of objects and people (*"The speech therapist worked really hard but my mom just couldn't understand any symbol form"* [P2]). The high-technology aids mentioned by participants who are familiar caregivers, were an eye gaze system (*"We trial everything even an eye gaze system but even that didn't work due to my son's nystagmus"* [P3]), Lightwriter (*"Initially, we started simple but later my husband progressed to typing a message on the Lightwriter"* [P7]) and applications on tablets (*"My son used to love playing chess and Solitaire on his tablet"* [P3]). Solitaire, an application on the high technology aid, was included as this was a leisure activity and provided a conversational topic for caregivers. Although the persons were exposed to both high and low technology communication aids, caregivers lacked confidence when implementing both forms of communication due to the low level of responsiveness of the person, the inconsistency of responses as well as the significant cognitive, motor, linguistic and sensory difficulties of the person.

Communication functions conveyed through nonverbal communication behaviours by persons who are minimally conscious

Table III includes a description of the communication functions that persons who are minimally conscious conveyed through nonverbal communication as perceived by familiar caregivers. The communication functions reported were classified according to the communication function categories in the Communication Matrix (Rowland, 2011).

According to familiar caregivers, persons who are minimally conscious conveyed a total of 36 communication functions through their nonverbal communication. Level 1 (pre-intentional communication) included six communication functions with the

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Table III . Communication functions displayed by persons who are minimally conscious as perceived by familiar caregivers (application to Communication Matrix, Rowland, 2011).

Matrix level	Nr	Communication function		Definition	Behaviour observed by caregiver	Mentioned by (Part nr)
Level 1: Pre-intentional behaviour	1	Wakefulness and alertness		Displaying signs of coma recovery coma/regaining consciousness.	Prolonged eye gaze	P3, P7
	2	Disorientation		Disorientation of person, place and time.		P3, P7
	3	No recognition		Not recognising familiar objects or people.	Prolonged eye gaze, eye blinking or frowning	P5, P6
	4	Searching behaviour	Object	Searching for an object in the environment.	Lateral eye movement or prolonged gaze	P7
			Person	Searching for a person in the environment.	Lateral eye movement, reaching, turning head slowly	P1, P4, P5
	5	Expressing components related to physical functioning		Communication regarding the physical functioning of the person.	Reflexive behaviours (see Figure 2)	P2, P3, P4, P5, P6
	6	Expressing	Pain	Physiological expression of pain.		P3
			Discomfort	Expressing components related to discomfort.		P2, P3, P4
Level 2: Intentional behaviour	7	Recognition	Object	Recognising an object such as a photo of a past event or a book.	Smiling, laughing, photos of real objects and people	P1
			Familiar person	Recognising a familiar person such as a friend, relative or corporate connection.		P1, P2
	8	Drawing attention		Focussing the communication partner's attention on a specific object, person or event.	Prolonged eye gaze, pointing, reaching, saying the initial sound or naming the object/ person or event	P2
	9	Expressing affect	Positive	Communicates positive emotions (e.g. happy).	Smiling, laughing	P1, P2, P6
			Negative	Communicates negative emotions and feelings (e.g. anger, stress, fear, frustration).	Frowning, crying, pulling mouth, prolonged eye closure	P1, P2, P3, P4, P5, P6, P7
Level 3: Unconven-tional communi-cation	10	Communication intent (basic)		Indicating an intent to communicate.	Reaching, grabbing hand, pulling head and body	P1, P2, P3, P4, P5, P6, P7
	11	Refusing to communicate		Indicating no desire to communicate despite having communication intent.	Prolonged eye closure, pulling mouth, sign language, shaking head	P7
	12	Comprehending messages (basic)		Understanding the intent of a message produced by a communication partner.	Eye blinking, nodding, vocalizations	P7
	13	Choice making		Conveying personal preferences to the communication partner.	Eye blinking, nodding, shaking head, pointing, vocalizations	P1, P2, P3, P4, P5, P6, P7
	14	Expressing basic wants and needs		Expressing wants and needs.		P1, P2, P3, P4, P5, P6, P7
	15	Beginning communication support		Using unaided communication to represent basic messages.		P1, P2, P3
Level 4: Conventio-nal communi-cation	16	Greeting		Following social etiquette rules, e.g. saying "hello" or "goodbye".		P4, P5, P6
	17	Engagement in interaction	Active	Attending to the communication partner through active listening and body engagement.	Prolonged eye gaze, nodding, vocalizations, silences	P1, P2, P3, P4, P5, P6, P7
			Passive	Being physically present during communication but not actively engaged (i.e. disinterested in communication).	Prolonged eye closure	P1, P4, P5, P6

(*Continued*)

Table III (*Continued*).

Matrix level	Nr	Communication function		Definition	Behaviour observed by caregiver	Mentioned by (Part nr)
	18	Turn taking		Displaying turn-taking (i.e. reciprocity) with communication partners.	Prolonged eye closure, nodding	P4, P5, P6, P7
	19	Following of instructions		Understanding an instruction by a communication partner.	Gestures	P1, P2, P3, P4, P5, P6, P7
	20	Functional use of objects		Knowing the function of an object (e.g. using a comb).	Gestures functional use of object	P7
	21	Requesting	Object	Requiring the communication partner to provide an object (e.g. toothbrush or comb).	Pointing, turning head slowly, prolonged eye gaze, reaching, licking lips, PCS symbols, alphabet chart	P4
			Action	Requiring the communication partner to fulfil a task (e.g. pointing to the light-requesting the light on/off).		P4
			Physical presence	Requiring physical closeness from the communication partner.	Reaching, grabbing hand, prolonged eye gaze	P1, P2, P3, P4, P7
			Information	Requiring the communication partner to provide more information.		P7
	22	Responding (basic)		This refers to a voluntary response to a communication partner's initiation to communicate.	Nodding, vocalizations and word approximations	P1, P3
	23	Refusing	Object	Requiring the communication partner to provide an object (e.g. food, toothbrush or comb).	Prolonged eye closure, shaking head	P3, P4
			Action	Requesting partner to fulfil a task (e.g. take food away).	Spitting food out, pulling mouth, pulling head and body away, reflexive behaviours	P5
			Physical presence	Requiring a lack of physical closeness from the communication partner (e.g. requesting the partner to leave).	Prolonged eye closure	P1, P2, P3, P4
			Information	Requiring the communication partner to provide no information.		P7
Level 5: Concrete communi-cation	24	Imitating/Repeating		Imitating or repeating an action, object or person.		P7
	25	Naming		Labelling an object, person or event in the person's environment.	Word approximations, vocalisation, gestures	P2, P5
	26	Commenting		Providing comments during the conversation.		P7
	27	Answering	Yes/no questions	Responding to the communication partner's questions (yes/no).	Word approximations, vocalizations, eye blinking, nodding, shaking head, smiling, frowning, squeezing hand.	P1

(*Continued*)

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Table III (*Continued*).

