Pragmatic- and discourse problems after severe traumatic brain injury from the perspective of caregivers

by

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SUMMARY

Background: Pragmatic and discourse problems after severe traumatic brain injury may have a negative impact on communication interaction. Caregivers are in a position where they observe these problems and have to deal with them. According to the *International Classification of Functioning, Disability, and Health framework* (developed by the World Health Organization, 2001), communication interaction problems due to impaired physiological and psychological functioning after severe TBI will influence performance and participation in everyday life situations. One of the main objectives of speech-language therapy services is to optimize individuals' ability to communicate in natural environments by serving individuals, families, groups, and the general public. Due to limited health care resources in South Africa, the Department of Health (DOH, 2001) implemented a home-based and community-based care programme. With this programme patients can be discharged sooner from in-patient rehabilitation into the care of family caregivers, thereby eliminating redundant facilities and services to reduce costs. Speech-language therapists can make a meaningful contribution to the implementation of the home-based care programme in South-Africa by empowering caregivers and family members of individuals with severe TBI with practical recommendations to improve communication interaction. Information on how caregivers experience and manage communication problems may better equip speech-language therapists to provide guidance to caregivers in the future.

Aims: The main aim of the present study was to determine the nature of pragmatic and discourse problems encountered during the chronic stage after severe TBI, from the perspective of caregivers, and to examine their ways of dealing with such problems in a natural environment. The following sub-aims were formulated in order to achieve this main aim:

- To determine how caregivers perceive the communication interaction of the individual with severe TBI they are caring for during the chronic stage after TBI.
- To determine how caregivers deal with the communication interaction problems they observe to assist the individual with severe TBI to communicate more effectively in a natural environment.
To deepen the understanding of these findings by reflecting on the data gathered during semi-structured interviews, particularly with regard to caregivers’ ways of managing the communication interaction problems they observe and what recommendations they propose for managing these problems.

**Method:** To obtain the requisite information on how caregivers perceive and deal with pragmatic and discourse problems of individuals with severe TBI, the research project was carried out in two phases. A qualitative approach was used during both phases.

During Phase 1, semi-structured interviews were conducted to determine the nature of the pragmatic and discourse problems during the chronic stage of severe TBI, from the perspective of the caregiver, as well as to ascertain how they deal with these communication problems. Based on a range of published assessment tools, a semi-structured interview guide was developed and face-to-face interviews were conducted with ten caregivers of individuals with severe TBI. Thematic analysis was used during data analysis and processing.

Phase 2 involved a focus group discussion with six of the participants of the semi-structured interviews. The participants included spouses, mothers, and siblings acting as caregivers of the individuals with severe TBI. A focus group discussion guide was developed as an agenda for conducting the discussion. The three key questions of the focus group discussion were based on the data collected during the semi-structured interviews. A successive process of coding was followed during data analysis. The process of coding involved open coding, followed by axial coding and then selective coding.

**Results:** The results of Phase 1 identified the communication interaction problems perceived by caregivers. These problems included inadequate content of information being conveyed during conversation, a lack of pragmatic competence, and decreased integration into the community. According to the results, caregivers choose to deal with perceived communication interaction problems in different ways. Caregivers either make the individual aware of the problems by addressing the problems, or they choose not to make the individual with severe TBI aware of the problems in order to avoid certain negative behaviours.
The results of Phase 2 yielded recommendations for dealing with communication interaction problems. Recommendations included different approaches to making the individual with severe TBI aware of communication interaction problems. These included subtle approaches vs addressing the problem directly, and addressing the problem within the conversation or afterwards. The overall best approach could not be determined during the focus group discussion because each participant had a different motivation for using a certain approach. A possible explanation for this may be that the participants of the focus group discussion stood in various relationships to the individuals with severe TBI. The results also provided some insights concerning the decreased capacity of individuals with severe TBI to use and interpret pragmatic aspects of communication interaction. Responses of the participants during the focus group discussion regarding these aspects of communication gave the impression that the participants did not understand the full extent of these behaviours and did not know how to deal with them. The results further showed that caregivers do acknowledge the importance of community reintegration, although they are very unsure what exactly the process involves and how to address it.

Conclusion: Caregivers perceived pragmatic and discourse problems during interaction with individuals with severe TBI. The perceived communication interaction problems can influence relationships negatively. Caregivers have different ways of managing the communication interaction problems, while an important shared consideration was the need to maintain good relationships and also to protect the self image of the individual with severe TBI.

Caregivers did not fully comprehend the concept and manifestation of problems in the following areas: non-verbal communication behaviour, and the potential influence of a conversation partner or the context of a conversation. They were also not fully aware of the importance of community reintegration and strategies for enhancing this process. It is a primary role of the speech-language therapist to treat the communication problems associated with the severe TBI, but also to educate caregivers and family members involved with these individuals. Preliminary guidelines for assisting caregivers and family members in managing pragmatic and discourse problems during the chronic stage of TBI are proposed.
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DEFINITION OF TERMS

This study utilises terminology that is used jointly by divergent (though related) disciplines such as the various branches of Linguistics, Social Psychology, Philosophy, and Speech-Language Pathology. The specific terms, and their definitions or explanations provided here, are those generally adopted within the field of Speech-Language Pathology, and may therefore not always be in exact agreement with preferences and interpretations accepted by the other related fields of study. Every possible care has been taken to clarify terms and justify the selection of particular nomenclature.

The terms listed below in alphabetical order are, in most cases, accompanied by a definition or explanation when they occur in the text for the first time. This list is intended to facilitate interpretation of text subsequent to first appearance of the terminology, or as additional clarification.

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Definitions

**Coherence** refers to the pragmatic and semantic connectedness of sentences within a conversational message (De Beaugrande & Dressler, 1981); thus the underlying logical connectedness of any use of language (Crystal, 1997:423). Judgments of coherence are typically based on rating spontaneous communication on the basis of the following: inclusion of adequate detail, word reference, plausibility, and conclusions (Ehrlich & Barry, 1989).

**Cohesion** refers to the ‘formal’ linkage between the elements of a discourse or text (Crystal, 1997:423); thus the grammatical and lexical linking within an extended utterance that holds the text together and gives it meaning. Meaning across sentences is linked through the use of cohesive markers (Halliday & Hasan, 1976). A cohesive marker is a word that completes meaning in text by leading the listener to information elsewhere in the text. Pronouns are significant cohesive markers in both English and Afrikaans. Cohesion allows the speaker to successfully present the listener with complete semantic relationships (Coelho, 1999).

**Communication** (here limited to human communication) is the meaningful exchange of information between two or more people through the exchange of thoughts, messages, or information, as by speech, visuals, signals, written, or behaviour. One definition of communication is “any act by which one person gives to or receives from another person information about that person's needs, desires, perceptions, knowledge, or affective states. Communication may be intentional or unintentional, may involve conventional or unconventional signals, may take linguistic or non-linguistic forms, and may occur through spoken or other modes” (De Valenzuela, 1992). The components of communication are generally listed as: context, sender/encoder, message, medium, receiver/decoder, and feedback.

**Communication interaction** allows a person to take part in life situations where knowledge, information, ideas, or feelings are exchanged within a social context (Eadie, Yorkston, Klasner, Dudgeon, Deitz, Baylor, Miller & Amtmann, 2006). It is a reciprocal process in which each participant should be alert to the informational needs of the other to ensure a successful transition of intended meanings during conversation (Owens, 2001). The act of communicating draws on several
interpersonal and intrapersonal skills. These include speaking, listening, observing, questioning, processing, analyzing, and evaluating (Rudebusch & Wiechmann, 2006; Yorkston, Baylor, Dietz, Dudgeon, Eadie, Miller & Amtmann, 2008). The quality and success of communication interaction is determined by the participants in the conversation, the conversational message, and the environment in which interaction takes place. Participants are those who are involved in the interaction, continuously changing roles as senders or recipients of a conversational message.

**Conversation** is the spoken exchange of ideas, observations, opinions, or feelings (Nordquist, 2014).

**Conversational environment** refers to the setting in which the communication interaction takes place. Every conversational environment is unique and each participant in a communicative exchange is implicitly required to follow a range of well-established communication norms (Angeleri, Bara, Bosco, Colle, Sacco & Zettin, 2008).

**Discourse**, in linguistics, refers to a unit of language longer than a sentence; or, more broadly, the use of spoken or written language in a social context (Nordquist, 2014). A simple definition of discourse in spoken communication is “continuous spoken language” (Naudé, 2006).

**Extra-linguistic** is a term generally used to indicate anything (other than language, i.e. beyond the bounds of language) to which language can relate (Crystal, 1997:427). Extra-linguistic levels of comprehension within a conversation include the ability to recognize emotions expressed by other people both in their voice and in their facial expression, information processing, abstraction, reasoning, and understanding the subtle rules surrounding the conversational context (Shorland & Douglas, 2010).

**Interactional behaviours** involve non-verbal communication behaviour as well as interactional behaviours, as described by Turkstra, Brehm and Montgomery (2006). Interactional behaviours include both physical and linguistic behaviours observed in spontaneous social exchanges as a function of interaction between conversation partners. Physical behaviours include eye contact, nodding, and gesturing toward the listener; and linguistic behaviours include back-channel responses (e.g., saying
‘uh-huh’ during the partner’s utterances). Interactional behaviours contribute to the perception that communication partners are responsive to each other (Turkstra, Brehm & Montgomery, 2006).

**Intonation** in linguistics, refers to variations in spoken pitch not used for distinguishing between words (in some languages pitch variation does distinguish words) but for a range of functions such as indicating the attitudes and emotions of the speaker, signalling the difference between statements and questions, and between different types of question, focusing attention on important elements of the spoken message and also helping to regulate conversational interaction (Wells, 2006:11-12). Although intonation is primarily related to pitch variation, certain functions attributed to intonation (e.g. the expression of attitudes and emotions, highlighting aspects of grammatical structure) almost always involve concomitant variation in other prosodic features. According to Crystal (1975:11): “...intonation is not a single system of contours and levels, but the product of the interaction of features from different prosodic systems – **tone, pitch, range, loudness, rhythmicity** and **tempo** in particular”.

**Non-verbal** is a term used to indicate communication that does not use words, e.g. gestural communication (Crystal, 1997:433). Certain aspects of speech are also described as non-verbal. The non-verbal elements of speech are those that communicate the paralinguistic information such as attitude, emotions and intentions (Thati, 2012). Prosody is a non-verbal element of communication, which contributes to generate the pragmatic meaning of a communication act (Angeleri et al., 2008). Non-verbal communication behaviour such as eye contact, body language, facial expressions, hand gestures, and the various ways of revealing emotional state are very powerful in conveying social information and affect (Burgoon, Guerrero & Floyd, 2010; Spell & Frank, 2000; Watts & Douglas, 2006).

**Non-verbal vs non-linguistic:** The various branches of linguistic research are widely diverse and writers from different schools of thought often use the same terms to express different concepts, or use different terms to express the same concept. The two terms **non-verbal** and **non-linguistic** seem to be used interchangeably in Linguistics and related (e.g. Social Psychology) literature and may be regarded as synonymous. Both terms are used to indicate coding devices that are not formally
governed by verbal rules but that contribute to a message, e.g. smiling, nodding, posture, gestures. The issue is compounded, however, by the fact that clinical literature also utilise some of the traditionally linguistic terminology. The term non-verbal, for example, is often used in Speech Pathology literature to describe persons who do not speak or have limited speech. This latter interpretation is not used in the present study.

**Non-verbal behaviour vs non-verbal communication:** The distinction between non-verbal behaviour and non-verbal communication is not always easy to maintain in practice. Non-verbal behaviour includes behaviour that might occur without the awareness of the encoder, whereas non-verbal communication refers to a more active process whereby encoder and decoder transmit and interpret behaviours according to a shared code of meaning (Hall, 2007).

**Paralinguistic** refers to features of speech or body language considered to be marginal to language, which serve to convey meaning (e.g. whispering to add a 'conspiratorial' meaning to what is said) (Crystal, 1997: 171,433).

**Pragmatic:** The term Pragmatics has different conceptual content depending on the field of study. In Speech-Language Pathology, pragmatics refers to the use of language in a social, that is, a communication context (Hoffman, Martens, Fox, Rabidoux & Andridge, 2013: 198). Crystal (1997: 435) describes pragmatics as “the study of the factors influencing a person’s choice of language”. Pragmatic aspects of language use are dependent on the speaker, the addressee, and various other features of the context of utterance (SIL International, 2004). In the Speech-Language Pathology context, the term pragmatic competence has traditionally been used to indicate the ability to recognize and use appropriate and functional language in a situational context (e.g. Carrow-Woolfolk, 1999), and the ability to understand another speaker's intended meaning. In this respect, pragmatics explains how language users are able to overcome apparent ambiguity, since meaning relies on the manner, place, time, etc. of an utterance. The linguistic contexts include accent, pronunciation, even idiosyncratic voice mannerisms. The extra-linguistic contexts are aspects of communication used in addition to speech: facial expression, posture, loudness of voice, for example.
Prosody is a term typically employed to refer to the linguistic use of pitch, loudness, tempo, and rhythm (Crystal, 1997: 435) The term prosody is used in this study to indicate an element of pragmatics that is concerned with the meanings conveyed by variations in intonation, loudness, speed, rhythm, and silence during speech production (Perkins, 2007). These aspects constitute the prosodic features of speech. Prosody can be used to express emotion and attitude toward the propositional content of one’s utterances (Perkins, 2007). Prosody is a tool of human expression that is conveyed acoustically by way of durational, intensity, and frequency cues. To these conventional cues, one could add linearity (e.g., abrupt vs. smooth changes in pitch, loudness, or duration) as a possible fourth dimension (Boutsen, 2003). Boutsen (2003) distinguishes between intrinsic and extrinsic prosody: “In stress-timed languages such as English, common prosodic processes include phrasal stress so that certain words receive relative prominence. Since phrasing and syntax are also particular to a language, it follows that the marking of boundaries by way of pausing, pitch resetting, and syllable lengthening are also language specific. The terms intrinsic and extrinsic prosody describe motor speech functions that are motivated by the linguistic code on the one hand, and use of the code for pragmatic effect on the other. Intrinsic prosody taps into left laterialized cortical circuits (including the anterior insula) that are part of a distributed loop involving the cerebellum and the basal ganglia (BG). In this regard, data suggest that the left hemisphere, more so than the right, is dedicated to faster speech activities, including voice onset time (VOT) and the production of consonants (transients). Extrinsic prosody refers to more deliberate modulations that yield meaningful yet subtle differences in the way words are spoken. Unlike intrinsic prosody, it is probably driven by right hemisphere mechanisms, particularly if it involves intonation or is to effect longer perceptual groupings”.

Speech in Speech-language Pathology terms, refers to motor movements executed in a specific sequence in order to produce recognisable sequences of speech sounds or words. Speech production is the ability to produce sounds by coordinating and moving specific oral motor structures (e.g., tongue, mouth) at the right time (SLP-Allied Health Staffing Network, 2014).
Supra-linguistic is defined in the Oxford dictionary as: Not involving or beyond the bounds of language. In Speech-language Pathology, supra-linguistic understanding refers to the ability to analyze language at a level not ordinarily required when dealing with only word meaning and order. This includes understanding of nonliteral language, gathering meaning from context, inferring meaning when the information needed is not "right there," and recognizing ambiguity in sentences (Walsh, 2007). In the Comprehensive Assessment of Spoken Language (CASL) (Carrow-Woolfolk, 1999) it is used to refer to the comprehension of complex language whose meaning is not directly available from lexical or grammatical information. Abilities tested include: Nonliteral Language, Meaning from Context, Inference, and Ambiguous Sentences.

Traumatic brain injury refers to an injury to the brain caused by trauma to the head (Lezak, Howieson & Loring, 2004). Primary damage to the brain is sustained at the moment of impact, although subsequent pathological processes may cause secondary brain damage. These processes include brain swelling, intracranial hematoma, and the effects on the brain of extracranial events such as blood loss, arterial hypotension, and pulmonary complications. Diffused ischemic brain damage is often a result of the combined effects of these secondary processes (Rosenthal, Griffith, Bond & Miller, 1990). The widespread nature of diffused ischemic brain damage causes a large number of physical, cognitive, emotional, and behavioral effects (Bener, Omar, Ahmad, Al-Mulla & Rahman, 2010).
CHAPTER 1
LITERATURE REVIEW, PROBLEM STATEMENT AND RATIONALE

1 INTRODUCTION TO CHAPTER 1

Effective communication interaction forms the foundation for establishing new and maintaining existing relationships. The ability to communicate effectively is a prerequisite for participation in many activities of daily living and typically requires competence in both verbal and non-verbal communication skills (Yorkston & Baylor, 2011). Effective communication interaction furthermore not only facilitates acceptance by peers and family members, but allows a person to meet the social communication demands within the extended community (Coelho, Ylvisaker & Turkstra, 2005; Dahlberg, Hawley, Morey, Newman, Cusick & Harrison-Felix, 2006; Graesser, Millis & Zwaan, 1997). An effective communicator is able to perform a number of tasks simultaneously; to quote Turkstra, McDonald and Kaufmann (1995:329), to “meet the informational needs of the listener, verbalize ideas in a logical and coherent sequence, share the burden of conversation with a partner, and monitor the appropriateness of one’s speech in a particular context”.

Communication interaction with individuals after they have sustained a severe traumatic brain injury (TBI) has been reported to be less enjoyable, less interesting, and less rewarding - a description which implies that the demands for effective communication interaction are not met (Brooks, McKinlay, Symminton, Beatie & Campsie, 1987; Coelho, Youse & Le, 2002; Dahlberg et al., 2006; Paterson & Stewart, 2002). The communication interaction of these individuals is influenced by a combination of pre-morbid and injury-related factors that have a direct impact on their ability to participate effectively in conversation (Snow & Douglas, 1999; Struchen, Pappadis, Sander, Burrows, & Myszka, 2011). Verbal interaction may be confusing, inappropriate, and inaccurate due to difficulties with initiation and organization of discourse, inadequate volume control during speech production, and/or difficulty relinquishing a conversational turn during communication interaction with others (Douglas, Bracy & Snow, 2007). Problems at extra-linguistic (i.e. beyond the bounds of language) levels of comprehension within a conversation are also commonly associated with severe TBI. These may include the inability to recognize
emotions expressed by other people both in their voice and in their facial expression, information processing, abstraction, reasoning, and understanding the subtle rules surrounding the conversational context (Shorland & Douglas, 2010). All of these problems contribute to the poor management of communication exchanges. Poor management of communication exchanges leads to communication that is mainly restricted to the home setting because it involves fewer social relationships, and a limited ability to function in society (Galski, Tompkins & Johnston, 1998; Hammond, Hart, Bushnik, Corrigan & Sasser, 2004; Milton, Prutting & Binder, 1984; Sander, Clark & Pappadis, 2010).

The World Health Organization (WHO) considers human functioning in society (natural environment) to be a vital component of health. The International Classification of Functioning, Disability and Health (ICF) framework was developed by the WHO (2001) to provide an internationally recognized framework to explain human functioning and disability. The framework allows us to understand, describe, and measure the impact on peoples’ lives of communication problems after severe TBI. Larkins (2007) depicts the framework as having two parts. Part one describes the individual in terms of body function and structures, including physiological and psychological functioning. This component also considers how the individual performs at and participates in a given task in a life situation. The second part examines contextual factors including environmental and personal factors contributing as either barriers or facilitators. Disability and functioning are viewed as outcomes of the interactions between health conditions and contextual factors (Larkins, 2007). According to the ICF framework, communication interaction problems due to impaired physiological and psychological functioning after a severe TBI will influence performance and participation in everyday life situations. Within this framework, caregivers of individuals with severe TBI form part of the interactive context. They can, with the right support and training, act as facilitators in the natural environment to help individuals with TBI communicate more effectively (Togher, 2010).

The present study paid attention to cognitive, functional, and social communication related problems associated with severe TBI, as perceived by caregivers of individuals with severe TBI. The study was concerned with the nature of pragmatic
and discourse difficulties during the chronic stage after severe TBI, from the perspective of caregivers and their ways of dealing with such difficulties. The study investigated two aspects: (1) how caregivers perceive communication interaction difficulties and (2) how they deal with the problems arising from these difficulties. The focus was on pragmatic and discourse problems encountered during communication with individuals with severe TBI.

2 LITERATURE REVIEW

This section presents a brief review of the literature which aims to specify and describe applicable theoretical concepts regarding severe TBI, communication interaction, and the characteristics of individuals with severe TBI, as well as the role of the caregiver during the chronic stage of severe TBI. The theoretical concepts are presented in systematical order and grounded in recent literature to serve as a foundation for planning and executing this study.

2.1 Severe traumatic brain injury

The term Traumatic Brain Injury (TBI) generally refers to an injury to the brain caused by trauma to the head (Lezak, Howieson & Loring, 2004). Usually, some period of unconsciousness and post-traumatic amnesia result from the trauma to the head. Information in this regard is important to guide the classification of severity of the brain damage. A severe TBI is classified according to the Glasgow Coma Scale (Teasdale & Jennett, 1974) as a score indicating a state of unconsciousness (a score on admission ranging between 3 and 8), or Post-Traumatic Amnesia for a period of 7 days or more after the injury occurred.

Primary damage to the brain is sustained at the moment of impact, although subsequent pathological processes may cause secondary brain damage. These processes include brain swelling, intracranial hematoma, and the effects on the brain of extracranial events such as blood loss, arterial hypotension, and pulmonary complications. Diffused ischemic brain damage is often a result of the combined effects of these secondary processes (Rosenthal, Griffith, Bond & Miller, 1990). The widespread nature of diffused ischemic brain damage causes a large number of physical, cognitive, emotional, and behavioural effects (Bener, Omar, Ahmad, Al-
Mulla & Rahman, 2010). Studies have repeatedly shown that disruptions of behavioural, cognitive, and communicative function are amongst the most prevalent and persistent TBI sequelae, interacting to produce a major barrier to activities of daily living and societal participation (Braden, Hawley, Newman, Morey, Gerber & Harrison-Felix, 2010; Dahlberg et al., 2006; Hammond et al., 2004).

2.2 Communication interaction and the individual with severe TBI

Functioning in society requires the ability to interact and communicate effectively. Communication interaction allows one to take part in life situations where knowledge, information, ideas, or feelings are exchanged within a social context (Eadie et al., 2006). It is a reciprocal process in which each participant should be alert to the informational needs of the other to ensure a successful transition of intended meanings during conversation (Owens, 2001). The act of communicating draws on several interpersonal and intrapersonal skills. These include speaking, listening, observing, questioning, processing, analyzing, and evaluating (Rudebusch & Wiechmann, 2006; Yorkston et al., 2008). The quality and success of communication interaction is determined by the participants in the conversation, the conversational message, and the environment in which interaction takes place. Participants are those who are involved in the interaction, continuously changing roles as senders or recipients of a conversational message. Competent participants should be able to convey messages effectively but also interpret messages accurately.

A conversation entails both verbal and non-verbal elements. The verbal elements of the message involve the spoken words and how they are combined into phrases and longer units to make grammatical and semantic sense. Communication also comprises non-verbal elements. The non-verbal elements of interaction are those that communicate the paralinguistic information such as attitude, emotions and intentions (Thati, 2012). Non-verbal communication behaviour such as eye contact, body language, facial expressions, hand gestures, and the various ways of revealing emotional state are very powerful in conveying social information and affect (Burgoon, Guerrero & Floyd, 2010; Spell & Frank, 2000; Watts & Douglas, 2006). Prosody is an element of speech, which contributes to generate the pragmatic meaning of a communication act (Angeleri, Bara, Bosco, Colle, Sacco & Zettin,
The term *conversational environment* refers to the setting in which the communication interaction takes place. Every conversational environment is unique and each participant in a communicative exchange is implicitly required to follow a range of well-established communication norms (Angeleri et al., 2008). Recipients of a message must be able to identify the intent of the sender, take into account the context of the message, resolve any misunderstandings, accurately decode the information, and decide how to act on it. These skills enable participants to encode and decode a conversational message successfully and are essential for learning, forming healthy relationships, creating a sense of community, and achieving success in the workplace (Channon & Watts, 2003).

According to Sarno (1980), individuals with TBI are able to speak very well, but communicate very badly. As a result they have marked difficulties in functional conversation and social interaction (Gauvin-Lepage & Lefebvre, 2010; Huang, Ho & Yang, 2010). Research has shown that the range of communicative deficits resulting from severe TBI cannot be adequately explained in terms of linguistic impairment, because these individuals do not display classical aphasic symptoms (Angeleri et al., 2007; Cummings, 2007; McDonald, 1993). Syntactic and lexical abilities are often normal and performance on conventional language assessment protocols is appropriate. The outcome of these investigations indicates that the substantial difficulties survivors of TBI have in managing interactions in their everyday life goes beyond the comprehension and production of correct lexical and syntactic aspects of communication (Angeleri et al., 2008).

Cognitive impairments related to severe TBI cause disturbances in attention, memory, sequencing, categorization, and associative abilities (Hagan, 1984; Mathias & Wheaton, 2007). These disturbances result in impaired capacity to organize and structure incoming information, emotional reactions, and the flow of thought. Disorganization in cognitive-communication skills are reflected in language use that is characterized by irrelevant utterances that may not make sense, difficulty inhibiting inappropriate utterances, word-finding difficulties, and difficulty in ordering words and propositions (Hagan, 1984; Shorland & Douglas, 2010; Snow, Douglas & Ponsford, 1998; Struchen et al., 2011). Interactions with these individuals leave the listener
with the impression that they are off-target, tangential, or disorganized (Angeleri et. al., 2008; Glosser, 1993; Luria, 1967).

The communication interaction problems associated with severe TBI will be explained according to existing literature under the aspects of communication interaction displayed in Figure 1. For the purpose of the current study the same divisions were used during the semi-structured interviews used for collecting data.

### 2.2.1 The content of information conveyed during communication interaction

The content of a conversation is determined by the quantity, the quality, and the efficiency of the information being conveyed during conversational interaction (Coelho, 2007). Coelho, Ylvisaker and Turkstra (2005) reviewed the outcomes of studies investigating the communicative abilities of brain-injured individuals and found that one of the main conversational impairments associated with severe TBI involves errors in the content of information conveyed during conversation, such as verbal disruptions, difficulties with word finding, errors in the transfer of information, and decreased response adequacy.

**Quantity.** Quantity of information refers to the amount of information being conveyed during communication interaction (Coelho, 2007). An important rule in conversation is for a speaker to be as informative as required, ensuring that his/her contribution to the conversation does not contain too much or too little information (Grice, 1975). Studies have found that survivors of severe TBI violate this rule by conveying either too much information during communication interaction or too little. Some research studies show that individuals with severe TBI have a limited ability to produce proficient conversation discourse because there is a lack of conversational content due to diminished verbal output (Coelho, 2007; Groher, 1977; Kilov, Togher, & Grant, 2009; Snow et al., 1998).
Figure 1: Aspects of communication interaction
In contrast, the results of a study by Turkstra, Brehm and Montgomery (2006) suggest that these individuals tend to convey too much unnecessary information during conversation. The results of Turkstra et al. (2006) are in agreement with earlier studies describing discourse of TBI survivors as long-winded, poorly organized and tangential (Angeleri et al., 2008; Coelho, 2007; Glosser, 1993; Luria, 1976; Penn, 1999).

Quality. The quality of the information being conveyed during communication interaction is judged in terms of how accurate the information is (Grice, 1975). The quality of a speaker's message should ensure that the conversation partner does not misinterpret what is being said. Conversational message inaccuracy associated with severe TBI is a result of memory impairment, poor self-monitoring, disinhibition, or confabulation (Douglas et al., 2007). As a result, communication interaction with these individuals is often described as irrelevant, redundant, off-target, or overly personalized (Coelho, 2007; Goldblum, 2005; Penn, 1999; Shorland & Douglas, 2010).

Efficiency. Efficiency of communication interaction refers to the conciseness of the content of the conversational message (Coelho, 2007; McDonald, Togher & Code, 1999). Individuals with severe TBI consistently demonstrate decreased efficiency in their discourse as a result of lengthier and slower spoken language (Coelho, 2007; McDonald et al., 1999), characterizing social interactions with individuals with severe TBI as effortful, less interesting, and unrewarding (Galski et al., 1998).

2.2.2 Cohesion and coherence

Cohesion and coherence (to be defined below) imply analyzing structures and relations of communication interaction beyond the level of the sentence, including the overall organization of discourse and the logical progression of ideas (Perkins, 2007). Cohesion is considered part of the language system, and is realized through the use of explicit linguistic devices. Coherence, on the other hand, relies on cognitive systems such as memory, and executive functions such as planning, sequencing, and self-monitoring in conjunction with linguistic and sensorimotor systems (Perkins, 2007: 132). Impaired cohesion and coherence compromise the effective communication interaction because of an increased effort required from the
Cohesion. The term cohesion refers to the grammatical and lexical linking within an extended utterance that holds the text together and gives it meaning. Meaning across sentences is linked through the use of cohesive markers (Halliday & Hasan, 1976). A cohesive marker is a word that completes meaning in text by leading the listener to information elsewhere in the text. Cohesion allows the speaker to successfully present the listener with complete semantic relationships (Coelho, 1999). Jorgensen and Togher (2009) noted that survivors of TBI, most of whom were severely injured but had recovered a high level of functional language, used significantly fewer cohesive markers per communication unit than controls who had not suffered TBI. These findings provide evidence that the discourse of speakers who suffered TBI lacked continuity (Hartley & Jensen, 1991; Mentis & Prutting, 1987). The use of inadequate cohesion patterns by individuals with TBI is related to reduced linguistic processing abilities, limited pragmatic abilities, and attempts at compensating for linguistic deficits (Mentis & Prutting, 1987).

Coherence. Coherence refers to the pragmatic and semantic connectedness of sentences within a conversational message (De Beaugrande & Dressler, 1981). Judgments of coherence are typically based on rating spontaneous communication on the basis of the following: inclusion of adequate detail, word reference, plausibility, and conclusions (Ehrlich & Barry, 1989). In order to produce discourse that is perceived as coherent one should have intact access to semantic memory representation of real-world knowledge, as well as both the perceptual and conceptual integration necessary to maintain the plan and overall organization of discourse (Van Leer & Turkstra, 1999). Finally, coherence depends on an intact ability to simultaneously attend to and mentally manipulate information required for coordinating the speaker’s plan and the listener’s perspective (Glosser & Deser, 1990). Individuals with TBI show significantly impaired coherence compared to non-injured subjects, which greatly compromises their performance on descriptive tasks and referential communication tasks in terms of information content and its organization (Glosser & Deser, 1990; McDonald, 1993).
2.2.3 Pragmatic aspects of communication interaction

The term *Pragmatics* has different conceptual content depending on the field of study. In Speech-Language Pathology, *Pragmatics* refers to the use of language in a social, that is, a communication context (Hoffman, Martens, Fox, Rabidoux & Andridge, 2013: 198). Pragmatic aspects of language use are dependent on the speaker, the addressee, and various other features of the context of utterance (SIL International, 2004). In the Speech-Language Pathology context, the term Pragmatics has traditionally been used to indicate the ability to recognize and use appropriate and functional language in a situational context (e.g. Carrow-Woolfolk, 1999).

The social demands during a conversation include the ability to maintain an ongoing awareness of the needs of all conversational partners, to engage in appropriate turn-taking, to initiate and change topic throughout the interaction, to inhibit comments and other behaviours that are inappropriate to the exchange, to understand metaphorical and figurative language, and to continually monitor the overall flow of the conversation and make necessary adjustments as needed (Berko-Gleason & Ratner, 2009; Coelho, 1999). Social communication interaction requires both verbal and non-verbal skills that allow one to understand the communication intentions of others, but also the ability to express oneself appropriately in a manner that conveys the intended meaning (Prutting, 1982; Ylvisaker, Feeney & Urbancyzk 1993).

Pragmatic behaviour, therefore, refers to appropriate use of linguistic as well as nonlinguistic aspects of language for the purpose of communication (Cherney, 1998; Perkins, 2007). Impaired pragmatic behaviour after severe TBI has the potential to disrupt or penalize conversational interactions (Coelho, 2007), which typically results in decreased social contact (Björkdahl, 2010; Sander et al., 2010; Shorland & Douglas, 2010). The impaired pragmatic behaviours associated with severe TBI are the following: inadequate use of prosody, poor turn-taking, inappropriate comments, difficulty in managing the topic of conversation, inaccurate interpretation, and use of non-verbal communication behaviour.

**Impaired prosody.** The term *prosody* is used in this study to indicate an element of pragmatics that is concerned with the meanings conveyed by variations in intonation,
loudness, speed, rhythm, and silence during speech production (Perkins, 2007). Prosody can be used to express emotion and attitude toward the propositional content of one’s utterances (Perkins, 2007). Impaired elements of prosody that have been associated with communication after severe TBI include frequent incomplete responses, extended silences, and slow conversational style (ASHA, 2002; Shorland & Douglas, 2010; Struchen et al., 2011), as well as poor control over voice production to express emotion and attitude (ASHA, 2002; Perkins, 2007). Neumann (2010) suggested that individuals with TBI have a decreased capacity to experience, perceive, and empathize with emotions, resulting in inappropriate or inadequate social responses in that particular conversation. The responses of individuals with TBI have been described as oblivious to needs, displaying an inability to give comfort in times of sadness or worry, showing lack of participation in joy, and unresponsive to frustrations. Croker and McDonald (2005) suggested that the alteration in subjective emotional experience correlated significantly with emotion recognition performance. ASHA (2002) reported that individuals may seem either overemotional (overreacting) or "flat" (without emotional affect). Most frustrating to families and friends, a person may have little to no awareness of just how inappropriately he or she is acting. In general, communication can be very frustrating, misleading, and unsuccessful. It is clear that the individual with TBI often does not have the capacity to respond effectively in a social environment, due to a limited ability to interpret social demands successfully.

**Poor turn-taking.** Natural dialogue consists of an alternation of turns. Turn-taking forms part of the structure of a conversation, according to the Cognitive Pragmatic theory (Angeleri et al., 2008). Poor turn-taking, characterized by an excessive number of conversational turns, has been associated with severe TBI (Coelho, Liles & Duffy, 1991; Milton et al., 1984).