Matrix level	Nr	Communication function		Definition	Behaviour observed by caregiver	Mentioned by (Part nr)
			Concrete questions	Responding to general contextual questions focusing on the current environment (e.g. "What are you doing?").		P4, P5, P6
			Abstract questions	Responding to simple abstract questions about the communication partner (e.g. "How do you feel today?").	Lightwriter, WhatsApp, writing, tablet	P2
	28	Requesting a turn		Initiating interaction or requesting to participate in the conversation.	Grab hand, prolonged eye gaze, silences	P7
	29	Initiate conversation		Requesting reciprocal interaction from a communication partner.		P4, P7
Level 6: Abstract	30	Modelling		Using simple gestures to demonstrate what is required of the communication partner (e.g. "I am hungry").	Gestures	P2
Level 7: Linguistic	31	Narrative		Telling a story.	Word approximations, vocalisations, sign language, Lightwriter, alphabet board, writing, WhatsApp	P4, P5, P6, P7
	32	Arguing		Debating the person's point of view.		P7
	33	Leading the conversation		Leading the conversation by focusing on topics related to the person's concerns or interests (e.g. humour and gossip).	Physical objects such as Lightwriter, writing, WhatsApp	P6, P7
	34	Observing social etiquette		Using words that are socially appropriate or inappropriate.	Alphabet chart	P4, P5, P6
	35	Termination/disengagement		Withdrawing from the conversation.	Prolonged eye closure	P1, P2, P6
	36	Conversational pause		The speaker takes a rest, hesitates, or temporarily stops.	Silences or gesture	P4, P5, P6

majority of participants mentioning that persons who were minimally conscious expressed components related to physical functioning with reflexive behaviours ("*I could see my dad was uncomfortable as he used to turn L-R in his bed and fidget a lot*" [P4]). Level 2 (intentional behaviour) also included three communication functions, of which the ability of persons who are minimally conscious to convey positive affect was mentioned by three participants while expressing negative affect was mentioned by all seven of the participants ("*My husband used to get irritated with me when I pulled his ear and he would just close his eyes and not respond*" [P1]). All the familiar caregiver participants mentioned that persons who are minimally conscious conveyed communication functions on Level 3 (unconventional communication) which focussed on the person indicating intent to communicate, choice-making and expressing wants and needs. One participant mentioned that her son would grab her hand to indicate to her that he didn't want her to leave and that he wanted her to talk to him (P3).

Level 4 (conventional communication) included eight communication functions with active engagement in interaction and following instructions being mentioned by all of the participants ("*We would always organise family gatherings and my mom would smile and look at us*" [P2]). Communication functions included in Level 5 (concrete communication) were mentioned by less than half of the participants referring to persons who are minimally conscious answering concrete questions with word approximations, while Level 6 (abstract communication) included only one communication function, specifically that the person modelled what they required from the partner. Lastly, Level 7 (linguistic communication) included six communication functions observed by participants. The communication function mentioned by more than half of the participants included narratives for which persons who were minimally conscious used word approximations, vocalisations, sign language, a Lightwriter and WhatsApp.

Discussion

From the findings of this study, familiar caregivers are willing and eager to interact with persons who are minimally conscious, despite the challenges related to restricted interaction. The communication attempts (both initiation and responses) of familiar caregivers typically includes both verbal and nonverbal communication during interaction with persons who are minimally conscious. These caregivers naturally use some form of multimodal communication and attempt to adapt to these communication strategies. However, these caregivers are often unsure whether they are implementing and integrating these strategies appropriately. This may be due to the caregivers attempting communication with the person but perceiving the person who is minimally conscious as not responding. Alternatively, they may focus on specific communication strategies which they are familiar with (e.g. verbal

communication) and may receive limited healthcare practitioner support to provide them with the confidence to effectively integrate multiple modes of communication during interaction with these persons (Wallace, Purdy, & Skidmore, 2014). Healthcare practitioners therefore have an important role to play to support familiar caregivers during the initial and extended phases of caring. When supporting caregivers during the extended care phases healthcare practitioners may learn which communication strategies caregivers perceive as successful and provide them with the support and confidence to effectively implement these strategies. Additionally, healthcare practitioners can utilise these strategies of caregivers in the extended care phase and teach them to caregivers in the initial care phase to reduce caregiver anxiety. Preisig et al. (2018) mention that although verbal and nonverbal communication is produced through different channels, they originate from a shared communication intention. Therefore, by integrating multimodal strategies, the opportunity of having successful interaction is increased, because if a communication breakdown occurs in one modality the partner can switch to another, thereby allowing greater communication capacity (Wallace et al., 2014). This study supports the notion that caregivers use multimodal communication and that they learn this skill over time, but often do not know how to observe and identify subtle communication attempts from the person who is minimally conscious during the initial/early stages. If caregivers are supported during the initial phases, early rehabilitation can take place which results in improved emergence of consciousness (Eapen, Georgelutty, Subbarao, Bavishi, & Cifu, 2017).

The caregivers in this study did identify some communication attempts of persons in a MCS such as kinesics; specifically, eye movement was identified as the most prominent means to communicate – specifically prolonged gaze and prolonged eye closure. Eye movement is often present during all stages of recovery and is the first sign that the person is recovering consciousness (Ting, Perez Velazquez, & Cusimano, 2014). Visual tracking is characteristic of both the MCS- and MCS + subcategories of the MCS (Giacino, Fins, Laureys, & Schiff, 2014). Eye movement was the most prevalent strategy displayed by persons who are minimally conscious; but a discrepancy exists as only three familiar caregivers mentioned that their own facial expressions and body language are important when communicating with these persons. This may be that familiar caregivers have limited knowledge and skills on how to effectively observe and respond to this communication form in persons who are minimally conscious (Wallace et al., 2014). This implies that even although they are regarded as "expert" partners – they might not be aware of the full bouquet of possible forms of communication.