**Inappropriate comment.** The communication interaction behaviour of individuals with severe TBI has often been described as unskilled and inappropriate (McDonald, Tate, Togher, Bornhofen, Long, Gertler & Bowen, 2008). Problems include insensitivity toward others, overly familiar and disinhibited remarks, inappropriate levels of self-disclosure and egocentricity – in brief, self-focused conversation without interest in other people (Kilov et al., 2009; McDonald et al., 2008; Struchen et
Several studies found that the communicative inappropriateness of individuals with severe TBI represents the most debilitating obstacle to social reintegration (Björkdahl, 2010; Milton et al., 1984; Sander et al., 2010; Shorland & Douglas, 2010; Struchen et al., 2011).

**Difficulty in managing the topic of conversation.** In their literature review on the communication interaction behaviour associated with severe TBI, Galski, Tompkins and Johnston (1998) summarized several studies confirming that individuals with severe TBI display impairments in initiating, maintaining, expanding, shifting, and/or terminating topics of conversation. Studies using non-standardized measurements also identified decreased initiation and maintenance of conversational topic as most useful measures for identifying conversational impairments (Coelho et al., 2005). Recent research suggests that it is difficult to engage individuals with severe TBI in topics that are not personally relevant, and point to problems with immediate memory resulting in poor topic maintenance and reliance on additional conversational prompting (Kilov et al., 2009; Turkstra et al., 2006; Struchen et al., 2011).

**Inaccurate interpretation and use of non-verbal communication behaviour.** The ability to communicate effectively is influenced by non-verbal communication behaviour (Spell & Frank, 2000). Non-verbal communication behaviour refers to body language, gestures, facial expressions, and wordless responses carrying conversational or emotional meaning - for example, a sigh of relief or throat clearing to point out irony (Perkins, 2007; Spell & Frank, 2000). Non-verbal communication behaviour allows one to convey information, but also emotion (Frank & Spell, 2000; Perkins, 2007; Watts & Douglas, 2006). Fundamental to achieving effective communication and social interaction is the ability to recognize, interpret, and respond to non-verbal communication behaviour (McDonald, 2000; Rousseaux, Verigneaux & Kozlowski, 2010; Watts & Douglas, 2006). Individuals with TBI often reflect unusual patterns of non-verbal communication behaviour in terms of use, but also interpretation (Bara, Cutica & Tirassa, 2001; Turkstra et al., 2006).

Turkstra et al. (2006) describe non-verbal communication behaviour as interactional behaviours. Interactional behaviours include both physical and linguistic behaviours observed in spontaneous social exchanges as a function of interaction between
conversation partners. Physical behaviours include eye contact, nodding, and gesturing toward the listener; and linguistic behaviours include back-channel responses (e.g., saying ‘uh-huh’ during the partner’s utterances). Interactional behaviours contribute to the perception that communication partners are responsive to each other (Turkstra et al., 2006). Studying the communicative impairment in TBI, Angeleri et al. (2008) investigated the difficulties in manipulating different kinds of pragmatic phenomena in non-verbal communication. They found that individuals with TBI show significant difficulty in the production of assertions, questions, requests, and commands by communicating only through gestures.

The interpretation of non-verbal communication behaviour greatly influences communication competence. Non-verbal communication behaviour is generally understood to play a crucial role in communication, conveying both information and emotion. An individual’s ability to recognize, interpret, and respond to non-verbal cues is fundamental to achieving effective communication and social interaction (Morton & Wehman, 1995). The impaired ability to interpret non-verbal communication behaviours accurately is one of the reasons individuals with severe TBI display deficits in social and communication activities (Jackson & Moffat, 1987; Ross & Monnot, 2008; Spell & Frank, 2000; Watts & Douglas, 2006). A significant proportion of individuals with severe TBI present with social perception deficits, including deficits in understanding basic emotions, subtle emotions, speakers’ beliefs and intentions, and the meaning of conversational inference (McDonald & Flanagan, 2004). Such social difficulties contribute to a diminished capacity to function successfully in the community and to form social relationships (Karrow & Connors, 2003).

2.2.4 Communication interaction context

Communication is a prerequisite for adequate and appropriate interaction in all settings of daily living including work, social, academic, leisure, or community activities. The conversational setting refers to the context in which the communication exchanges occur. Within the communicative context different elements can have an impact on the participants’ conversational competence. These include the listeners and the speaker, the physical surroundings, the type of conversation, and the purpose of the conversation (Starkweather, 1987). The context
is described in terms of the nature of the social interaction that is taking place, the channel through which the conversational message is transmitted, and the nature of the participants, their status and roles within a particular conversation (Halliday, 1985; Hartley, 1990). Speakers select words, sentences, and modes of communication based on their knowledge of the cognitive and social status of the communication partner, of the physical context or setting of the communication, and of the linguistic and non-linguistic context. Additionally, a well-performed conversation is governed by norms related to politeness and the social status of the participants in a particular communicative context (Angeleri et al., 2008). A range of collective norms, defined and accepted within a specific communicative context, determines the social appropriateness of a specific communicative exchange. Such norms refer to when and how a person may speak and what a person is allowed to say, in relation to the social status and the hierarchical position of the interlocutors, and the formality versus informality of the context (Angeleri et al., 2008).

Social communication abilities allow us to use language in context, with various communication partners and in various settings (Struchen et al., 2011). Shorland and Douglas (2010) reviewed studies addressing the social outcome of TBI in the long term. These studies suggested a pattern of decline in interpersonal relationships after TBI, especially those with people outside of the family network. As a result, social networks of individuals with TBI decrease in size over time. In the end family members rather than friends make up the injured person’s social network. The poor communication skills displayed by individuals with TBI contribute to difficulty in engaging in social situations, leading to uncomfortable interactions with others. Such unsatisfactory interactions often contribute to rejection by others, which can in turn be conducive to negative self-concept, depressed mood, loneliness, and withdrawal from social situations (Coelho et al., 2005).

The communication interaction context is furthermore influenced by environmental factors such as family functioning, social support, government policies, and accessibility. According to the ICF framework social integration outcomes are not only a result of injury-related impairments, but also ensue from the interaction of impairments with these environmental factors that can serve as barriers to community participation (Sander et al., 2010).
2.3 Role of the caregiver during the chronic stage of severe TBI.

The transition from hospital to home forms a distinct and critical part of rehabilitation after TBI. It is typically a time of adjustment during which individuals with TBI and their family members attempt to reorganize their routines and occupational roles (Nalder, Flemming, Foster, Cornwell, Shields & Khan, 2012; Turner, Fleming, Ownsworth & Cornwell, 2007). Survivors of severe TBI are frequently left with a variety of deficits that have a lasting impact on their ability to function productively in their everyday lives (Knight, Devereux & Godfrey, 1998). These individuals encounter difficulties such as reduced independence in activities of daily living, need for greater reliance on others, difficulties re-engaging in social and occupational roles, and emotional distress (Nalder et al., 2012). Adapting to reduced competencies, problematic behaviours, and role changes following discharge from acute care can be a difficult process for the caregiver (Knight et al., 1998). Detrimental psychosocial and communicative consequences of severe TBI frequently limit the ability of the survivors to engage effectively in service encounters, participate in social activities, and maintain pre-morbid social roles. The manifestation of inappropriate and sometimes disturbing communicative behaviour is often difficult to manage, particularly within a community setting (Togher, McDonald, Code & Grant, 2004). Consequently, the management of communication interaction problems after severe TBI is an area of concern for the caregiver in the long term.

The combination of strengths and difficulties regarding communicative skills differ in relation to the individual’s age and pre-injury functioning, the nature and severity of the injury, and treatment available after injury (Ylvisaker & Feeney, 1998). Caregivers, who are in most cases family members of the injured individual, can make a meaningful contribution to the identification of communicative impairments. With their knowledge of the individual’s pre-morbid functioning, they are well placed to evaluate post-injury change in communication ability and to do so from within the same socio-demographic context as that of the individual with severe TBI (Douglas et al., 2007). Family members are also able to observe the individual with TBI consistently over time to identify communication interaction changes and how the individual responds to different attempts from the caregiver to improve communication interaction. Caregivers will be a communication partner in most
conversations. As communication partners, caregivers can have a significant effect on the communicative opportunities for individuals with severe TBI and contribute to increased conversational competence (Togher, 2010).

The need for coping strategies regarding problematic communication behaviour is highlighted in the literature. The nature of the coping strategies used by families who take care of the individuals with TBI is strongly predictive of their overall adjustment (Kosciulek, 1994; Krautzer, Stjeskal, Godwin, Powell & Arango-Lasprilla, 2010; Rotondi, Sinkule, Balzer, Harris & Moldovan, 2007). This is congruent with the findings of Sinnakaruppan and Williams (2002) that guidance for the family with regard to effective communication is one of the principle needs of caregivers. In existing literature on the impact of TBI on communication skills, the need for strategies to enhance effective communication interaction has been identified several times (Gideon, 2009; Rotondi et al., 2007; Struchen et al., 2011), but the unavailability of such strategies remains a major obstacle to all individuals involved with survivors of severe TBI (Shorland & Douglas, 2010; Struchen, Clark, Sandera, Mill, Evans & Kurtz, 2008).

2.4 Home-based care in South Africa

In South Africa there has been a significant increase in the overall burden of disease and disabilities, all of which impact on families and communities throughout South Africa (Department of Health, DOH, 2001). In an attempt to provide relevant support, the South African government published the National Guideline on Home-Based Care/Community-Based care for people with chronic diseases, disabilities and the geriatric population in December 2001 (DOH, 2001).

The DOH believes that through home-based and community-based care the limited health care resources in South Africa can be optimized. Home care is defined by the WHO as ‘the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person’s maximum level of comfort, function and health including care towards a dignified death’ (DOH, 2001:1). The rationale for home-based care, according to the DOH, is firstly limited health care resources in South Africa that may lead to the unavailability of hospital and other institutional care. Secondly, home-based care will provide support for people
who need extended care, not necessarily hospital care, or patients who are discharged early from hospital. The home-based care programme is directed at individuals who need basic support to continue to live in their community, which includes individuals with TBI. Home-based care and community-based care are built on the following three pillars: Integrated management and referral service organization, training and development of community personnel and professional/technical support personnel, and integration into the district health system (decentralisation).

When home-based and community-based care is implemented, patients can be discharged earlier from in-patient rehabilitation into the care of family caregivers, thereby eliminating redundant facilities and services to reduce costs. Speech language therapists, as professional personnel, can make a meaningful contribution to the implementation of the home-based care programme in South-Africa, by assisting caregivers of individuals with severe TBI with communication interaction difficulties.

2.5 Role of the speech-language therapist in the chronic stage after severe TBI

According to the American Speech-Language-Hearing Association (ASHA) one of the main objectives of speech-language therapy services is to optimize individuals’ ability to communicate in natural environments, and thus improve their quality of life. Speech-language therapists serve individuals, families, groups, and the general public through a broad range of professional activities (American Speech-Language-Hearing Association, 2008). Regarding individuals with severe TBI the role of the speech-language therapist is to deal directly with the communication problems associated with the injury, but also to educate caregivers on how compromised communication skills may impact on performance in conversation and to support them in how to handle these problems during the different stages of recovery (Snow & Douglas, 1999).

The recovery process after severe TBI can be divided into four stages: (1) acute care; (2) in-patient rehabilitation; (3) return home, a transitional period that typically lasts about 3 or 4 months after discharge from in-patient care; and (4) the chronic stage that could be described as “life in the community” (Rotondi et al., 2007:17).
Different intervention goals are important in each particular stage. The communication intervention goals of the speech-language therapist during the acute and in-patient recovery stage will typically focus on the assessment and treatment of changes in communication behaviour and cognitive processes that underpin the manifestations of disturbances in conversation discourse and interactional ability (Snow & Douglas, 1999). During these stages, intervention takes place in a structured environment, where the variables of communication are controlled by the speech-language therapist. The emphasis of communication intervention during the third stage and chronic fourth stage of the recovery process is to facilitate the use of these skills in everyday conversational interactions that are generally unstructured and often more complex (Snow & Douglas, 1999). It is important for the speech-language therapist, therefore, to find out more about the needs and experiences of caregivers that have to deal with and manage the communication interaction problems in natural unstructured social contexts during the chronic stage of recovery.

3 PROBLEM STATEMENT AND RATIONALE

Recent literature highlights the need for rehabilitation professionals to focus their long term intervention programmes on community re-entry, and maintenance of everyday skills in the life of the individual with TBI (Björkdahl, 2010; Sander et al., 2010; Shorland & Douglas, 2010; Snow & Douglas, 1999). This emphasis is in accord with the policy of the DOH in South Africa (DOH, 2001) which highlights the need for home-based and community-based care.

The tendency of health care services to discharge individuals with TBI from in-patient rehabilitation much sooner than previously contributes to the development of new problems. For example, by implementing home-based and community-based care too early, the number of days a patient spends in a rehabilitation facility is decreased, limiting the ability of the speech-language therapist to identify and address changes in communication interaction behaviour of the individual with TBI adequately (Frosch, Gruber, Jones, Myers, Noel, Westerlund & Zavisin, 1997). As a result, caregivers are not educated about the communication interaction changes they may experience during the chronic stage of the severe TBI. This leaves
caregivers ill-equipped to deal with these problems (Frosch et al., 1997; Nalder et al., 2012). An important rationale for the present study was that a better understanding of communication problems associated with severe TBI and the availability of suggested strategies to manage such problems may contribute to more effective communication interaction.

A further concern in the chronic stage of recovery is the possibility of intervention reaching a plateau, because of the impact of cognitive deficits on the extent to which individuals with severe TBI are able to compensate for their impairments or to learn and apply new knowledge and skills (Togher et al., 2004). Rotondi et al. (2007) suggested that family caregivers need targeted support and education to adjust to these permanent changes in the functioning of the individuals with TBI. Caregivers also need guidance on how to assist these individuals during the process of community re-integration (Nalder et al., 2012). Researchers have been investigating the value of training caregivers, specifically during the chronic stage of recovery, as part of a community re-integration intervention programme (Sinnakaruppan & Williams, 2002; Rotondi et al., 2007). Their investigations were motivated by the fact that caregivers form part of most of the communication interaction to which the individual with TBI is exposed and are therefore present to assist the individual when communication problems occur in a natural environment. Additionally, several studies suggested that training caregivers and family members, in conjunction with the person with TBI, led to improved perceived communication outcomes (Douglas, O’Flaherty & Snow, 2000; Togher et al., 2004; Togher, McDonald, Tate, Power & Rietdijk, 2009). The role of the speech-language therapist is not only to educate caregivers about ways in which compromised communication skills may impact on performance in conversation, but also to support caregivers in how to handle these problems (Snow & Douglas, 1999). In the literature, however, there are no published strategies or guidelines based on the experiences of caregivers regarding management of communication interaction problems and assistance of the individual with severe TBI to communicate more effectively in a natural environment. If speech-language therapists knew more about these problems and understood how caregivers experience them in an unstructured, natural environment, they would be better equipped to support individuals with severe TBI and provide guidance to
contribute to more effective communication (Chronistera, Chan, Sasson-Gelman & Chiu, 2010).

The long-term impact of severe TBI on communication interaction necessitates the availability of practical guidelines to help caregivers to enhance effective communication interaction in various communication settings (Braden et al., 2010). According to the literature there is limited empirical evidence to guide the treatment of communication interaction deficits in unstructured, natural environments. This scarcity of information highlights the need for the development and investigation of theoretically based interventions (Coelho, 2007; Wood & Alderman, 2011). Information on how caregivers experience and handle communication problems may better equip speech-language therapists to provide guidance to caregivers in future.

The aim of the present study was to determine the nature of pragmatic and discourse problems during the chronic stage after severe TBI, from the perspective of family caregivers and their ways of dealing with such problems in a natural environment.

The two research questions guiding this study are:

1) How do caregivers perceive the communication interaction problems of the individual with severe TBI they are caring for during the chronic stage after TBI?

2) How do caregivers deal with the problems they observe and what are the recommendations they offer to manage these problems to assist the individual with severe TBI to communicate more effectively in a natural environment?
CHAPTER 2
METHOD

1 INTRODUCTION TO CHAPTER 2

The aim of the present study was to investigate the diverse communication problems observed during the chronic stage after severe TBI, but to do so from the perspective of family caregivers. The study also recognizes the contribution of these caregivers to the communication wellness of the people they took into their care, by noting their ways of managing communication problems in a natural environment. In order to achieve these objectives the research was conducted in two phases. This chapter provides an explanation of the research method that was followed in the present study. The purpose of the study as well as the research design is described, followed by an explanation and description of the two research phases.

2 RESEARCH AIMS

The main aim of the present study was to determine the nature of pragmatic and discourse problems during the chronic stage after severe TBI, from the perspective of family caregivers and their ways of dealing with such problems in a natural environment. The following sub-aims were formulated in order to achieve this main aim:

- To determine how caregivers perceive the communication interaction of the individual with severe TBI they are caring for during the chronic stage after TBI (Individual semi-structured interviews – Phase 1).

- To determine how caregivers deal with the communication interaction problems they observe to assist the individual with severe TBI to communicate more effectively in a natural environment (Individual semi-structured interviews – Phase 1).

- To deepen the researcher’s understanding of the findings of Phase 1 by means of a focus group discussion with the participants and to particularly probe their suggestions regarding management of interaction problems (Focus group discussion – Phase 2).
The research process comprised two phases. During Phase 1, a series of semi-structured interviews served to collect data on caregivers’ perceptions and recommendations. During Phase 2, a focus group discussion was conducted with the participants of the semi-structured interviews. The chronological sequence of the various activities included in the research phases is represented in Figure 2.

3 PHASE 1

3.1 Phase 1: Aims

The first phase involved semi-structured interviews with caregivers. The purpose of this phase was in the first place to determine the nature of the pragmatic and discourse problems during the chronic stage of severe TBI, from the perspective of the caregiver. Secondly, this phase aimed to ascertain how caregivers deal with these communication problems and what recommendations they offer for managing these problems and assisting the individual with TBI to communicate more effectively in a natural environment.

3.2 Phase 1: Research design

Phase 1, during which semi-structured interviews were performed with caregivers, a collective case study approach was followed. It was carried out within a qualitative research framework. Qualitative research provides a means of studying individuals who function within a particular social setting. Through qualitative research the researcher gains access to unquantifiable information about the perspectives and experiences of individuals (Berg, 1998). Data were collected by means of semi-structured interviews. Interviewing can be defined as face-to-face interactions between an interviewer and an interviewee, where the purpose is to obtain qualitative descriptions of the life experiences and opinions of the interviewees as expressed in their own words (De Vos, 1998; Kvale, 1996). A semi-structured interview style was chosen for the present study. This type of interview involves a number of predetermined questions and/or topics typically asked in each interview in a systematic and consistent order (Berg 1998). The advantage of semi-structured interviews is that the interviewer is allowed freedom to probe and can facilitate the
bringing forward of information by the interviewee. This openness and flexibility ensures a higher completion rate and reduces the occurrence of invalid or incomplete answers (Babbie, 1973; Berg, 1998).

**PHASE 1**: Development and formulation of the semi-structured interview guide for caregivers of individuals who suffered a severe TBI.

(See part 3.5 of Chapter 2 and Appendix E for a full discussion and explanation of this questionnaire).

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Pilot study to determine the applicability of the questions to be asked during the interviews and subsequent modification of some of the questions.

(See part 3.6 of Chapter 2 for a description of the pilot study).

↓

Performing semi-structured interviews

↓

Processing of raw data and analysis of data collected during semi-structured interviews.

(See part 3.7 and 3.9 of Chapter 2 for a description of the data collection and analysis procedures)

↓

Description of analyzed data

(See part 2.1 of Chapter 3 for a description of the results)

↓

Discussion of results of the data collected during Phase 1

(See part 4 of Chapter 3 for a discussion of the results)

↓

**PHASE 2**: Development of the focus group discussion guide

(See part 4.4 of Chapter 2 for a description and explanation of the focus group discussion guide)

↓

Focus group discussion

↓

Processing of raw data and analysis of data collected during focus group discussion

(See part 4.5 and 4.7 of Chapter 2 for a description of the data collection and analysis procedures)

↓

Description of analyzed data

(See part 6.1 of Chapter 3 for a description of the results)

↓

Discussion of results

(See part 7 of Chapter 3 for a description of the results)

Figure 2: Chronological sequence of steps followed during Phases 1 and 2 of the research.
The responses of the caregivers were analyzed by performing a thematic analysis (Guest, Macqueen & Namey, 2012). Through the process of thematic analysis themes were identified that describe the problems caregivers experience regarding communication interaction and their ways in which they deal with such problems. Data collected during the semi-structured interviews served as foundation for planning the focus groups that followed.

3.3 Phase 1: Participants

Only caregivers of individuals with a severe TBI were considered for participation in the study, as the communication disorders experienced by these individuals would be serious enough to cause communication problems which will be obvious to caregivers (henceforth participants). The selection of participants started with identifying individuals who suffered a severe TBI. A sample of 20 individuals with severe TBI was recruited by means of purposeful sampling (Patton, 1990). With this strategy, particular settings and persons are deliberately selected in order to provide the information needed to answer the research question (Maxwell, 2005). These individuals were treated at an acute, in-patient rehabilitation centre in the Gauteng area, South Africa.

3.3.1 Criteria for the selection of individuals with severe TBI.

Severity of the TBI. Individuals with severe TBI were selected by purposeful sampling. The severity of the injury is indicated by the extent of altered consciousness experienced immediately following the head injury (McDonald et al., 1999). Two important clinical conditions indicate a severe brain injury: (1) a Glasgow Coma Scale (GCS) score ranging between 3 and 8 recorded immediately on admission (Teasdale & Jennett, 1976), or (2) post-traumatic amnesia (PTA), persisting for more than 24 hours (McDonald et al., 1999). Using the GCS, points are scored in three categories: eye opening, best motor response and best verbal response. PTA is the period of confusion immediately following coma, during this period a person fails to lay down new memories for ongoing events (Russell & Smith, 1961).
Place of residence. The individuals with severe TBI had to reside with participants after being discharged from a medical or rehabilitation setting. This ensured that the participants were familiar with the communication problems of the individual with severe TBI during everyday activities.

Age and gender. Gender was not a criterion for this study. The individuals with severe TBI had to be adults between the ages of 18 and 70 years to counteract the possible influence of age on language and communication ability.

Good speech intelligibility. The main focus of the present study was on communication interaction problems associated with severe TBI and not on communication problems caused by reduced speech intelligibility. For this reason only individuals with severe TBI who were able to produce intelligible speech were selected.

3.3.2 Criteria for the selection of interview participants.

The participants in this study included the caregivers of individuals with a severe TBI. Creswell (1998) recommends up to ten participants for a collective case study. A sample size of 20 participants was selected to take part in semi-structured interviews. Participants had to meet the following selection criteria:

Length of time since arrival at home. To ensure that participants had adequate time to observe communication abilities of the individual with severe TBI in a home and social environment, the length of time since arrival at home had to be at least six months. Furthermore, it was assumed that the participants had developed strategies to overcome communication difficulties associated with the severe TBI by such time. Explain why duration of care giving is given as 5 months for 3 individuals

Relationship. The participant had to be a family member to ensure that this person was familiar with the pre-morbid communication ability and style of the individual with TBI.

Age. Only participants over the age of 25 years and not older than 70 years were included in the study. To rule out the influence of possible hearing impairment and/or cognitive impairment related to old age, only participants younger than 70 years
were included in the study. They also had to be older than 25 years to ensure an adult view on style of communication.

*Spoken language.* The interviews and the focus group discussion were performed in either English or Afrikaans as these are the only languages the researcher can speak and understand. The participants had to be first language speakers of one of these languages.

### 3.3.3 Selection procedures.

The first step of the selection procedure was to obtain permission to access patient records, as described in Section 3.4. Recruitment of participants started with identifying individuals who suffered a *severe* TBI by accessing patient records. Medical history was evaluated, to ensure consistency with prescribed selection criteria of severe TBI: initial Glasgow Coma Scale (GCS) score ranging between 3 and 8, or post-traumatic amnesia persisting for a period of seven days or more after the injury occurred. All individuals with severe TBI received in-patient therapy at the acute rehabilitation centre for an average of 5 weeks before being discharged to home. Caregivers of these individuals were contacted telephonically and asked if they would be prepared to take part in the study which included a semi-structured interview and a focus group discussion. Appointments for the interview were scheduled with individuals who agreed to take part in the study.

### 3.3.4 Description of participants.

Twenty caregivers of individuals with severe brain injury were approached and requested to take part in the study. Only 10 of the selected participants agreed to take part in the study. A description of the participants is provided in Table 1. From the information in Table 1 it is clear that the majority of the participants were married females between the ages of 29 and 61 and mainly mothers or wives of the individual with TBI. Four of the individuals with severe TBI lived independently from the participant before the injury. These individuals were required to become a member of the family environment of the participant in order for the participant to perform the role of caregiver. After the injury all ten individuals with severe TBI were staying with the participant at home.
Table 1: Description of participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Marital status</th>
<th>Relationship to individual with TBI and language</th>
<th>Duration of care giving</th>
<th>Working status before incident and educational level</th>
<th>Working status after incident</th>
<th>Living situation before incident</th>
<th>Living situation after incident</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Female</td>
<td>55</td>
<td>Married</td>
<td>Mother Afrikaans</td>
<td>5 months</td>
<td>Housewife Passed Grade 12</td>
<td>Housewife</td>
<td>Living separately from individual with TBI</td>
<td>Living in a family environment with individual with TBI</td>
</tr>
<tr>
<td>2</td>
<td>Female</td>
<td>29</td>
<td>Married</td>
<td>Sister English</td>
<td>11 months</td>
<td>Full day employment Post-Matric qualification</td>
<td>Full day employment</td>
<td>Living separately from individual with TBI</td>
<td>Living in a family environment with individual with TBI</td>
</tr>
<tr>
<td>3</td>
<td>Female</td>
<td>54</td>
<td>Married</td>
<td>Mother Afrikaans</td>
<td>22 months</td>
<td>Housewife Post-Matric qualification</td>
<td>Housewife</td>
<td>Living separately from individual with TBI</td>
<td>Living in a family environment with individual with TBI</td>
</tr>
<tr>
<td>4</td>
<td>Male</td>
<td>61</td>
<td>Married</td>
<td>Husband English</td>
<td>7 months</td>
<td>Retired Post-Matric qualification</td>
<td>Half day employment</td>
<td>Living with spouse</td>
<td>Living with spouse</td>
</tr>
<tr>
<td>5</td>
<td>Female</td>
<td>50</td>
<td>Married</td>
<td>Mother Afrikaans</td>
<td>12 months</td>
<td>Full day employment Post-Matric qualification</td>
<td>Full day employment</td>
<td>Living in a family environment with individual with TBI</td>
<td>Living in a family environment with individual with TBI</td>
</tr>
<tr>
<td>6</td>
<td>Female</td>
<td>33</td>
<td>Married</td>
<td>Wife English</td>
<td>18 months</td>
<td>Housewife Passed grade 12</td>
<td>Half day employment</td>
<td>Living in a family environment with individual with TBI</td>
<td>Living in a family environment with individual with TBI</td>
</tr>
<tr>
<td>7</td>
<td>Female</td>
<td>34</td>
<td>Married</td>
<td>Wife Afrikaans</td>
<td>28 months</td>
<td>Half day employment Post-Matric qualification</td>
<td>Full day employment</td>
<td>Living in a family environment with individual with TBI</td>
<td>Living in a family environment with individual with TBI</td>
</tr>
<tr>
<td>8</td>
<td>Female</td>
<td>33</td>
<td>Married</td>
<td>Wife Afrikaans</td>
<td>5 months</td>
<td>Half day employment Post-Matric qualification</td>
<td>Full day employment</td>
<td>Living in a family environment with individual with TBI</td>
<td>Living in a family environment with individual with TBI</td>
</tr>
<tr>
<td>9</td>
<td>Female</td>
<td>51</td>
<td>Married</td>
<td>Mother Afrikaans</td>
<td>7 Months</td>
<td>Full day employment Post-Matric qualification</td>
<td>Full day employment</td>
<td>Living separately from individual with TBI</td>
<td>Living in a family environment with individual with TBI</td>
</tr>
<tr>
<td>10</td>
<td>Female</td>
<td>52</td>
<td>Married</td>
<td>Wife Afrikaans</td>
<td>5 months</td>
<td>Housewife Passed Grade 12</td>
<td>Half day employment</td>
<td>Living with spouse</td>
<td>Living with spouse</td>
</tr>
</tbody>
</table>
During an average of six months after the individual with TBI was discharged to the home environment five of the participants’ working status changed, either from housewife to half day employment or from half day employment to full day employment.

Furthermore, the living situation of most of the participants can be described as a family environment, including other individuals (spouses, siblings, etc.) in the family set-up.

3.4 Phase 1: Ethical considerations

- A letter explaining the purpose and nature of the study and requesting permission to access patient records to assist with the identification of patients with severe TBI was addressed to a local rehabilitation centre for individuals who had suffered brain damage (See Appendix A).

- The rehabilitation centre granted written consent to access patient records, contact numbers and the medical history of patients who suffered a severe TBI (See Appendix B).

- The Ethics committee of the Faculty of Humanities of the University of Pretoria was approached for ethical clearance. See Appendix C for the ethical clearance letter from the University of Pretoria.

- On first contact the purpose of the study was explained to the participant and they were asked to complete an informed consent form (see Appendix D).

3.5 Phase 1: Development of semi-structured interview guide

The semi-structured interview guide (see Appendix E) contained an outline of the sections, supportive sub-sections and suggested questions to be covered during the semi-structured interviews. In support of the first sub-aim, the sections and related questions of the guide focused on the nature of the communication interaction problems during the chronic stage after severe TBI as experienced from the perspective of the caregiver. In order to develop a comprehensive semi-structured interview guide various assessment tools focusing on possible communication interaction problems associated with severe TBI were used. These included the Pragmatic Protocol of Prutting and Kirchner (1987), Damico’s Clinical Discourse Analysis based on the Cooperative Principles of Grice (1975), the La Trobe
Communication Questionnaire (Douglas et al., 2000) and The Assessment Battery of Communication – AbaCo (Angeleri et al., 2008). The communication difficulties after severe TBI as defined by the American Speech Language and Hearing Association (2002) were taken into consideration, as well as literature focusing on communication interaction problems following severe TBI (Brooks et al., 1987; Galski et al., 1998; Hux, 2002; Lezak, et al., 2004; Penn, 1999; Snow et al., 1998; Turkstra et al., 1995; Ylvisaker, & Feeney, 1998). In Table 2 the justification for the sections and questions that were included in the questionnaire are summarized.

3.6 Phase 1: Pilot study

A pilot study was conducted to determine the appropriateness of the semi-structured interview guide. A great deal of time can be saved by ‘fine tuning’ the questions of the interview, before starting with formal data collection (Leedy & Ormrod, 2005). A pilot study additionally contributes to the credibility, reliability, and validity of the methods used during data collection (De Vos, 1998). In Table 3 the details regarding the pilot study are provided.

After making the recommended changes to the semi-structured interview guide and based on the feedback, the interview schedule was considered adequate for conduction of the main study.

3.7 Phase 1: Data collection procedures

The following procedure was followed during each semi-structured interview:

- Before the interview started the participants were provided with a context for the interview, defining the situation and the purpose of the interview (Kvale, 1996).

- The informed consent form was completed by each participant (see Appendix D)
Table 2: Description and justification of sections and questions included in the questionnaire.