Another communication means displayed by persons who are minimally conscious was vocalics. All the

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participants mentioned that vocalics such as using a familiar voice and singing to the person were some of the communication strategies they used. Singing in particular was displayed by the familiar partner and humming by the person as a communication means. According to Lancioni et al. (2021), this is beneficial as it increases neural activity, accelerates brain plasticity, and avoids sensory deprivation. Music stimulation of the auditory area (which is mostly unaffected) also increases the person's recovery process and increases the wellbeing and general functioning of the person (Lancioni et al., 2021). Additionally, a familiar voice provides personally relevant stimuli (i.e. with emotional, autobiographical, or self-related characteristics) which increases the chance of observing behavioural or brain responses compared to neutral stimuli (Sautet et al., 2022).

Artefacts were also mentioned as both a means of communication displayed by the person who is minimally conscious as well as a communication strategy of the familiar caregivers. However, participants mostly mentioned environmental objects as a communication strategy as opposed to physical objects. Physical objects were important to the person as perceived by familiar caregivers as it often included a communication aid. The person may have perceived these objects as important as it allowed them a means to communicate and also provided familiar stimuli which may have increased their level of responsiveness. However, familiar caregivers lacked confidence when implementing these communication aids. This may be due to their decreased awareness of scaffolding their communication intervention focussing on the residual language functioning of the person (Gillespie & Hald, 2017).

Communication attempts of persons in a MCS were mostly interpreted as conventional communication which included greeting, turn taking, functional use of objects, following instructions, requesting, responding and refusing. These observations of caregivers provide valuable diagnostic information for the classification of persons in a MCS. Behaviour observation remains the most frequently used method of differential diagnosis in DOC (Carrière et al., 2022). Therefore, by including caregivers in the assessment and intervention of persons who are minimally conscious can assist healthcare practitioners in obtaining information on familiar stimuli that the person responds best to, how the person responds to the stimuli and what the response could indicate. Including caregivers in a team approach may also assist healthcare practitioners to support both familiar caregivers in the initial and extended phases of care. Firstly by providing information on naturally occurring multimodal communication strategies to communicate with persons who are minimally conscious in the initial care phase and secondly, supporting extended care phase familiar caregivers to communicate with confidence. Additionally, healthcare practitioners can equip familiar caregivers with the skills to observe, identify, and respond to subtle communication attempts as this may improve the psychological state and confidence when interacting with persons who are minimally conscious (Ting et al., 2014).

Limitations of study

The small sample size limits the generalisability of the findings. However, the procedure used allowed for comprehensive and in-depth data on the participants' perspectives. Furthermore, the study included persons in a MCS due to various aetiologies (e.g. TBI, CVA, and Alzheimer's disease). Various aetiologies were included as the main focus was on a diagnosis of a MCS and not on the aetiology of the disorder. Additionally, these aetiologies assisted in including more caregivers who could recount their experiences based on the severity of the persons' communication capacity challenges. These caregivers were also selected as they have had long term exposure to the MCS and could reflect on the process. Future research could include retrospective interviews with persons who have recovered from a MCS to include their perceptions and experiences.

Conclusion

From the findings of this study, it is clear that familiar caregivers of persons who are minimally conscious realise the importance of communicating with these persons and over time acquire the skill to observe which stimuli elicit what response. Despite this, they appear to be unaware of this knowledge that they possess, and often remain unsure how to interpret subtle communication attempts. In this study, this caused the familiar caregivers to lack confidence when communicating with these persons as they were unsure how to scaffold their multimodal communication attempts to meet the persons needs and to adequately support the person. Furthermore, emphasis is placed on the inclusion of caregivers within the assessment and intervention of persons in a MCS by healthcare practitioners from the earliest possible stages to facilitate improved emergence of consciousness. This study also identifies areas of support that familiar caregivers require in the initial care phase and which can be remediated by healthcare practitioners.

Acknowledgements

We would like to thank Janine Ellis for providing the language editing for this article.

Declaration of interest

No potential conflict of interest was reported by the author(s).

Funding

The authors have no sources of funding to declare.

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Appendix H1: Letter of Informed Consent-Phase 2

Date:

Dear Participant

Thank you for your willingness to participate in this research study. Your input will aid in the adaptation of an existing communication-partner training programme for communication partners of persons who are minimally conscious (MCS+). This informed consent letter consists of 2 sections, namely a reply slip and a biographical questionnaire. If you are willing to participate in the research, kindly complete both and email them back to me before the interview.

Letter of informed consent and reply slip

Invitation to participate in an online interview

My name is Ariné Kuyler and I am a PhD candidate at the Centre for Augmentative and Alternative Communication at the University of Pretoria. In partial fulfilment for the requirements of this degree, I am requested to conduct a research project. Herewith, I request your consent to participate as a clinician with special interest in neurorehabilitation in an online interview.

Research Topic: Communication partner training programme to support persons in a minimally conscious state: Identifying and adapting an intervention programme

Why is this study important? Communication partners of persons in an MCS+ often experience challenges when providing long term patient care. These challenges can be due to financial constraints, decreased socialisation with neighbours, friends and family and ineffective person-partner communication. This ineffective communication can be even more challenging when communication partner's experience difficulty in recognising unaided communication behaviours of persons who are minimally conscious or if they misinterpret or misjudge communication attempts This may lead to a decreased duration of communication partner contact and may result in reduced motivation of persons who are minimally conscious to communicate. Communication partners would therefore benefit from communication-partner training as it may improve their communication with persons in an MCS+.

What are the aims of the study? This study aims to identify and adapt an evidence-based intervention in the form of a communication partner training programme to facilitate interaction between communication partners and persons in an MCS+. This is done by empowering communication partners to observe, assess, interpret and respond to the communication behaviours displayed by these individuals.

What will be expected of you when you participate? You will be requested to complete the attached consent form and biographical questionnaire, which is expected to take approximately 10 minutes to complete. Upon your consent, I will arrange a time and date convenient to you to participate in an online interview. This interview will be a once-off session of approximately 45- to 90-minutes using an online platform such as Zoom, Skype or Google Meet, depending on your choice. A link to this platform will be sent to you once the details

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have been confirmed with you. During this session you will be asked questions relating to your experience in disorders of consciousness, your opinion on a communication-partner training programme, your approach in working with these persons, and assessment and treatment of persons who are minimally conscious. The estimated time frame for this interview to be conducted will be during February 2022. These online interviews will be audio-recorded. Please note that the recording will be transcribed and sent back to you a week after the interview. You will be requested to review this transcript to ensure that your opinion is correctly reflected in the data. Based on your preference you will be able to review the transcript independently or with the researcher present.

Ethical considerations

Are there risks and possible disadvantages to participation? There are no anticipated risks related to this research.