<table>
<thead>
<tr>
<th>Sections of questionnaire</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Section A: Biographic information</strong></td>
<td>The biographic information was important for the selection of the participants. A description of the cause of the injury, when it occurred and the severity of the injury was obtained with questions A1-A3.</td>
</tr>
<tr>
<td>- Tell me about the cause of the brain injury</td>
<td></td>
</tr>
<tr>
<td>- When did the injury happen?</td>
<td></td>
</tr>
<tr>
<td>- Was the person in a coma after the incident?</td>
<td></td>
</tr>
<tr>
<td>- For what period of time was the person in the coma?</td>
<td></td>
</tr>
<tr>
<td><strong>Section B: History regarding pre-morbid communication skills of the individual with severe TBI</strong></td>
<td>Information obtained from this request was important for the interpretation of the data to ensure the communication problems caregivers are experiencing are the result of the TBI.</td>
</tr>
<tr>
<td><strong>Section C: Communication problems regarding the content of the conversation</strong></td>
<td>The content of conversations was investigated by asking questions regarding the quantity and the quality of the information being conveyed during conversational interaction (Coelho, 2007).</td>
</tr>
<tr>
<td><strong>Quantity:</strong></td>
<td></td>
</tr>
<tr>
<td>- During a conversation do you experience that the person is giving too much or maybe too little information?</td>
<td>Quantity of information: Individuals with severe TBI may either convey too much or too little information during communication interaction. (Coelho, 2007; Kilov et al., 2009; Penn, 1999; Struchen et al., 2001).</td>
</tr>
<tr>
<td>- Can you describe to me why you say this?</td>
<td></td>
</tr>
<tr>
<td>- Do you make the person aware of this?</td>
<td></td>
</tr>
<tr>
<td>- How do you generally deal with this problem when you are having a conversation with the person?</td>
<td></td>
</tr>
<tr>
<td><strong>Quality:</strong></td>
<td></td>
</tr>
<tr>
<td>- Do you experience that the person gives inaccurate or ambiguous information during conversation that influences the clarity of his/her message?</td>
<td>Quality of information: The quality of information conveyed during communication interaction is often reduced because the individual with severe TBI tends to convey information that is not accurate. This may result in confusion for the listener (Coelho et al., 2005; Coelho, 2007; Goldblum, 2005; Shorland &amp; Douglas, 2010; Togher et al., 2004).</td>
</tr>
<tr>
<td>- Can you tell me about these words and give a few examples?</td>
<td></td>
</tr>
<tr>
<td>- How do you generally deal with this?</td>
<td></td>
</tr>
</tbody>
</table>
Table 2 continued

<table>
<thead>
<tr>
<th>Sections of questionnaire</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Section D: Pragmatic competence</strong></td>
<td><strong>Prosody during communication interaction:</strong> Impaired elements of prosody that have been associated with communication skills after severe TBI include:</td>
</tr>
</tbody>
</table>
| **Prosody during communication interaction** | - Extended silences during conversation (ASHA, 2002)  
- Slow conversational style due to slow processing (Shorland & Douglas, 2010; Struchen et al., 2011)  
- Poor control over patterns of intonation and intensity to express emotion and attitude (ASHA, 2002; Perkins, 2007)  
- Decreased efficiency in their discourse as a result of lengthier and slower spoken language (Coelho, 2007; McDonald et al., 1999). |
| - Do you experience long silences during conversation that may disrupt the flow of the conversation?  
- Tell me about the disruptions you are observing  
- Do you make the person aware when this kind of disruptions occurs?  
- How do you generally deal with this? | **Pragmatic competence is important during interaction and aspects such as extended silences, slow conversational style and inappropriate voice intensity may impact interaction negatively.** |
| - How would you describe the intensity of the person’s voice during conversation, for example, is it too loud or too soft?  
- Do you make the person aware of this?  
- How do you generally deal with this? | |
| - How would you describe the rate of his/her speech production during conversation?  
- Do you make the person aware of this?  
- How do you generally deal with this? | |
| - How would you describe his/her ability to adequately use voice production to express emotion and attitude?  
- How does this impact on conversations?  
- How do you generally deal with this? | |
<table>
<thead>
<tr>
<th>Sections of questionnaire</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Turn taking</strong></td>
<td><em>Turn taking:</em> As early as 1984 the poor ability of individuals with severe TBI to take turns appropriately during conversational interaction was determined (Milton et al., 1984).</td>
</tr>
<tr>
<td></td>
<td><strong>Non-verbal communication behaviour:</strong> Non-verbal communication is extremely broad and complex. The <em>linguistic</em> (i.e. rule-governed) forms include accent, pronunciation, etc. The <em>extra-linguistic</em> forms are aspects of communication used in addition to speech: facial expression, posture, loudness of voice, for example. Certain forms of non-verbal communication, including wordless responses carrying conversational or emotional meaning for example a sigh of relief or throat clearing to point out irony, are often described as <em>supralinguistic</em> features – these require skills in inferring meaning from the social context (Walsh, 2007). For the purpose of this investigation, the general term <em>non-verbal communication</em> was used to refer to body language, gestures, facial expressions and voice intonations, as well as any other form of communication not primarily conveyed by words. Difficulty in recognizing, interpreting, and responding to non-verbal cues have been associated with the TBI population, contributing to a diminished capacity to function successfully in the community and form social relationships (Karrow &amp; Connors, 2003; Spell &amp; Frank, 2000; Turkstra et al., 2006; Watts &amp; Douglas, 2006).</td>
</tr>
</tbody>
</table>
| In conversation is the person able to wait appropriately for a speaking turn? | - Do you make the person aware that he/she is not appropriately waiting for a speaking turn?  
- How do you generally deal with this? |
| How would you describe the person’s use of gestures during conversation? | - And is he/she able to maintain eye contact appropriately? |
| Would you describe his/her facial expressions as appropriate during conversation? | - How does this influence the conversation?  
- How do you generally deal with it? |
### Table 2 continued

<table>
<thead>
<tr>
<th>Sections of questionnaire</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Section E: Discourse competence</strong></td>
<td><strong>Inappropriate comments.</strong> The communication interaction behaviour of individuals with severe TBI has often been described as unskilled and inappropriate. Problems include insensitivity toward others, inappropriate responses to social conversation, and egocentricity (Kilov et al., 2009; McDonald, et al., 2008; Struchen et al., 2011).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Inappropriate comments</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Does the person ever give inappropriate comments during a conversation?</td>
<td></td>
</tr>
<tr>
<td>- How do you generally deal with this?</td>
<td></td>
</tr>
</tbody>
</table>

**Management of topic of conversation: Initiating**

| - Does the person need encouragement to start a conversation? |
| - How do you encourage him/her to start a conversation? |

**Management of topic of conversation: Maintaining**

| - Would you say the person is able to maintain the topic of conversation adequately? |
| - Tell me more about the problems you are experiencing regarding topic maintenance. |
| - Do you refer the person back to the topic of conversation? |
| - How do you generally deal with this? |

**Management of topic of conversation: Expanding**

| - Would you say the person is able to adequately expand on a conversational topic? |
| - How do you generally deal with this? |
### Table 2 continued

<table>
<thead>
<tr>
<th>Sections of questionnaire</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Management of topic of conversation: Shifting</strong></td>
<td></td>
</tr>
<tr>
<td>• When a particular topic of discussion has been closed and the conversation is moving on to another topic, is the person able to move on to the new topic?</td>
<td></td>
</tr>
<tr>
<td>- Do you make him/her aware of the fact that the conversational topic has changed?</td>
<td></td>
</tr>
<tr>
<td>- How do you generally deal with this?</td>
<td></td>
</tr>
<tr>
<td><strong>Management of topic of conversation: Termination</strong></td>
<td></td>
</tr>
<tr>
<td>• Is the person able to appropriately end a conversation?</td>
<td></td>
</tr>
<tr>
<td>- Tell me why you say he/she is not able to end a conversation appropriately?</td>
<td></td>
</tr>
<tr>
<td>- Do you make the person aware that the conversation has ended?</td>
<td></td>
</tr>
<tr>
<td>- How do you generally deal with this?</td>
<td></td>
</tr>
<tr>
<td><strong>Cohesion and coherence</strong></td>
<td></td>
</tr>
<tr>
<td>• How would you describe the overall organization of a conversation and the logical sequencing of ideas of the person?</td>
<td></td>
</tr>
<tr>
<td>- How do you generally deal with this?</td>
<td></td>
</tr>
</tbody>
</table>

*Cohesion and coherence.* Disrupted patterns of cohesion and coherence have been associated with communication problems after severe TBI, contributing to discourse lacking continuity (Coelho, 2007; Hagen, 1984; Hartley & Jensen 1991).
Table 2 continued

<table>
<thead>
<tr>
<th>Sections of questionnaire</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Section F: Conversational settings</strong></td>
<td>TBI subjects' conversational style in demanding conversation contexts is often described as slow, frequently demonstrating incomplete responses, numerous pauses and reliance on set expressions (McDonald et al., 1999; Thomsen, 1975). Conversational style may differ in different situations so that the range of communication behaviours could be probed.</td>
</tr>
<tr>
<td>- In view of the possible communication problems you have identified, how do different conversational settings impact on his/her communication?</td>
<td></td>
</tr>
<tr>
<td>- One-to-one communication situation?</td>
<td></td>
</tr>
<tr>
<td>- In a conversation where a few people are present?</td>
<td></td>
</tr>
<tr>
<td>- In a public place where many people are present?</td>
<td></td>
</tr>
<tr>
<td>- Conversations with familiar people vs. strangers</td>
<td></td>
</tr>
<tr>
<td>- Conversation in different environments for example on the telephone or in motor vehicle.</td>
<td></td>
</tr>
</tbody>
</table>
Table 3: The pilot study

<table>
<thead>
<tr>
<th>Aim of the pilot study</th>
<th>The aim of the pilot study was to improve the reliability and validity of the questions in the semi-structured interview guide, to investigate the applicability of the semi-structured interview guide regarding the aims of the study, and to determine the intelligibility of the compound questions for participants (Fink &amp; Kosecoff, 1998; Leedy &amp; Ormrod, 2005).</th>
</tr>
</thead>
</table>
| Participants selected for pilot study | Participants of the pilot study included:  
  - Two speech-language therapists, specializing in neurological speech-language disorders with a minimum of 3 years working experience, and  
  - One caregiver of an individual with a severe TBI. |
| Procedures | The questions of the semi-structured interview guide were given to the participants of the pilot study to review and make recommendations accordingly.  
  - Appointments with the pilot study participants were scheduled to discuss recommendations.  
  - Questions were adapted and changed according to recommendations. In this way the researcher endeavored to ensure that participants in the main study clearly understood the content of the questions (De Vos, 1998). |
| Results and recommendations | All the participants indicated that the questions of the semi-structured interview guide were clear and easily understandable. The participants made the following recommendations:  
  - Adding extra examples of challenging communication settings in Section F regarding the communications settings. The following examples were included:  
    - Telephone conversations  
    - Conversing in a vehicle  
    - Conversing with friends vs. conversing with strangers  
  - Reconsidering the organization and wording of some of the topics of the semi-structured interview guide. Aspects that were pointed out were attended to and included:  
    - Instead of using the words “pragmatic and discourse problems” participants recommended use of the words “communication interaction problems” as these are more descriptive to lay persons.  
    - Dividing the aspect of non-verbal communication interaction into the use and interpretation (respectively) of non-verbal communication. |
Audio recordings were made of each interview to guarantee that the original data are kept and that the data can be validated (Babbie & Mouton, 2002:212).

The use of an audiotape recorder was explained and the recording equipment was set up as unobtrusively as possible.

The semi-structured interview guide (See Appendix E) was used to guide the researcher during conduction of the interviews.

After all the questions of the semi-structured interview were discussed, the interviewer reviewed some of the main points gleaned from the interview with the participant.

Finally the semi-structured interview was closed with a debriefing – explaining how the information would be used in the upcoming focus group discussion with the aim to deepen the understanding by discussing how different caregivers experience and deal with communication interaction problems after severe TBI.

3.8 Phase 1: Equipment

A Panasonic RQL 10 audiotape recorder was used during the semi-structured interviews. An audio recording allows a more complete and uninterrupted recording of data than handwritten notes; furthermore, the collected data can be listened to repeatedly to ensure more accurate data analysis (Greef, 2002; Leedy & Ormrod, 2005).

3.9 Phase 1: Data analysis and data processing

For the purpose of the first phase of the study thematic analysis was used to determine the nature of communication problems during the chronic stage of severe TBI from the perspective of caregivers and also their ways of dealing with such problems in a natural environment. Thematic analysis is a qualitative analytic method for ‘identifying, analyzing and reporting patterns (themes) within data’ (Braun & Clarke, 2006:6). The six phases of thematic analysis provided by Braun and Clarke (2006) were used during this study:
a) Becoming familiar with the data.

The audio recordings of each interview were transcribed immediately after the interview (See Appendices G-J). The process of transcription is a key phase of data analysis and an important way to start familiarizing oneself with the data (Riessman, in Braun & Clark, 2006). Recordings were replayed repeatedly to ensure accuracy, correctness and verification of the transcriptions. According to Braun and Clark (2006:16) “it is vital to immerse yourself in the data to the extent that you are familiar with the depth and breadth of the content”. This was achieved through repeated reading of the transcriptions.

b) Generating initial codes.

Through the process of coding, features of the data were identified regarding how caregivers experience and deal with communication interaction problems (Boyatzis, 1998). Open-coding was used to categorize the data. It involves the naming and categorization of experiences through critical examination of the data (Strauss & Corbin, 1990, 1998). Within each category characteristics and dimensions were identified. Verbatim transcriptions were organized in computer files and important themes were identified. The process is essential for the integration of the data.

c) Searching for themes and sub-themes.

The data were sorted into potential themes and sub-themes by collating all the relevant coded data extracts into categories, using constant comparative analysis within and across transcripts to identify conceptually discrete units (Glaser & Strauss, 1967). For the identification of potential themes and sub-themes regarding the first sub-aim (the communication problems caregivers are experiencing) the main sections of the interview guide and also the researcher's study of literature regarding communication problems served as a pre-existing coding frame (Braun & Clark, 2006). Hence, a “theoretical” thematic analysis approach was used to identify potential themes and sub-themes regarding communication problems experienced by participants in interaction with their charges (Braun & Clark, 2006; Guest et al., 2012). With this approach, theory guided the examination of communication problems according to existing literature on communication problems associated with TBI (Guest et al., 2012).
Potential themes and sub-themes for the second sub-aim (to determine how individual caregivers deal with these communication problems and the strategies they have developed to assist the person with severe TBI to communicate more effectively) were identified by using an “inductive” thematic analysis approach. This approach has a descriptive and exploratory orientation (Guest et al., 2012). Common themes and subthemes regarding how caregivers are dealing with communication problems were identified to generate hypotheses for further investigation during the focus group discussion (Guest et al., 2012).

**d) Reviewing themes and sub-themes.**

During the fourth phase the potential themes and sub-themes were reviewed and refined to ensure they form a coherent pattern. This phase involved two levels. At the first level data extracts supporting each potential theme and sub-theme were read again to refine potential themes and sub-themes. Certain themes were eliminated or collapsed into each other because it became evident there were not enough data to support them, or the data are too diverse. For example the majority of the caregivers did not provide sufficient information regarding the nature of communication interaction problems they experience in different conversational settings, mainly because the everyday conversational settings to which individuals with TBI are exposed are not really diverse. The theme “different conversational settings” was eliminated and a new theme was created: Decreased integration into the community. The responses regarding exactly how caregivers managed a specific communication problem were too diverse to be accorded separate themes. The themes on how caregivers managed communication interaction problems were collapsed into two main themes: caregivers who opt for making the individual with TBI aware of communication interaction problems and those who choose not to.

A similar process was followed at the second level in relation to the entire transcription. The transcripts were re-read to ascertain whether the themes and sub-themes accurately reflect the meanings evident in the transcriptions and to code any additional data within themes that were missed during the initial coding stages (Braun & Clark, 2006). For example, additional data was coded from the transcriptions to support the new theme created at level one: Decreased community integration.
e) Defining and naming themes and sub-themes.

Phase five involved identifying the “essence” of what each theme and sub-theme is about by describing the scope and content of each theme (Braun & Clarke, 2006:22). A representative name for each theme was also finalized during this phase. The main themes and sub-themes identified during this study are presented in Table 4.

f) Producing the report.

The last phase of thematic analysis involved the writing of a report on the analyzed data. The validity of the analysis is addressed in the next section. The report provides evidence to support the themes and sub-themes with the use of key participant quotations to demonstrate the prevalence of the theme.

3.10 Phase 1: Validity and reliability

Validity. To ensure validity in this research project participants and interview questions were selected so that accurate conclusions could be drawn regarding communication problems after severe TBI based on participants’ experiences (Leedy & Ormrod, 2005). Leedy and Ormrod describe validity as ‘the accuracy, meaningfulness and credibility of the research project as a whole’ (Leedy & Ormrod, 2005:97). Internal validity of a research study implies that the study has sufficient controls to ensure that the conclusions drawn are truly justified by the data, and external validity means that the collected data can be generalized to other contexts (Leedy & Ormrod, 2005).
Table 4: Defining and naming main themes and sub-themes identified in Phase 1 as a guide to further processing of data

<table>
<thead>
<tr>
<th>Themes relating to Sub-aim 1 (To determine how caregivers perceive the communication interaction problems of the individual with severe TBI they are caring for during the chronic stage after TBI).</th>
<th></th>
</tr>
</thead>
</table>
| Theme 1: Inadequate content of information conveyed during conversation: | Sub-theme 1: Too much information conveyed during communication interaction.  
Sub-theme 2: Incomplete information conveyed during communication interaction.  
Sub-theme 3: Inaccurate information conveyed during communication interaction. |
| Theme 2: Lack of pragmatic competence | Sub-theme 1: Problematic prosodic aspects of communication.  
- Impact of conversational context on the ability to increase or decrease loudness of voice appropriately.  
- Impact of limited intonation on communication efficiency.  
Sub-theme 2: Inaccurate interpretation of non-verbal communication behaviour  
Sub-theme 3: Poor turn taking and maintaining topic of conversation  
Sub-theme 4: Inappropriate comments |
| Theme 3: Decreased integration into the community | Sub-theme 1: Loss of interest in meeting new people; communication maintained only with family and friends  
Sub-theme 2: Certain conversational partners elicit inappropriate communication behaviour |
| Themes relating to Sub-aim 2 (To determine how caregivers deal with the problems they observe and what are the recommendations they offer to manage these problems to assist the individual with severe TBI to communicate more effectively in a natural environment). |  |
| Theme 1: Caregivers made the individual with TBI aware of communication problems. | Sub-theme 1: Addressing the communication problem by using a subtle approach.  
Sub-theme 2: Addressing the communication problem directly during the conversation or afterwards. |
| Theme 2: Caregivers did not make the individual with TBI aware of communication interaction problems. | Sub-theme 1: Keeping them in the conversation  
Sub-theme 2: Avoiding eliciting negative reaction from the individual with TBI. |
The following steps were taken in order to accomplish internal validity:

- The selection of participants was done with truthfulness and only subjects who comply with the specific criteria for participation in the study were approached. The participants were caregivers of the individuals with severe TBI and they were related to these individuals and knew their styles of communication.
- A complete literature review was conducted to ensure that the questions of the semi-structured interview guide were relevant and in keeping with current research.
- A pilot study was conducted to verify the applicability, relevancy, and accuracy of each question in the interview questionnaire.

The following strategies were used to enhance the external validity of the present study:

- A real-life setting: Data was collected regarding the experiences of caregivers in a natural environment, thus yielding results with broader applicability to other real-world context (Leedy & Ormrod, 2005).
- A representative sample: Ten caregivers of individuals with severe TBI were interviewed. This is a small sample size and results cannot necessarily be generalized to the greater population of caregivers caring for individuals with severe TBI. Each caregiver's situation is unique and there are different variables that influence how they experience communication problems and even more how they deal with such problems. However, since the specific communication problems related to severe TBI are well known, the experiences of the participants may be very similar to the experiences of other caregivers who are caring for an individual with severe TBI.

To ensure the validity of the measurement instruments, questions posed during the semi-structured interviews were specifically designed to achieve the sub-aims of Phase 1 – therefore measuring what purports to measure (Leedy, & Ormrod, 2005:28). To address face validity (Leedy & Ormrod, 2005: 92) the questions of the interview guide aimed to determine the characteristics of the problems caregivers experience during communication interaction. Even though subjective judgment is usually seen as a disadvantage regarding the validity of a measurement instrument, the personal experiences of the caregivers were a key element of the first sub-aim.
(Leedy & Ormrod, 2005). Questions on the methods of managing identified communication problems reflected construct validity since these methods were not directly observed and measured by the researcher (Leedy & Ormrod, 2005).

**Reliability.** Kvale (1996) stresses the importance of reliability during the interviewing, transcribing, and analyzing stages of a research project.

- The interview: The language used in the semi-structured interview guide and during the semi-structured interviews was modified according to the recommendations of the participants in the pilot study to prevent any uncertainties or ambiguity of terminology.
- Transcribing: The content of each interview was captured with audio recordings to ensure consistency during transcription and data analysis procedures.
- Analyzing: To prevent unreliable data as well as any biases, a second coder was asked to study the transcripts of three participants (randomly selected by the second coder) and categorize the data into potential themes, by using the process of open-coding. The second coder holds a Masters degree in Communication Pathology, has had more than three years of clinical experience in dealing with individuals with TBI, and is still active in the field of TBI. When the categories for potential themes of the researcher and second coder were compared, it was found that they had identified similar themes regarding the communication interaction problems the caregivers experienced, but different themes for how caregivers dealt with these problems. Through discussion, they agreed on dividing the responses into two main themes: caregivers who made the individual with TBI aware of communication problems, and caregivers who did not.

4 PHASE 2

4.1 Phase 2: Aims

The second Phase involved a focus group discussion with the participants of the semi-structured interviews. The objective of the second phase was to reflect on the
data gathered during the semi-structured interviews, particularly with regard to sub-aim 2. This sub-aim focused on the way caregivers manage the communication problems they observe.

4.2 Phase 2: Research Design

A focus group discussion is defined by Powell and Single (1996:499) as “a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research”. As a qualitative research method, a focus group discussion is both naturalistic and inductive (Krueger & Casey, 2009). This study was naturalistic in the sense that the focus group discussion offered contextual data for understanding how caregivers deal with communication interaction problems they are experiencing in real life with individuals with severe TBI (Brotherson, 1994). The study was also inductive as particular facts and examples were used to deepen the understanding of how individual caregivers deal with these communication problems and the strategies they have developed to assist the person with severe TBI to communicate more effectively in a natural environment. A focus group discussion usually involves between six and twelve participants, a moderator, and in some cases an assistant moderator (Berg, 1998; Brotherson, 1994; Krueger, 1994).

To deepen the understanding of the findings from Phase 1, a focus group discussion was conducted during Phase 2 with the participants of the semi-structured interviews. The aim of the focus group was to identify management strategies for communication interaction problems based on the recommendations the caregivers offer to assist the individual with severe TBI to communicate more effectively in a natural environment. Berg (1998) explains that during individual interviewing the opportunity to observe interaction for greater amounts of detail on various approaches, opinions, and experiences is restricted. The participants of the semi-structured interviews consequently also formed the members of the focus group discussion (Berg, 1998). The interaction among and between group members stimulated the discussions and coping strategies were evaluated and reconsidered from different personal perspectives. The ‘synergistic group effect’ of a focus group discussion allowed participants to brainstorm collectively (Berg, 1998), and a larger number of ideas and recommendations for managing communication interaction
problems after severe TBI could be generated. Furthermore, the focus group discussion can offer rich contextual data (Brotherson, 1994) for understanding how caregivers experience and deal with communication interaction problems associated with severe TBI in different contexts.

4.3 Phase 2: Participants of the focus group discussions

Participants of the focus group discussion included a moderator (the researcher), an assistant moderator and six participant caregivers. It was not possible to arrange a time that suited all 10 participants and only six were available. It was the responsibility of the moderator to guarantee effective and comprehensive data collection by gaining information from the participant caregivers regarding the topics of importance, to guide discussions back from irrelevant topics and make transitions into another question. An assistant moderator was present. This assistant was a qualified neuropsychologist who works in the field of TBI. She was present throughout the focus group discussion, conducted the ‘de-briefing’ discussion at the end of the focus group, and discussed insights and perceptions with the moderator directly after the group discussion (Brotherson, 1994). Six of the ten Phase 1 participants were able to attend the focus group discussion. This number of participants allowed diversity within the group, but also created closeness for all members to talk and share their thoughts (Krueger, 1994; Krueger & Casey, 2009; Morgan, 1996). Participants who took part in the focus group discussion comprised Participants 1 to 6 as captured in Table 1.

4.4 Phase 2: Development of the focus group discussion guide

The focus group discussion guide was developed as an agenda for the discussion. Development of the focus group discussion guide is a vital task because it establishes an outline for the discussion and provides the structures within which the group members will interact (Stewart & Shadasani, 1990). It is important to keep in mind that a focus group discussion involves a process that is continuously emergent and flexible (Patton, 1990). The questions of the focus group guide provided a framework that could be changed and expanded on, based on the unique context of the focus group. The following categories, suggested by Krueger (1994), were used to develop questions to guide the moderator during the focus group discussion.
• Opening question: In order to establish which characteristics the group members share, participants were asked to introduce themselves to each other, as well as to provide some background about the individual with TBI they were caring for.

• Introductory question: To introduce the general topic of the focus group discussion, group members were asked to tell the group more about the challenges they experience regarding communication interaction with individuals with TBI.

• Transitional question: The transitional question serves as a link between the introductory question and the key questions. Members were asked whether or not they make the individual with TBI aware of problematic communication behaviour. During the discussion of this question the participants become aware of how others view the topic (De Vos, 1998).

• Key questions: The three key questions of the focus group discussion were based on the data collected during the semi-structured interviews. In Table 5 the key questions are provided and the aim of each question is summarized. The first key question was asked to deepen the understanding regarding why caregivers choose to make individuals with TBI aware of communication interaction problems or why they choose not to. With the second key question the moderator aimed to define and describe certain communication problems in more detail. These problems included the decreased capacity of the individuals with TBI to use prosodic features of speech appropriately to express their propositional attitude or emotional state and the impaired ability to interpret non-verbal communication behaviours accurately (Angleri et al., 2008). The third key question related to the importance of integration into the community. In order to gain an understanding of these critical issues, specific follow-up and probing was used during the focus group discussion (De Vos, 1998).

• Ending question: The last question allowed the participants to identify the most important aspects that were discussed. Krueger (1994) points out the importance of a summary of the main view points to pull the focus group
discussion together and verify the information with participants. The focus group discussion was closed with a short de-briefing discussion under the guidance of the assistant moderator, the neuropsychologist.

4.5 Phase 2: Data collection procedures

The course of the proceedings during the focus group discussion was as follows:

- Following the semi-structured interview a feedback letter was provided to all participants. They were requested to take part in the second phase of the research. An information letter was given to participants following the semi-structured interview. This letter stated the aim of the second phase as: To deepen the understanding of the findings from Phase 1 regarding the communication problems that caregivers observed and experienced as well as how they deal with these communication problems and the strategies they have developed to assist the person with severe TBI to communicate more effectively in a natural environment. Participants were provided with an incentive to attend by mention of the contribution they could make in empowering other individuals who in future may find themselves in the same position.

- A date and time for the focus group discussion was scheduled at the participants’ convenience. It occurred at a location that was centrally situated for all participants. A small boardroom was chosen to provide a private, quiet environment.
Table 5: Key questions of the focus group discussion

<table>
<thead>
<tr>
<th>Question</th>
<th>Aim of the question</th>
</tr>
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<tbody>
<tr>
<td><strong>1.</strong> Why do you make the individual with TBI aware of inappropriate or inaccurate communication interaction behaviours, or why do you choose not to?</td>
<td>During the semi-structured interviews participants had contrasting approaches regarding whether or not to make the individual with TBI aware of his/her inappropriate or inaccurate communication behaviours. With this question more detail could be obtained regarding why and how participants dealt with communication interaction problems in a certain way.</td>
</tr>
<tr>
<td><strong>2.</strong> Most of you mentioned that non-verbal communication behaviour is one of the most difficult problems to handle. Can you please expand on this and let us discuss how one can handle these problems.</td>
<td>During the semi-structured interviews the researcher found that the participants understood the use of prosodic features of speech to express propositional attitude or emotional state as part of non-verbal communication behaviour. For that reason the term ‘non-verbal communication behaviour’ was used during the focus group discussion. In the focus group discussion, ‘non-verbal communication behaviour’ referred to the following: prosodic features of speech, gestures, facial expressions, gaze, and body posture. Regarding the use of prosody, several of the participants experienced a lack of emotion during conversations with the individual with TBI. This often caused confusion and misinterpretation of the intended message, for both the participant and the individual with TBI. In terms of the interpretation of facial expressions, gaze, and body posture, most of the participants experienced problems with the individual with TBI being either oversensitive to the non-verbal communication behaviours of others or they misinterpret it completely. As a result the response of the individual is inappropriate/inaccurate. This frequently caused confusion and even tension during conversations. This question had two objectives: Firstly, to gain a better understanding of the prosodic and non-verbal communication behavioural problems caregivers perceived during communication interaction with the individual with severe TBI and the impact of these problems on conversations. Secondly, to gain a better understanding of their ways of dealing with these problems.</td>
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Table 5 continued

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<thead>
<tr>
<th>Question</th>
<th>Aim of the question</th>
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<tr>
<td>3. What are your observations regarding community reintegration and how do you address this?</td>
<td>During the interviews caregivers frequently acknowledged that the conversational interactions to which individuals with TBI are exposed mostly involve family and friends—in other words, people who know and understand what happened to the patient. Family and friends are more ‘forgiving’ and make allowances for most of the problems that have been identified. With this question more detailed information could be obtained regarding what participants’ perceptions were regarding community reintegration.</td>
</tr>
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</table>

- All members of the focus group discussion were welcomed and introduced by the moderator. Members were provided with a context for the focus group discussion by an introduction that defined the situation and the purpose of the group (Kvale, 1996).

- The use of a tape recorder was explained and the recording equipment was set up as unobtrusively as possible. The assistant moderator operated the taping equipment and monitored the noise levels in the room. She also made field notes about the group dynamics and changes in the course of discussion. Ground rules were described to encourage interaction (Brotherson, 1994)

- The focus group discussion guide was used to guide the moderator during the course of the discussion.

- The group discussion was closed with a short ‘de-briefing’ discussion under the guidance of the neuropsychologist.

- All members were thanked for their attendance and contributions with a small gift of appreciation.

- To improve the reliability of the data, the perceptions of the moderator and assistant moderator were discussed immediately after the termination of the focus group discussion.
4.6 Phase 2: Equipment

A Panasonic RQL 10 audio tape recorder was used during the focus group discussion. An audio recording allows a more complete and uninterrupted recording of data than handwritten notes, furthermore the collected data can be listened to repeatedly to ensure more accurate data analysis (Greef, 2002; Leedy, & Armrod, 2005).

4.7 Phase 2: Data analysis procedures

Qualitative data analysis involves a process to reduce transcribed text from the focus group discussion in such a way that it becomes refined to essentials (Tesch, 1990). In order to initiate this process Tesch (1990) suggested the development of a systematic framework to distinguish meaningful units, isolate them and place them together again in conceptual categories.

During data analysis a systematic framework was developed to distinguish communication interaction problems and the strategies for handling these specific communication problems. Tesch (1990) suggests that the development of the systematic framework be based on: a) the main aim of the focus group discussion, b) the initial framework of the focus group discussion protocol, c) the concepts suggested by related studies and d) the actual data. A successive process of coding, proposed by Strauss and Corbin (1990, 1998), was followed during data analysis. The process of coding involved open coding, followed by axial coding and selective coding (Strauss & Corbin, 1990, 1998).

First, open coding was used to divide the data into segments and to scrutinize it for commonalities that reflected themes. The three key questions of the focus group discussion guide provided the foundation for the three main themes. The themes included: recommendations for dealing with perceptible communication interaction problems, decreased capacity of the individuals with severe TBI to use and interpret pragmatic aspects of communication appropriately, and aspects of community integration after TBI. Axial coding followed, during which more detail about each theme was determined in terms of (a) conditions that gave rise to a specific communication interaction problem, (b) conversational context in which it occurred,
(c) the strategies family members used to manage the problem and (d) the outcome of those strategies. From this systematic reviewing sub-themes arose. Finally the interrelationship between communication interaction problems and proposed management strategies were combined by selective coding. This procedure allowed the researcher to describe the nature of communication problems during the chronic stage of severe TBI, from the perspective of caregivers, and furthermore their ways of dealing with such problems in a natural environment. There is an interrelationship, for example, between the impact of the communication interaction problems on a conversation and the management strategy that is used. An interrelationship also exists between the strategy that is applied and the influence it has on the individual with severe TBI.

4.8 Phase 2: Trustworthiness of the focus group discussion

Qualitative research has often been described as lacking reliability and validity, but because the nature and purpose of qualitative traditions are different from those of quantitative research, it is erroneous to apply the same criteria of worthiness or merit to both research types (Krefting, 1991). Guba (1981) proposed the following four criteria to consider in qualitative research studies in pursuit of a trustworthy study:

- Credibility (in reference to internal validity)
- Transferability (in reference to external validity)
- Dependability (in reference to reliability)
- Confirmability (in reference to objectivity)

The strategies that were used to accomplish trustworthiness during the second phase of the study are explained in Table 6.
Table 6: Strategies used to enhance trustworthiness of the data

<table>
<thead>
<tr>
<th>ASPECT OF TRUSTWORTHINESS</th>
<th>STRATEGY</th>
<th>APPLICATION IN THE PRESENT STUDY</th>
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<tbody>
<tr>
<td><strong>Credibility</strong></td>
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<td>deals with the question:</td>
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<tr>
<td>”How congruent are the</td>
<td></td>
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<tr>
<td>findings with reality?”</td>
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<td></td>
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<tr>
<td>(Merriam, 1998)</td>
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<td></td>
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<tr>
<td>Interpretative credibility (member checking) (Bryman, 2004):</td>
<td>In the present study member checks was done at the end the focus group discussion. The focus group discussion concluded with a summary of the main points of view to pull the focus group discussion together and verify the information with the participants.</td>
<td></td>
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<tr>
<td>Member checks involve the submission of data relevant to an investigation for checking by the people who were the source of the data. The goal is to ensure that the researcher’s understanding of the data corresponds with that of the participants. Through member checks the researcher is able to ensure whether the data being collected is accurate. Member checks may take place during the data collection dialogues or at the end (Shenton, 2004).</td>
<td></td>
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<tr>
<td>Peer debriefing (Given, 2008):</td>
<td></td>
<td>Regarding the present study the perceptions, integrations and conclusions of the second phase were discussed with the assistant moderator, a qualified and experienced neuropsychologist, immediately following the focus group discussion. The assistant-moderator was not involved in the research but understood the nature of the research.</td>
</tr>
<tr>
<td>A peer debriefing (also called analytic triangulation) between the researcher and other experts in the field may widen the researchers’ vision as their experiences and perceptions are discussed. These meetings furthermore provide an opportunity for the researcher to recognise personal biases and preferences through probing from others. The use of external peers is regarded as a technique to enhance the credibility and trustworthiness of qualitative research (Given, 2008).</td>
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</table>
Table 6 continued

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<thead>
<tr>
<th>ASPECT OF TRUSTWORTHINESS</th>
<th>STRATEGY</th>
<th>APPLICATION IN THE PRESENT STUDY</th>
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<tbody>
<tr>
<td><strong>Transferability</strong></td>
<td>Rich description (Lincoln &amp; Guba, 1985): Rich descriptions refer to the collection of sufficiently detailed descriptions of data in context and reporting them with sufficient detail and precision to allow the reader to determine if the findings are transferable.</td>
<td>In the present study the perspectives of the participants enabled the researcher to provide a rich, contextual description of how caregivers experience and deal with communication interaction problems after severe TBI. The six participants of the focus group discussion all had different perspectives regarding the strategies they use. These diverse strategies of different participants may reflect the perceptions of the broader community and allow judgements about transferability to be made by the reader.</td>
</tr>
<tr>
<td></td>
<td>Purposive sampling (Olivier, 2006): Purposive sampling is a form of non-probability sampling during which possible participants are selected by the researcher, based upon a variety of criteria.</td>
<td>Participants were selected to represent a specific population which in this case was caregivers of individuals with severe TBI who were related to the individual with TBI and were familiar with their premorbid communication ability and style.</td>
</tr>
<tr>
<td><strong>Dependability</strong></td>
<td>Through an in-depth description of procedures the reader is permitted to develop a thorough understanding of the methods and their effectiveness, and to assess the extent to which proper research practices have been followed (Shenton, 2004).</td>
<td>To ensure dependability of the present study the processes within the study were reported in detail in terms of the research design, selection criteria and procedures regarding participants, procedures for collecting and analysis of data as well as ethical considerations, thereby enabling a future researcher to repeat the study, if not necessarily to obtain the same results.</td>
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### Table 6 continued

<table>
<thead>
<tr>
<th>ASPECT OF TRUSTWORTHINESS</th>
<th>STRATEGY</th>
<th>APPLICATION IN THE PRESENT STUDY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conformability</td>
<td></td>
<td>A data-orientated approach was followed during the present study (Shenton, 2004). A data-orientated approach shows how the data eventually leading to the formation of recommendations were gathered and processed during the course of the study. Conformability was furthermore ensured by the second rater, a qualified neuro-psychologist, who assisted in making conclusions from the data that developed into the formulation of recommendations.</td>
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Conformability ensures that the findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher.
(Shenton, 2004)
5 SUMMARY

This chapter provided an explanation of the planning and implementation of the research that describes two issues: firstly, the nature of pragmatic and discourse problems during the chronic stage of severe TBI, from the perspective of caregivers; and secondly, the caregivers’ ways of dealing with such problems in a natural environment.