What are your rights? Your participation in this research is completely voluntary and you may withdraw at any time during the interview without negative consequences to you or the person in your care. As an incentive the adapted programme will be sent to you upon completion of the study.

Will your information be kept confidential? Your information will be kept confidential as no identifying information will be reported in any publications or presentations resulting from this study. The information provided during the interviews will be kept safely, and the information will only be viewed by myself and my PhD supervisors. The data obtained will be securely stored for a period of 15 years on an online data storage platform regulated by the University of Pretoria.

Will you see the results*?* If you wish to receive a copy of the results of the study, you may contact me directly. The results from this study will be reported in general terms in the PhD thesis, in manuscripts submitted for publication in scientific journals related to the thesis, and in oral and/or poster presentations at scientific meetings, seminars, and/or conferences. If the need arises, data may be used for future research.

It would be greatly appreciated if you would consider this request favourably. If you agree, kindly submit the signed reply slip to indicate your willingness to participate. Thank you for your time and consideration of this request. Should you need any further information on the study, you are welcome to contact me or my supervisors. I look forward to receiving your response.

Kind Regards

Ms Ariné Kuyler
(Researcher)
Email: [redacted]
Tel: [redacted]

Prof Juan Bornman
(Supervisor)
Email: [redacted]
Tel: [redacted]

Dr Ensa Johnson
(Co-supervisor)
Email: [redacted]

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Appendix H2: Letter of Informed Consent Reply Slip- Phase 2

Name of participant:					
Project title:	**Communication partner training programme to support persons in a minimally conscious state: Identifying and adapting an intervention programme**				
Researcher:	Ariné Kuyler [redacted]	**Supervisor:**	Prof Juan Bornman [redacted]	**Co-supervisor:**	Dr Ensa Johnson [redacted]

I, _____,
(full names and surname) hereby acknowledge that:

- My participation in the online interview is completely voluntary.
- I may withdraw from the study at any time, without negative consequences.
- I will not be exposed to harmful situations during the stages of the study.
- I acknowledge that the online interview sessions will be audio recorded.
- The information I supply for the PhD study will be kept confidential and confidentiality will be maintained if any publications or conference proceeding arise.
- The data may be analysed further or used in future research, but that confidentiality of personal information will be maintained.
- I understand that the data will be securely stored for a period of 15 years on an online data storage platform regulated by the University of Pretoria.

(Please tick appropriate block)

I give consent		**I do not give consent**	

_____ _____
Signature of participant Date

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Biographical information

Please complete all the following questions by filling in the empty spaces supplied for the answers or alternatively where multiple options are given please mark your answer with an X.

Your information				
1. How old are you?	_____ years			
2. What is your gender?	Male	Female	Other	
3. What is your first language?				
4. What other languages do you speak?				
5. What is your highest education level?	Matric	Diploma	Bachelor's Degree	
	Master's Degree	PhD	Other: _____ (Please state)	
6. What is your employment status?	Unemployed	Employed full time	Employed part time	
7. What is your occupation?				
8. In what context do you work?	Private practice	Neurorehabilitation centre	Hospital	
	Clinic	Other:		
9. How long have you been working in this context?				
10. How long have you been working in your field?				
11. How often do you see persons who are minimally conscious?	Daily	Weekly	Monthly	Annually
12. Do you see the person:	Individually	Group	Both	
13. In what setting do you see the person?	Inpatient	Outpatient	Home care	Care facility
	Other:			
14. Do you provide caregiver support?	Yes		No	
15. How do you provide caregiver support (e.g., online, face-to-face)				
16. How often do you provide caregiver support? (e.g., once a week)				
17. What guidance do you give caregivers?				
Training information				
18. Do you feel that your undergraduate degree prepared you to work with persons who are minimally conscious?	Yes		No	
19. What contributed mostly to your learning in the field of disorders of consciousness?				
20. Have you participated in courses that train you to work with persons who are minimally conscious?	Yes		No	
21. If yes, please specify?				
22. Do you feel that you would want more training in this field?	Yes		No	
23. What components do you require training on?				
24. For individuals with limited knowledge on disorders of consciousness what support is most important to facilitate their learning?				

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Appendix I: Layout of CPT

TBIconneCT Program at a Glance

Module	Topic	Specific content focus
1	**Introductions**	• Setting the scene for the processes and content within the TBIconneCT program • Discussing communication goals • Tuning in to various aspects of conversation (via videos)
2	**TBI and Communication**	• Background information about TBI • Identifying 'ingredients' required for good conversation • Common problems with communication after TBI
3	**Playing Your Role**	• Communication situations that require a "formula" (or 'scripts' to follow) • Strategies for playing our part • Changing approach depending on context • Generating key words to define one's ideal communication approaches
4	**Effective Speaking and Listening**	• Communication as a cooperative process involving effective speaking, listening, and turn-taking • Discussing personally relevant strategies for the above • Progress review
5	**Collaboration**	• Watching resource video examples for evaluating 'working together' and supporting one another • Discussing personally relevant strategies for the above
6	**Elaboration**	• Watching resource video examples for evaluating 'making conversation deeper' and supporting one another in conversation • Discussing personally relevant strategies for the above
7	**Asking Questions**	• Discussing different question types and how they link to skills covered in Modules 5 and 6 above • Discussing personally relevant strategies • Progress review
8	**Putting it all Together 1**	• Revising strategies from Modules 1–7; troubleshooting
9	**Putting it all Together 2**	• Revising strategies from Modules 1–7; troubleshooting
10	**Putting it all Together 3**	• Discussing achievements • Discussing next steps and reviewing resources for maintaining and continuing progress

Source: *Rietdijk, Power, Brunner, Attard et al., 2019*

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Appendix J: Permission to Adapt TBI Connect CPT

Gmail

Arine Kuyler <[redacted]>

TBI Express
5 messages

Arine Kuyler <[redacted]> Fri, Jul 9, 2021 at 10:18 AM
To: [redacted]
Cc: Ensa Johnson <[redacted]>, Juan Bornman <[redacted]>

Dear Professor Togher

I hope this email finds you well. My name is Arine' and I am currently a PhD candidate at the Centre for Augmentative and Alternative Communication, in South Africa. I am currently conducting my PhD research on communication-partner training for familiar caregivers of persons who are minimally responsive in collaboration with my two supervisors Prof. Juan Bornman and Dr. Ensa Johnson. From the research that I have conducted your programme, TBI Express, is well-researched and has substantial evidence to support the effectiveness thereof.