The aims of the research project were formulated, followed by a justification of the chosen research design. An explanation of the two phases of the research followed. This included the participant selection criteria, selection procedures and description of participants, description of the research equipment, as well as data collection and analysis procedures. The validity, reliability and trustworthiness of the present study, as well as relevant ethical aspects, were also discussed. The results will follow in the next chapter.
CHAPTER 3
RESULTS AND DISCUSSION OF RESULTS

1 INTRODUCTION TO CHAPTER 3

In this chapter the results of the research project are presented and discussed according to the two research phases as explained in sections 2.2 and 2.3 of Chapter Two. The results of both Phase 1 (semi-structured interviews) and Phase 2 (focus group discussion) are described and discussed in accordance with the formulated sub-aims of the present study.

2 PHASE 1: SUB AIM 1

The first sub-aim of the present study was to determine how caregivers perceive the communication interaction of the individuals with severe TBI they are caring for during the chronic stage after TBI. There were three themes identified from the semi-structured interview data. Further review of the transcripts resulted in the identification of sub-themes under each main theme. A sub-theme was formulated when a particular communication problem was evident in responses from at least five (50%) of the ten participants. Table 7 outlines the main themes and sub-themes regarding the communication interaction problems disclosed during the semi-structured interviews with caregivers of individuals with severe TBI.

2.1 Sub-aim 1: Description of results

2.1.1 Theme 1: Inadequate content of information conveyed during conversation

Sub-theme 1: Too much information conveyed during communication interaction.

Five caregivers reported problems with the tendency of the individual with severe TBI to provide too much, unnecessary information during conversation interaction. They described the communication interaction of these individuals as long-winded and redundant.
Table 7: Themes and sub-themes regarding communication interaction problems reported during semi-structured interviews.

<table>
<thead>
<tr>
<th>THEME</th>
<th>SUB-THEMES</th>
<th>Number of participants who experienced the problem (N=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theme 1: Inadequate content of information conveyed during conversation</td>
<td>Sub-theme 1: Too much information conveyed during communication interaction. Sub-theme 2: Incomplete information conveyed during communication interaction. Sub-theme 3: Inaccurate information conveyed during communication interaction.</td>
<td>5 5 7</td>
</tr>
<tr>
<td>Theme 2: Lack of pragmatic competence</td>
<td>Sub-theme 1: Problematic prosodic aspects of communication:  - Impact of conversational context on the ability to increase or decrease loudness of voice appropriately.  - Impact of limited intonation on communication efficiency. Sub-theme 2: Inaccurate interpretation of non-verbal communication. Sub-theme 3: Poor turn taking and topic maintenance. Sub-theme 4: Inappropriate comments.</td>
<td>6 7 6 8 6</td>
</tr>
<tr>
<td>Theme 3: Decreased integration into the community</td>
<td>Sub-theme 1: Loss of interest in meeting new people. Only communicates with family and friends. Sub-theme 2: Certain conversational partners elicit inappropriate communication behaviour.</td>
<td>6 5</td>
</tr>
</tbody>
</table>

The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived. Although most of the examples quoted below were drawn from the relevant discussions, in some cases the participants made remarks referring to the particular aspect during discussion of a different topic. The examples are included under the heading referring to the theme rather than the specified topic.
- “Too much: Oh yes definitely. She can tell you a story from beginning to end in more detail that you need to know…very yappie-yappie.” [Appendix G; Section C; Question 1a & 1b; Participant 2]
- “Ja…Vreeslik baie inligting.” (“Yes, oh yes….An awful lot of information.”) [Appendix G; Section C; Question 1a; Participant 8]
- “Ek sal sê eerder te veel. Hy sal nogal praat en praat oor ’n punt.” (“I would rather say too much information. He will talk and talk on a specific topic.”) [Appendix G; Section C; Question 1a & 1b; Participant 7]
- “There is a slight tendency to go off on a tangent.” [Appendix G; Section C; Question 1b; Participant 4]
- “Ja te veel, byvoorbeeld hy sal ’n storie by ’n storie las om by die antwoord uit te kom, te veel.” (“Yes, too much, for example, he will add a story to a story to get to the conclusion. This happens too often.”) [Appendix G; Section C; Question 1a & 1b; Participant 10]

Sub-theme 2: Incomplete information conveyed during communication interaction.

In contrast to excessive information being conveyed during communication interaction a number of caregivers experienced problems with information that is incomplete and insufficient. They described the individual with severe TBI as being quiet and not very conversant. In most cases this problem was associated with memory difficulties that the individual with severe TBI experiences during conversation. According to the caregivers it has a negative impact on the effectiveness of the conversation and frequently leads to confusion and even conflict. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “Sy brei nooit uit nie.” (“She will never elaborate on something.”) [Appendix G; Section C; Question 1b; Participant 3]
- “Ek kan nie regtig vir jou sê nie, maar ek sal eerder sê te min inligting. Hy is nie meer so gretig om te praat nie. Hy praat net die nodige, maar sal nie bietjie uitbrei nie. Hy sukkel nog met onthou.” (“I couldn’t really say, but I would rather say too little information. He is not so keen to talk anymore. He only speaks the necessary without
embroidering on anything. He has trouble remembering things.”) [Appendix G; Section C, Question 1a & 1b; Participant 5]

- “Ons gesels oor dinge, maar as jy nou vir hom iets sê, dan later vergeet hy weer…. Hy self kom dit nie agter ingesprekke nie, hy dink om iets te sê, maar dan vergeet hy. Sy probleem is hy vergeet baie maklik.” (“We talk about things, but if you tell him something now he forgets about it afterwards….. He doesn’t catch on to it himself during conversations, he intends to say something but then he forgets. The problem is that he forgets very easily.”) [Appendix G; Section C; Question 1b; Participant 1]

- “Hy sal sommer net stilbly in die middel van ’n sin. Ek dink hy vergeet soms wat hy wou sê.” (“Sometimes he just stops in the middle of a sentence. I think he just forgets what he wanted to say.”) [Appendix G; Section D; Question 1b; Participant 5]

- “He probably gives too little information. He forgets a lot.” [Appendix G; Section C; Question 1a & 1b; Participant 6]

- “Hy onderbreek homself want dan kan hy nie onthou waaroor die gesprek verder gaan nie, dan kan hy nie onthou hoekom hy dit begin het nie.” (“He often interrupts himself because he cannot then remember what the conversation is about. He doesn’t recall why he started the topic of the conversation.”) [Appendix G; Section D; Question 1b; Participant 10]

- “Te min. Ek moet alles uit haar trek….Sy is absoluut baie privaat. Sy vergeet goed, dit is waar die verwarring in kom. Dit veroorsaak konflik.” (“Too little. I have to drag everything from her. She is absolutely very private. She forgets things, and that’s where the confusion comes in. It causes conflict”) [Appendix G; Section C; Question 1a, 1b & 1c; Participant 9]

Sub-theme 3: Inaccurate information conveyed during communication interaction.

The majority of caregivers reported problems with inaccurate information being conveyed during communication interaction. Several caregivers misinterpreted the question and referred to word finding difficulties that influenced the accurate transfer of information. According to caregivers, inaccurate information is conveyed as a result of word finding difficulties and a lack of structure and organization of conversational speech. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.
“She is not very clear. She struggles to find words to describe what she is trying to say.” [Appendix G; Section C; Question 2a & 2b; Participant 2]

“Ek kom dikwels agter dat haar sinne nie verband hou nie. Dit maak dit moeiliker om haar te volg.” (“I often realize that her sentences don't link or relate to any logical sequence. This makes it difficult to understand what she really wants to say.”) [Appendix G; Section E; Question 7a; Participant 9]

“Ja ja dit gebeur dikwels. Hy raak deurmekaar en gebruik dan die verkeerde woorde of hy sukkel om op die regte woorde te kom.” (“Yes it often happens that he gets confused and uses the wrong words or struggles to find the right words.”) [Appendix G; Section C; Question 2a & 2b; Participant 5]

“Ja. Hy sal party keer die verkeerde naam sê. Hy ruil partykeer goeters om, soos name.” (“Yes, he will sometimes use the wrong word. He sometimes switches his words around, for example names.”) [Appendix G; Section C; Question 2a & 2b; Participant 7]

“Yes, I can't think of anything specific. But sometimes when we are in a conversation, I will not always understand what he is saying. There will be misunderstandings, he will explain something and at the end I realize that I have no clue. Maybe that is because he is not giving accurate information.” [Appendix G; Section C; Question 2a & 2b; Participant 6]

“He often does not make sense. And it confuses me. I do get frustrated and I know I shouldn’t.” [Appendix G; Section E; Question 7a; Participant 6]

“Dit gebeur nogal dat wanneer hy vir my iets probeer verduidelik, dat ek nie mooi byhou nie, ek weet nie mooi hoe om dit te verduidelik nie, maar hy praat half deurmekaar.” (“Absolutely, he often does it. I cannot immediately recall an example. It happens quite often when he tries to explain something to me, I can’t always keep track of what he wants to say. I can not explain it, it is just very muddled.”) [Appendix G; Section E; Question 7a; Participant 8]

“Ja, verseker. Ek kan nie aan ‘n voorbeeld dink nie, maar kommunikasie is baie moeiliker.” (“Yes definitely. I cannot think of an example, but it does cause communication to be much more difficult.”) [Appendix G; Section C; Question 2a & 2b; Participant 9]

“Wat ek wel agter gekom het is dat wanneer hy oor die foon praat is sy stories baie keer deurmekaar.” (“I do realize that his telephone conversations are very disorganized/muddled.”) [Appendix G; Section E; Question 7a; Participant 5]
2.1.2 Theme 2: Lack of pragmatic competence

Sub-theme 1: Problematic prosodic aspects of communication

- **Impact of conversational context on the ability to increase or decrease loudness of voice appropriately.**

Caregivers reported that the individuals with severe TBI struggle to control the loudness of their voices in acoustically complex conversational situations for example in a noisy environment or in a motor vehicle. Five of the caregivers reported that the individuals with severe TBI tend to speak too loudly in larger groups of people or when they become excited. Two caregivers reported that the individuals with severe TBI they are caring for struggle to raise their voices adequately in a noisy environment and/or during a telephone conversation. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “She’s gone very loud suddenly, especially when she screams.” [Section D; Question 2a; Participant 2]
- “Sy praat net baie sag, veral oor ‘n foon. Bietjie sag en baie grof. Dit maak dat jy haar nie altyd kan hoor nie.” (“She just speaks very softly, especially on the telephone. It causes that one cannot hear what she says.”) [Appendix G; Section D; Question 2a; Participant 3]
- “Ja, ja vreeslik sag, soos veral as ons in ‘n kar ry, dan sit ek baie keer agter by ons dogtertjie. Dan sukkel jy verskriklik om hom te hoor.” (“Yes, very softly, especially when we are driving in a car. I often sit at the back with our little daughter. It is extremely difficult to hear anything.”) [Appendix G; Section D; Question 2a; Participant 8]
- “Partymaal as hy opgewonde raak praat hy baie hard. Ook partymaal in die kar.” (“Sometimes he gets very excited, then he speaks very loudly, also in the car.”) [Appendix G; Section D; Question 2a; Participant 5]
- “When she tries to shout at the dogs, her tone is very different, almost out of control.” [Appendix G; Section D; Question 2a; Participant 4]
- “As hy baie excited raak is sy stemtoon baie hard.” (“When excited, his tone of voice becomes very loud.”) [Appendix G; Section D; Question 2a; Participant 10]
Impact of limited intonation on communication efficiency.

Nearly all the caregivers reported problems with monotone speech production during communication interaction, due to a lack of intonation variation. According to the caregivers monotone speech production decreased the lucidity of the individual’s message, especially regarding emotion (excitement, disappointment, relief), impacting on how they (the caregivers) perceive and respond to the individual’s conversational message. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “She is absolutely monotone. She gave her testimony in church and one of the comments of one of the ladies that knew her, is that she is completely monotone. She did not show any emotions all the way through.” [Appendix G; Section D; Question 4a, Participant 2]
- “Ja, dit is wanneer hy moeg raak.” (“Yes, he is monotone when he is tired.”). [Appendix G; Section D; Question 4a, Participant 8]
- “Ja, ek kry dit. Jy kan nie op sy gesig sien wat is fout nie.” (“Yes, I do get it (that his speech id monotone). One cannot see on his face what is wrong.”) [Appendix G; Section D; Question 4a, Participant 5]
- “Her tone is completely different. The intonation is not what it should be.” [Appendix G; Section D; Question 4a, Participant 4]
- “That is totally him (monotone). It does confuse him and me.” [Appendix G; Section D; Question 4a & 4b, Participant 6]
- “Dit is baie monotoon. Dit is een geluid wat uikom. As hy opgewonde is bly dit dieselfde, as hy terneer gedruk is bly dit dieselfde.” (“It is very monotone. Only one sound (pitch) comes out. When he is excited it stays the same, when he is depressed, it still remains the same.”) [Appendix G; Section D; Question 4a, Participant 10]
- “Sy praat heeltyd op een toon. Sy wys geweldig min emosie.” (“She speaks all the time in one tone of voice. She shows extremely little emotion.”) [Appendix G; Section D; Question 4a, Participant 9]
Sub-theme 2: Interpretation of non-verbal communication behaviour.

Caregivers indicated that the individuals with severe TBI are oversensitive to delayed responses of the other communication partner, and they are unable to interpret facial expression and other aspects of non-verbal communication. They misinterpret the intentions, inferences and emotions of conversational partners and this often leads to tension and confusion of all participants in the conversation. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “Ja, hy is vreeslik sensitiw. En party keer raak dit bietjie erg. Soos as ek besig is en as hy met my praat en ek antwoord hom nie dadelik nie, is hy onmiddelik kwaad.” (“Yes, he is extremely sensitive. Sometimes it becomes rather bad. For example, when I am busy and he talks to me and I don’t answer him immediately, he becomes angry instantly.”) [Appendix G; Section D; Question 9a; Participant 8]
- “Ja, nou en dan. Met sy pa baie.” (“Yes, it happens sometimes. Often with his father (i.e. cannot interpret his mood.”) [Appendix G; Section D; Question 9a; Participant 5]
- “She is if anything, over sensitive.” [Appendix G; Section D; Question 9a; Participant 4]
- “Yes, he gets agitated for example when I raise my voice, even if I am not really.” [Appendix G; Section D; Question 9a; Participant 6]
- “Sy doen dit permanent met my. Sy vat dinge baie ernstig op. Dinge is baie konkreet en set in stone. Dit veroorsaak verwarring en soms konflik.” (“She continually does it with me. She takes it very, seriously. Things are extremely concrete to her, as set in stone. It causes confusion and sometimes conflict.”) [Appendix G; Section D; Question 9a; Participant 9]

Sub-theme 3: Turn taking and maintaining topic of conversation.

Six (60%) of the caregivers reported problems regarding poor turn taking during conversation interaction. Poor turn taking was described as inappropriate interruptions during communication interaction. These interruptions by the individual with severe TBI usually did not relate to the topic of conversation at a particular moment. All of the caregivers believed the individual with TBI to be unaware of interrupting or to be interrupting unintentionally. It does however often lead to
embarrassment. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “Ja, soos by sy sussie se troue. Ons het almal buite gesit en gesels. En iemand het nog nie eers klaar gepraat nie toe chip hy in. Ja, hy chip in.” (“Yes, like at his sister’s wedding. We were all sitting outside and talking. And somebody had not finished speaking yet when he chipped in. Yes, he chips in.”) [Appendix G; Section D; Question 5a; Participant 8]

- “Verskriklik baie, en praat onnodige goeters wat nie van toepassing is op die gesprek nie.” (“Very much and he talks about unnecessary things which have no bearing on the conversation.”) [Appendix G; Section D; Question 5a; Participant 5]

- “Yes…… she has on occasion chipped in and you can tell sometimes it is a thought that comes to her mind and it is no longer about what everyone else is talking about.” [Appendix G; Section D; Question 5a & 5c; Participant 4]

- “He often interrupts people while they are talking. Someone will be talking and he will just talk over them.” [Appendix G; Section D; Question 5a; Participant 6]

- “Ja, hy doen dit baie.” (“Yes, he often does it.” (interrupt people)) [Appendix G; Section D; Question 5a; Participant 10]

- “She will start her own topic, in the middle of the conversation. Not realizing it has nothing to do with what we are talking about.” [Appendix G; Section E; Question 3a; Participant 2]

Sub-theme 4: Inappropriate comments.