Based on the evidence-base for the TBI express programme, we would like to purchase this programme and to ask your permission to adapt the programme to target the specific population that we are working with? The adaptations that we are considering will entail adapting the communication strategies to assist communication with non-verbal TBI patients who are minimally responsive. Thank you for considering this request and we look forward to hearing from you.

Kind regards
Arine'

Leanne Togher [redacted] Wed, Jul 21, 2021 at 3:24 AM
To: Arine Kuyler [redacted]
Cc: Rachael Rietdijk [redacted]

Dear Arine'

Thank you for your email and your interest in TBI Express. There is considerable work happening with communication partner training internationally however I am not aware of anyone conducting the kind of work you are proposing which sounds very interesting! Once you have your copy of the program, and you are working on the adaptation I would be happy to offer any advice or help I can. Since publishing TBI Express, we have also published TBI ConneCT, which may also be of interest to you. This program does not have a group component and focuses on individual treatment (either face to face or via telehealth) with the person with TBI and their family member.

https://www.sydney.edu.au/medicine-health/our-research/research-centres/acquired-brain-injury-communication-lab/tbiconnect.html

We have also just launched an online training program for anyone who may need to interact with people with acquired brain injury. It is free. You are welcome to complete this course as well:

https://abi-communication-lab.sydney.edu.au/courses/interact-abi-lity/

TBI Express and TBI ConneCT are both available through ASSBI Resources

https://www.assbi.com.au/Treatments-to-Buy

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A pdf version can be sent through to you to save on postage too.

To move forward with this, I have been in touch with our legal department at The University of Sydney, as any use and adaptation of these products will require you to complete a short form license to allow your South African team to access and adapt TBI Express. What is your timeline to adapt the TBI Express materials?

Thanks!

Leanne

LEANNE TOGHER

Professor of Communication Disorders Following Traumatic Brain Injury
Senior NHMRC Elizabeth Blackburn Research Fellow

Supervisor, Communication Sciences

Executive Leadership Team, Brain and Mind Centre
Speech Pathology | School of Health Sciences| Faculty of Medicine and Health

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Director, speechBITE www.speechbite.com
Director, Acquired Brain Injury Communication Lab

Chief investigator, NHMRC Centre of Research Excellence in Aphasia Rehabilitation

Board of Governors, International Brain Injury Association.

International Board member, Journals Board, American Speech Language and Hearing Association (ASHA)

Development Group Member for TBI, World Health Organization

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Appendix K1: Letter of Informed Consent-Phase 3

27/05/2022

Dear Participant

Thank you for your willingness to participate in this research study. Your input will aid in determining the clinical utility of an adapted communication-partner training programme for communication partners of persons who are minimally conscious (MCS+). This informed consent letter consists of 2 sections, namely a reply slip and a biographical questionnaire. If you are willing to participate in the research, kindly complete both and email them back to me before the online nominal group discussion.

Letter of informed consent and reply slip

Invitation to participate in an online nominal group discussion

My name is Ariné Kuyler and I am a PhD candidate at the Centre for Augmentative and Alternative Communication at the University of Pretoria. In partial fulfilment for the requirements of this degree, I am requested to conduct a research project. Herewith, I request your consent to participate as a clinician with special interest in neurorehabilitation in an online nominal group discussion.

Research Topic: Communication partner training programme to support persons in a minimally conscious state: Identifying and adapting an intervention programme

Why is this study important? Communication partners of persons in an MCS+ often experience challenges when providing long term patient care. These challenges can be due to financial constraints, decreased socialisation with neighbours, friends and family and ineffective person-partner communication. This ineffective communication can be even more challenging when communication partner's experience difficulty in recognising unaided communication behaviours of persons in an MCS+ or if they misinterpret or misjudge communication attempts This may lead to a decreased duration of communication partner contact and may result in reduced motivation of persons in an MCS+ to communicate. Communication partners would therefore benefit from communication-partner training as it may improve their communication with persons in an MCS+.

What are the aims of the study? What are the aims of the study? This study aims to identify and adapt an evidence-based intervention in the form of a communication partner training programme to facilitate interaction between communication partners and persons in an MCS+. This is done by empowering communication partners to observe, assess, interpret and respond to the communication behaviours displayed by these individuals.

What will be expected of you when you participate? You will be requested to complete the attached consent form and short biographical questionnaire, which is expected to take approximately 10 minutes to complete. Upon your consent, I will arrange a time and date convenient to you to participate in an online nominal group discussion. This group will be a once-

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off session of approximately 60 minutes using an online platform such as Microsoft Teams. In the session you will be shown a Power Point presentation of the suggested adaptations of an identified communication-partner training programme. Additionally, during this session you will be expected to provide your perspective on the suggested adaptations as well as the clinical utility of this programme by means of a whiteboard plugin in Microsoft Teams. This online group discussion will occur on the suggested date (31 May 2022 at 19:00) with other speech-language therapists. You will receive a link to this meeting on the suggested platform a day before. The online session will be audio and video recorded purely for the sake of revision in case certain aspects were unclear. Please note that additional questions may be sent to you one week after the discussion to ask for revision and clarification and to ensure that your opinion is correctly reflected in the data.

Ethical considerations

Are there risks and possible disadvantages to participation? There are no anticipated risks related to this research.

What are your rights? Your participation in this research is completely voluntary and you may withdraw at any time during the discussion without negative consequences to you or the person in your care. As a token of appreciation, the adapted programme will be sent to you upon completion of the study.

Will your information be kept confidential? Your information will be kept confidential as no identifying information will be reported in any publications or presentations resulting from this study. The information provided during the nominal group discussion will be kept safely, and the information will only be viewed by myself and my PhD supervisors. The data obtained will be securely stored for a period of 15 years on an online data storage platform regulated by the University of Pretoria.

Will you see the results*?* If you wish to receive a copy of the results of the study, you may contact me directly. The results from this study will be reported in general terms in the PhD thesis, in manuscripts submitted for publication in scientific journals related to the thesis, and in oral and/or poster presentations at scientific meetings, seminars, and/or conferences. If the need arises, data may be used for future research.

It would be greatly appreciated if you would consider this request favourably. If you agree, kindly submit the signed reply slip to indicate your willingness to participate. Thank you for your time and consideration of this request. Should you need any further information on the study, you are welcome to contact me or my supervisors. I look forward to receiving your response.

Kind Regards

Ms Ariné Kuyler
(Researcher)
Email: [redacted]

Prof Juan Bornman
(Supervisor)
Email: [redacted]

Dr Ensa Johnson
(Co-supervisor)
Email: [redacted]

Name of participant:	

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Appendix K2: Letter of Informed Consent Reply Slip-Phase 3

Project title:	**Communication partner training programme to support persons in a minimally conscious state: Identifying and adapting an intervention programme**				
Researcher:	Ariné Kuyler [redacted]	**Supervisor:**	Prof Juan Bornman [redacted]	**Co-supervisor:**	Dr Ensa Johnson [redacted]

I, _____, (full names and surname) hereby acknowledge that:

- My participation in the online nominal group is completely voluntary.
- I may withdraw from the study at any time, without negative consequences.
- I will not be exposed to harmful situations during the stages of the study.
- I acknowledge that the online group discussion sessions will be audio recorded.
- The information I supply for the PhD study will be kept confidential and confidentiality will be maintained if any publications or conference proceeding arise.
- The data may be analysed further or used in future research, but that confidentiality of personal information will be maintained.
- I understand that the data will be securely stored for a period of 15 years on an online data storage platform regulated by the University of Pretoria.

(Please tick appropriate block)

I give consent		**I do not give consent**	

_____
Signature

_____
Date

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Appendix K3: Biographical Questionnaire-Phase 3

Clinician nr:

Biographical information

Please complete all the following questions by filling in the empty spaces supplied for the answers or alternatively where multiple options are given, please mark your answer with an X.

Your information				
1. How old are you?	_____ years			
2. What is your gender?	Male	Female	Other	
3. What is your first language?				
4. What other languages do you speak?				
5. What is your highest education level?	Bachelor's Degree		Master's Degree	
	PhD	Other: _____ (Please state)		
6. What is your occupation?				
7. In what context do you work?	Private practice	Neurorehabilitation centre	Hospital	
	Clinic	Other:		
8. How long have you been working in this context?				
9. How long have you been working in your field?				
10. How often do you see persons who are minimally conscious?	Daily	Weekly	Monthly	Annually
11. Do you see the person:	Individually	Group	Both	
12. In what setting do you see the person?	Inpatient	Outpatient	Home care	Care facility
	Other:			
13. Do you provide communication partner support?	Yes		No	
14. How do you provide communication partner support (e.g., online, face-to-face)				
15. How often do you provide communication partner support? (e.g., once a week)				
16. Please briefly describe the type of guidance that you provide to communication partners.				
Training information				
17. Do you feel that your undergraduate degree prepared you to work with persons who are minimally conscious?	Yes		No	
18. What contributed mostly to your learning in the field of disorders of consciousness?				
19. Have you participated in courses that train you to work with persons who are minimally conscious?	Yes		No	
20. If yes, please specify?				
21. Do you feel that you would want more training in this field?	Yes		No	
22. What components do you require training on?				

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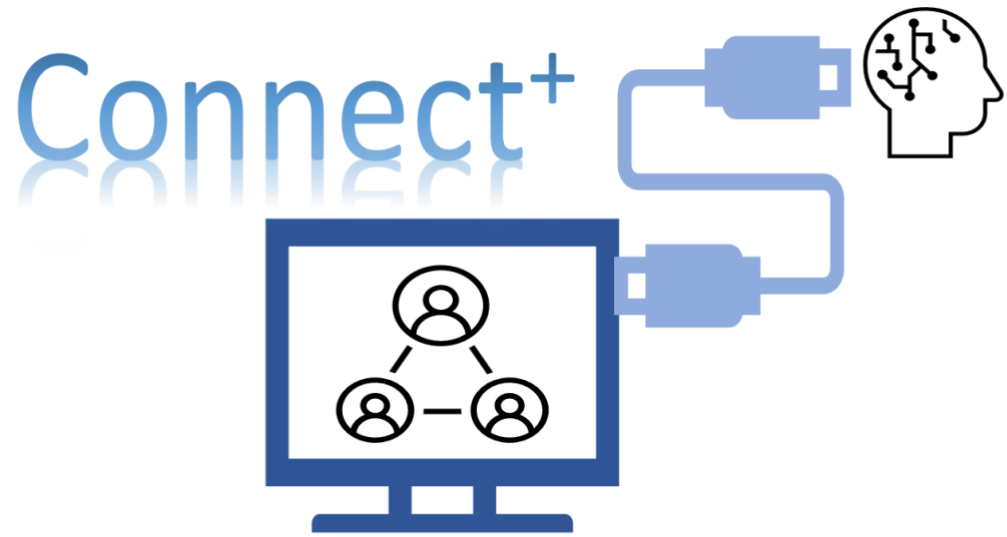
Appendix L: PowerPoint Presentation Nominal Group Technique

Slide 1



https://www.youtube.com/watch?v=2ZnRgcynxsw&list=PL7CCClw6dlYMAirK4FMPlj5agwwFZTOw4

Notes

The aim of this brief presentation is to explain how the Connect+ programme works. I would like to introduce it by showing you a short video on its core concepts as well as its background. This video will provide a foundation for our discussion that will follow. This programme can be purchased from the authors at the Australian Society for the study of brain impairment at a cost of R2160. It is available in both hard copy as well as pdf. Please use the link for more information. Evidence suggests that the TBI Connect programme is beneficial in supporting conversations between persons with a TBI and their familiar caregivers. However, for the purpose of my study that focuses on the person who is minimally conscious and their familiar caregiver, some adaptations were required. In the following 8 slides we will discuss these adaptations both to the content and design of the programme.

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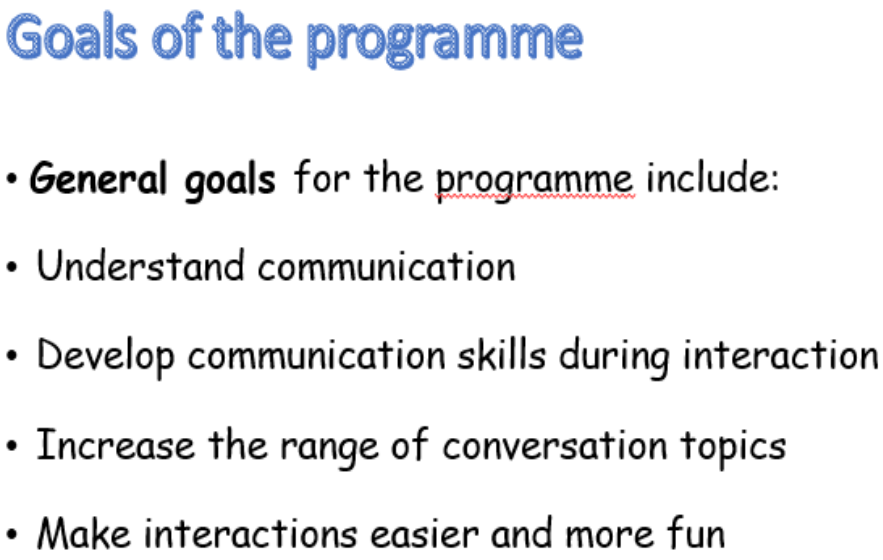
Slide 2



Notes

The goals suggested in the original Connect+ programme remain the same but can also be tailored to the needs of this study's target population. The program's general goals include understanding of communication which was expanded for the purpose of this study to also focus on the unaided communication behaviours displayed by persons who are minimally conscious as well as the multimodal communication strategies utilised by their familiar caregivers. Specific emphasis is placed on developing multimodal communication strategies used by these caregivers by strengthening their observation skills to facilitate interaction. The programme aims to increase the range of discussion topics as well as the communication functions that the person who is minimally conscious can have access to, through unaided communication strategies. Finally, caregivers should enjoy interactions with persons who are minimally conscious and be present during the interaction moments.

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Slide 3

Notes

The original TBI Connect programme suggests at least 10 sessions, once a week, each lasting one-and-a-half hours. However, from the familiar caregiver reports and perspectives of healthcare practitioners obtained in the study, it appears that although there was a general consensus that the session durations were appropriate, they expressed their concerns that the content presented in some of the Modules was not applicable for this population. As most of these persons who are minimally conscious display unaided communication behaviours that occur inconsistently, the focus in training cannot be on the conversation but should rather be on communication or interaction. To ensure that both the caregiver and person benefit from training a degree of flexibility is allowed to meet their individual needs To ensure that optimal learning occurs in which trainees are engaged the sessions should consist of practising, and reviewing communication strategies together with the trainer for improved interaction. These components should be implemented during each session to ensure the maintenance of the skills learnt in training. Additional focus is also placed on having interactions between sessions, where the focus is on specific strategies. Part of this is making 1–2 interaction video recordings for trainers to review in the following session.

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Slide 4

Suggested adaptations to the content of the programme

Module 1:

- Introduction to programme
- Format and expectations of participants
- Procedure for video-recording, each session and homework

Module 2:

- Ingredients for effective communication
- Information on MCS
- MCS and the effect on communication
- Unaided communication

Notes

Module 1 introduces the programme and also provides the outline and format of the different sessions. In module 1, the majority of the suggested changes focused on terminology (e.g., changing conversation to interaction). Module 2 relates to the required ingredients for effective communication (e.g., listening, enjoying interaction and teamwork). The adaptation also entailed including background information on disorders of consciousness as well as the different subcategories including the minimally conscious state. This module also includes a detailed description of the unaided communication behaviours that persons within a minimally conscious state typically display as well as the communication functions these behaviours access. Additionally, individual components that cause barriers to communication were mentioned such as difficulty with self-and environmental awareness, decreased sensory awareness, memory, motor, cognitive and other limitations were mentioned. The ingredients for interaction were therefore subsequently adapted to ensure that facilitative strategies are utilized by caregivers to compensate for these individual difficulties.

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Slide 5

Suggested adaptations to the content of the programme (cont.)

Module 3:

- Role of the communication partner and scripted interactions
- What to do in unscripted interactions specifically considering communication changes when communicating with different people, in different environments, for different reasons and using different means.

Module 4:

- What is communication?
- Communication topics that the person is an expert on
- Observing interaction to identify the role of speaker and listener, the changing roles in interaction

Notes

Module 3 explains the importance of the role of the communication partner during interaction. Additionally, a description is given of scripted interactions such as ordering food at a restaurant. Unscripted interactions often require the communication partner to adapt to different people (considering talking to a child versus an adult), different environments (familiar environment such as the home of the person or unfamiliar environment such as a shop as well as environmental adaptations to facilitate interaction), different reasons to communicate (communication functions such as requesting or narratives) and using different means (using multimodal interaction including both verbal and verbal communication). Module 4 includes information on the aim of communication, communication topics that the person is an expert (e.g., making choices) on as well as the observing the role of the speak and listener and how these roles change during the interaction.

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Slide 6

Suggested adaptations to the content of the programme (cont.)

Module 5:

- Collaboration during interaction
- Metaphors to describe interaction and the caregivers interaction style
- Metaphors to provide support to others
- The importance of teamwork, key team members and accessing team support
- Thinking support, emotional support, positive questions and positive turns

Notes

Module 5 provides a description of the importance of collaborating between the person and caregiver during the interaction. Additionally, caregivers are asked to provide metaphors on how they describe interaction as well as how they would describe their own interaction style. They are also provided with examples of metaphors for support to others (for example using the idea of a dolphin that supports others). Furthermore, the importance of teamwork is described, identifying key team members that should be part of this specific individual's team as well as strategies for accessing optimal support from the different team members. Thinking support assists the caregiver in critically analysing interaction and identifying strategies to make interaction easier for the person who is minimally conscious. The caregiver is also taught how to support the person emotionally but also to support themselves. Finally, caregivers are trained to ask positive questions and to take positive turns during the interaction.

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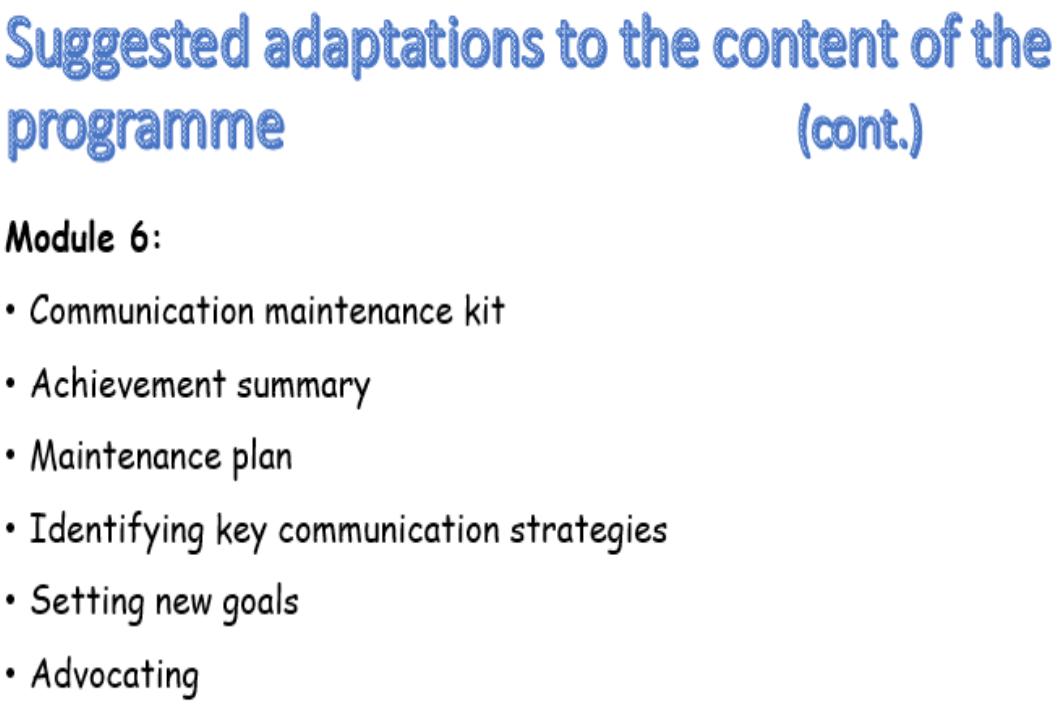
Slide 7



Notes

Module 6 focuses on the maintenance of skills learnt during the training. Caregivers are expected to write down their achievements throughout the course and to plan how these skills will be maintained during their daily schedules. A communication toolkit is compiled consisting of the key communication strategies that caregivers should use with persons who are minimally conscious, setting new goals and informing unfamiliar communication partners of the communication strategies displayed by persons who are minimally conscious.

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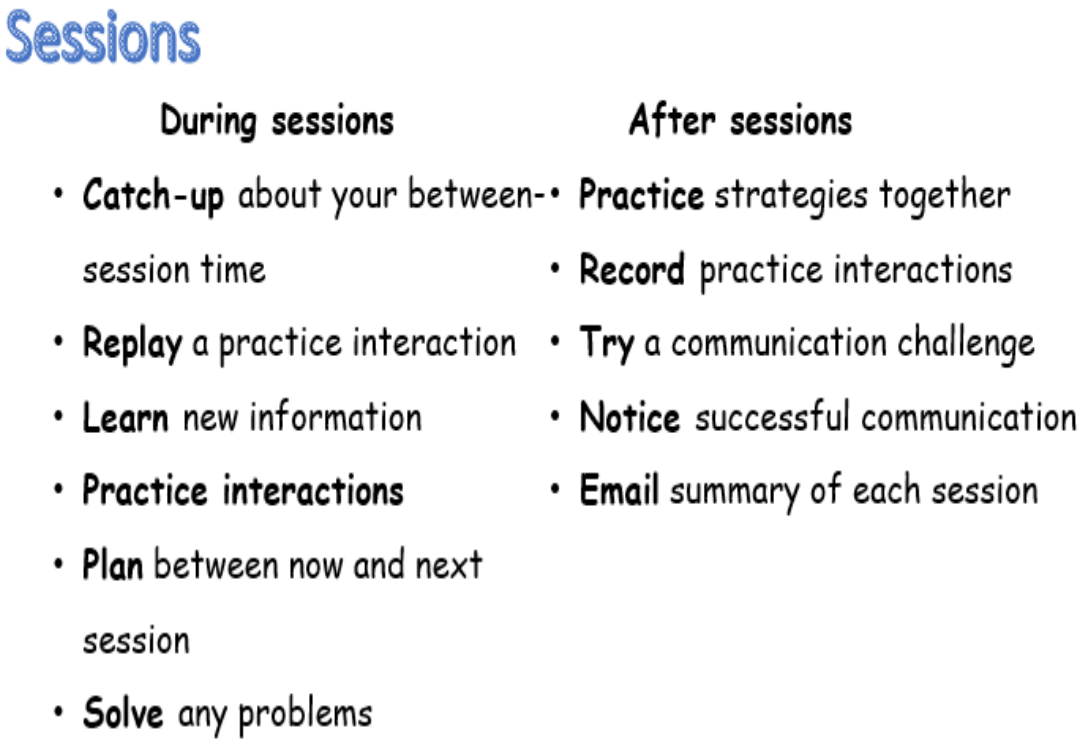
Slide 8



Notes

During each session time is made to catch up on progress from previous sessions, to replay practice interactions, to learn new information, to apply new information through practice, to plan for and solve any potential problems. Additionally, after each session strategies are practiced together, caregivers are expected to record interactions between them and persons who are minimally conscious, to try new communication challenges, to observe and notice communication strategies that were successful and to keep record of these events.

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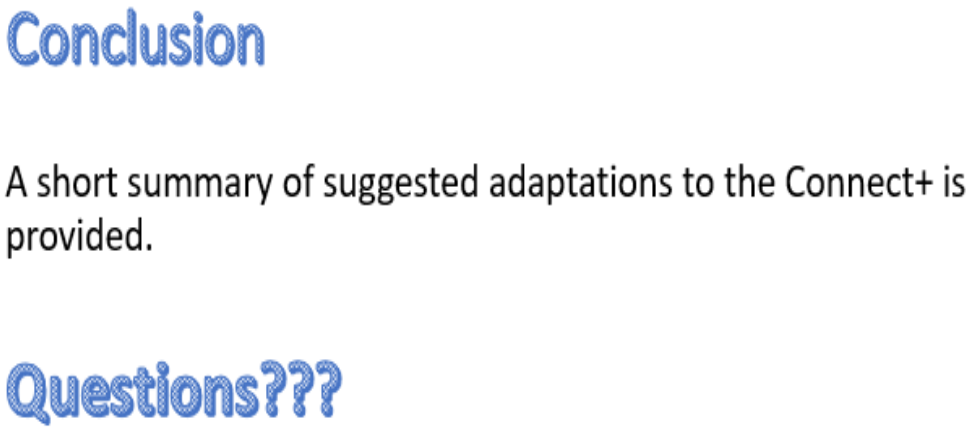
Slide 9



Notes

This presentation only provides a short summary of the suggested adaptations of the programme. The programme allows for changes to the length of the programme as well as limited changes to the content. As you noted we have made minimal changes to the content of the programme as to not compromise the fidelity. We have also consulted with the authors of the programme and they will evaluate the suggested adaptations. We will discuss these adaptations during our brainstorming session. Are there any specific questions pertaining to content of the slides?

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