The majority of the caregivers experienced problems with inappropriate comments during communication interaction. This problem often arose in a larger group of unfamiliar people. According to the caregivers, individuals with severe TBI tend to use inappropriate humour. Their remarks when they dislike or disapprove of something are tactless and sometimes offensive. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.
- “Sy is baie eerlik. Sy spaar niemand se gevoelens nie.” (“She is very honest. She spares nobody’s feelings.”) [Appendix G; Section E; Question 1a; Participant 9]
- “Ja, soos byvoorbeeld met sy oudste sussie, hy sal sommer met hulle seun raas en vir hom preek, soveel so dat haar man baie geirriteerd raak met hom want hy weet nie waar om op te hou nie. Hy sal sommer kommentaar lewer oor onderwerpe wat glad nie sy plek is nie soos iemand ander se geldsake en so.” (“Yes, for example towards his eldest sister. He would without reason berate their son. This irritates my brother-in-law terribly because he doesn’t know how and when to stop. He would also speak his mind on topics which he has no knowledge about, for example other people’s money matters, etc.”) [Appendix G; Section E; Question 1a; Participant 8]
- “Ja, dit gebeur, dit is baie beter nou.” (“Yes, it does happen, but it is much better now.”) [Appendix G; Section E; Question 1a; Participant 5]
- “Op die oomblik is hy baie aanvallend as hy praat oor ietsie kleins. Hy bedoel dit nie, maar hy sal op ‘n lelike manier vir jou iets sê.” (“At present he is very abusive even speaking about trivial matters. He doesn’t usually mean it but the way he says it is rude and insulting.”) [Appendix G; Section E; Question 1a; Participant 7]
- “Yes, she does. It is almost as if it is a build up of something and then she just blurts it all out.” [Appendix G; Section E; Question 1a; Participant 4]
- “Yes, totally. He tries to be funny, but it is not the right time and place. And it is often about sex. That is totally him. We had a work function where he said things that were very inappropriate.” [Appendix G; Section E; Question 1a; Participant 6]

2.1.3 Theme 3: Decreased integration into the community

Sub-theme 1: Loss of interest in interacting socially.

Caregivers’ description of the individuals with severe TBI before the injury clearly showed that these individuals were active participants in a broad range of community involvements. They were described as very outgoing and enjoyed interaction with a variety of people. After the injury, caregivers found active participation within the broader community a challenge because the individuals with severe TBI had lost interest in meeting new people and building new relationships. The communication interaction of these individuals is mostly limited to family and close friends. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section,
the particular question, and the individual participant) from which each quote was derived.

- “Sy is stiller by nuwe mense, stel nie regtig belang om nuwe mense te leer ken nie. Sy is skrikkerig, as sy voel iemand gaan haar te na kom sal sy terugtrek en wegbly van daardie person.” (“She is quieter when with new people (strangers) and isn’t really interested in getting to know new people. She is actually scared of someone being detrimental to her, so she avoids them.”) [Appendix G; Section F; Question 1; Participant 3]

- “Al waar sy verander het is sy gaan nie meer uit nie. Sy wil nie meer uitgaan na kuier plekke toe waar daar ’n klomp mense is nie.” (“What has definitely changed is that she never goes out anymore; especially to get together when there are many strangers.”) [Appendix G; Section F; Question 1; Participant 3]

- “Sy wil nie terug gaan universiteit toe nie, sy wil nie meer sin g nie. Sy het haarself heeltemal onttrek van sosiale interaksie, sy stel nie meer belang nie.” (“She doesn’t want to go back to university; she also doesn’t want to sing anymore. She has totally detracted herself from social interaction and has lost all interest.”) [Appendix G; Section F; Question 1; Participant 9]

- “Hy is stiller in die motor en in gesprekke met vreemde mense…..In ’n groep mense sal hy sommer loop.” (“He is more quiet in the motor car and in conversations with strangers…..In a group of people he will just walk out.”) [Appendix G; Section F; Question 1; Participant 1]

- “She is a bit more quieter in big groups. For example at my cousin’s birthdays there were a lot of strangers, we had to prompt her to take part in the conversation. There is definitely a lack of confidence.” [Appendix G; Section F; Question 1; Participant 2]

- “When meeting new people he lacks confidence and then he tries too hard……trying to put on a show.” [Appendix G; Section F; Question 1; Participant 6]

- “She is not so often in unfamiliar conversations. She needs prompting in conversations were there is lots of people.” [Appendix G; Section F; Question 1; Participant 2]

- “Die mense met wie sy kommunikeer is die wat haar ken en weet van die ongeluk. Daar is baie min vreemde mense met wie sy praat.” (“Most people she communicates with are those who know her and about her accident. There are very few strangers with whom she communicates.”) [Appendix G; Section F; Question 1; Participant 3]
- “Almal waarmee ons kuier is nou al gewoond dat as hy ‘inchip’ los hom dat hy klaar praat.” (“All of our friends are now used to his butting in and let him be to finish what he has to say.”) [Appendix G; Section F; Question 1; Participant 10]
- “Everybody that she speaks to pretty much knows she has been in an accident, so they take it were it comes from.” [Section F; Question 1; Participant 2]
- “Gelukkig, ek moet sê, al ons familie en vriende is nou al gewoond daaraan, hulle pas daarby aan, of hulle sal net aangaan.” (“Fortunately all our family and friends are now used to it and adapt to it. They just carry on.”) [Appendix G; Section F; Question 1; Participant 8]
- “We don’t really have a lot of contact with other people….. And mostly family.” [Appendix G; Section F; Question 1; Participant 4]

Sub-theme 2: Certain conversational partners elicit inappropriate communication behaviour.

Caregivers pointed out that the individuals with severe TBI tend to be impatient, unreasonable and offensive during communication interaction especially with younger children. In situations where the caregiver and the individual with TBI are spouses, this problem creates tension and often leads to conflict. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “Sy wip haar vreeslik vinning en is ekstra streng en ekstra misluk met hulle nog voordat hulle iets gedoen het, klim sy sommer in hulle keel af.” (“She is very easily angered and especially strict and extra nasty with them (children), even before they even do anything she flies at their throats”) [Appendix G; Section F; Question 1; Participant 3]
- “Sy is baie eerlik. Spaar niemand se gevoelens nie.” (“She is very straight forward and considers no one’s feelings.”) [Appendix G; Section F; Question 1; Participant 9]
- “Hy is baie ongeduldig. Hy word gou kwaad vir klein goedjies en dan amaak hy dit ‘n groot ding. Veral met die kinders is hy baie onreëlsig en streng.” (“He is very impatient. He is easily angered about trifling things and makes a great deal about it. Especially with the children he will be very unreasonable.”) [Appendix G; Section F; Question 1; Participant 7]
- “During the day she is with my aunt and there are a lot of children around. Then she gets irritated very quickly and she will scream at them. She would have never done it before.” [Appendix G; Section F; Question 1; Participant 2]
- “Sy is net vreeslik ongeduldig veral met kinders.” (“She is just very impatient, especially with children.”) [Appendix G; Section E; Question 1a; Participant 3]

3 PHASE 1: SUB AIM 2

The second sub-aim of Phase 1 of the study was to determine how caregivers deal with the problems they observe and what recommendations they offer for managing these problems in such a way as to assist the individual with severe TBI to communicate more effectively in a natural environment. From the preliminary review of the semi-structured interview data, two contradictive themes were identified: caregivers either make the individual with severe TBI aware of communication interaction problems, or they choose not to. Table 8 outlines the themes and sub-themes regarding management methods that were identified, as well as illustrative quotes from the transcripts. The quotes from the original transcript are provided with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

3.1 Sub-aim 2: Description of results

3.1.1 Theme 1: Caregivers make the individual with severe TBI aware of communication problems.

Sub-theme 1: Address the communication problem by using a subtle approach.

Five of the caregivers indicated that they choose to make the individual with severe TBI aware of his/her communication interaction problems by using subtle approaches. These approaches are usually applied within a conversation as the problem occur and include humour, unobtrusive gestures and prompting. Caregivers use humour to ease possible tension that the problem might have caused and to redirect the focus onto the joke instead of the error the individual with severe TBI has made. By the use of unobtrusive hand gestures or touch caregivers make the
individual with severe TBI aware that he/she is giving too much information, for example, or has interrupted someone else in the conversation. Prompting is used as an attempt to encourage the individual with severe TBI to solve the communication problem independently.

Sub-theme 2: Address the communication problem directly within the conversation or afterwards.

In some instances the caregivers address the communication problem by telling the individual with severe TBI directly as the problem occurs, or by discussing the problem afterwards in a more private environment. When problems occur, for example poor turn-taking or inappropriate comments, caregivers immediately tell the individual what he/she is doing and that it is inappropriate. Problems with memory, which interrupt the flow of conversation, are also addressed directly to guide the individual back to the conversation or to asking direct questions. Some caregivers choose to discuss communication problems afterward with the individual with severe TBI. Caregivers will describe the problem, the context in which it occurred, and participants involved, in order to help the individual be more aware of the problem and the impact it has on a conversation.

3.1.2 Theme 2: Not making the individual with severe TBI aware of communication interaction problems.

Five of the caregivers chose not to make the individual aware of communication interaction problems. The caregivers described mainly two reasons why they chose not to make the individual with severe TBI aware of these problems. This first reason (sub-theme 1) was to encourage the individual to participate in a conversation with confidence without feeling he/she is being judged. The second reason (sub-theme 2) was because of the negative reactions that were evoked when the individual with severe TBI was made aware of communication interaction problems. Negative reactions of the individuals with severe TBI include withdrawal from interaction and anger.
### Table 8: Themes and sub-themes regarding management methods reported during semi-structured interviews

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
<th>Illustrative quotes</th>
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| Theme 1: Caregivers make the individual with severe TBI aware of communication problems. | Sub-theme 1: Address the communication problem by using a subtle approach. | - “Ek moedig hom aan om meer akkurate woorde te gebruik.” (“I try to encourage him to use more accurate words”) [Appendix G; Section C; Question 2c; Participant 10]  
- “I tried to do it afterwards, because I don’t want to embarrass him.” [Appendix G; Section D, Question 5c, Participant 6]  
- “Ek probeer hom wysmaak dat as daar mense is wat praat moet wag vir sy beurt…Hy begin nous y hand opsteek en sê dis nou my beurt, maar dis alles games.” (“I try to make him understand that when people talk, he has to wait his turn and should not interrupt. He now starts putting up his hand and say it is now his turn to speak – It is all like a game.”) [Appendix G; Section D; Question 5b & 5c; Participant 10]  
- “Soos met die sin klaamaak sal ek vir hom sê:"Is daar iets wat jy wil sê?” sodat hy onthou, maar net so in die omtrek sodat hy dit nie agterkom nie.” (“I would, for example, say to him:’Is there something you want to say?’ It is to remind him about it without him realizing it”) [Appendix G; Section D; Question 1d; Participant 1]  
- “We kind of tell her in a joky way that we have enough information, and she will laugh it off.” [Appendix G; Section C; Question 1c & 1d; Participant 2]  
- “I will prompt her to describe it in a different way…..to think of other words to describe something.” [Appendix G; Section C; Question 2c; Participant 2]  
- “I chuckle about it with her or made a joke about it.” [Appendix G; Section E; Question 1b; Participant 4]  
- “Ek maak so “zip it” (handgebaar) en dan sal hy stilbly.” (“I’ll give him the “zip it” sign and he’ll then keep quiet.”) [Appendix G; Section D; Question 5b; Participant 5]  
- “Gewoonlik sit on slangs mekaar dan sal ek half liggies stamp.” (“I usually sit next to him and give him a nudge when he does so.”) [Appendix G; Section D; Question 5b; Participant 8]  
- “As ek agterkom hy vergeet dan sal ek maar vra of hom probeer herninner sodat hy dit nie agterkom nie.” (“If I realize that he forgot, I’ll try to remind him in a roundabout way by prompting him.”) [Appendix G; Section E; Question 3d; Participant 1] |
### Table 8 continued

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<tr>
<th>Theme</th>
<th>Sub-theme</th>
<th>Illustrative quotes</th>
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| - | **Sub-theme 2: Address the communication problem directly within the conversation or afterwards.** | - “I discussed her impatience with younger children with her several times.” [Appendix G; Section E; Question 1b; Participant 2]  
- “I address it immediately. This is how we overcome the problem, which works well. I feel it is correct to let him know and be aware of it….I try to bring him to think of it himself.” [Appendix G; Section D; Question 4c; Participant 6]  
- “Dan sal ek vir hom sê: “My man, jy praat nou bietjie hard.” (“I will tell him that he is talking too loud, which makes him aware of it himself.”) [Appendix G; Section D; Question 2b; Participant 10]  
- “Ek probeer vir haar verduidelik as ek agter kom sy het verkeerd verstaan, dit lyk tog of sy dan verstaan.” (“I try to explain to her when she hasn’t understood correctly. …it seems that she understands…..”) [Appendix G; Section D; Question 9c; Participant 9]  
- “Ek help hom reg deur te sê:”Nee man, dis mos…” (I correct him by saying,;” No man, isn’t it…..”) [Appendix G; Section C; Question 2c; Participant 7]  
- “I ask, I am very inquisitive” [Appendix G; Section C; Question 1d; Participant 6]  
- “I tried to do it afterwards, because I don’t want to embarrass him. But sometimes I will say:” Honey, he is still talking (within the conversation) trying not to make a big thing about it” [Appendix G; Section D; Question 5c; Participant 6]  
- “We will tell her:”No, you don’t need to say that, you might hurt someone’s feelings.” [Appendix G; Section E; Question 1b; Participant 2]  
- “Ek sê vir hom, nee praat sagter ek sit net hier langs jou.” (“I remind him to speak softer as I am sitting just next to him.”) [Appendix G; Section D; Question 2b & 2c; Participant 5]  
- “…ek het met hom gepraat het en vir hom gesê het jy moet nou tot orde kom. Mens sê nie sommer goed nie, jy dink voordat jy praat” (“…I seriously spoke to him and told him to bring himself to order and take control. He should not just speak his mind without thinking before he speaks.”) [Appendix G; Section E; Question 1b; Participant 5]  
- “Gewoonlik sa lek vir hom sê onthou net ek is besig met ons dogtertjie. Sy is nog klein, sy verstaan nie.” (“Usually I would tell him to remember that I’m busy with our little daughter who is till small and doesn’t understand.”) [Appendix G; Section D; Question 9c; Participant 8] |
### Table 8 continued

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<tr>
<th>Theme</th>
<th>Sub-theme</th>
<th>Illustrative quotes</th>
</tr>
</thead>
</table>
| **Theme 2:** Caregivers do not make the individual with severe TBI aware of communication interaction problems. | Sub-theme 1: To keep them in the conversation | - “Ek luister, jy kan hom nie kort knip nie, ek voel dit maak skade.” (“I listen. One cannot restrict him; I feel it can be harmful.”) [Appendix G; Section C; Question 1c & 1d; Participant 10]  
- “Ek het gevind dat as ek stil bly dan kry ek meer inligting uit haar uit, wat nooit voorheen so was nie.” (“I found though that I get more information from her when I just keep quiet, which was never so before.” [Appendix G; Section C; Question 1c & 1d; Participant 9]  
- “We tend to go on with hers (topic), because you are sensitive to the situation and we don’t want her to feel left out.” [Appendix G; Section E; Question 3c & 3d; Participant 2]  
- “Ons het ook nou al ons les geleer, want as jy hom daarvan bewus maak kan hy nie later onthou wat hy wou sê nie.” (“We have learned to just let him be when he interrupts; otherwise he forgets what to say….that is the way I keep in the conversation.”) [Appendix G; Section D; Question 5c; Participant 10]  
- “Ek los hom dat hy sy sê, sê, anders voel hy uit.” (“I leave him to say his say, or else he feels left out.”) [Appendix G; Section E; Question 3c & 3d; Participant 10] |
**Table 8 continued**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
<th>Illustrative quotes</th>
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</table>
|       | **Sub-theme 2:** To avoid eliciting negative reaction from the individual with severe TBI. | - “As jy ook kritiseer, dan vat hulle dit half verkeerd op. Hy is nie goed met kritiek nie. So dis beter om dit te ignorer.” (If you dare to criticize, they interpret it in a negative way. He does not endure any criticism. Thus, it is better to just ignore it.) [Appendix G; Section C; Question 1c & 1d; Participant 8]  
- “Mens moet haar glad nie in die rede val as sy praat nie, want dan hou sy net op. Ons stry, ons baklei soos ons nog nooit in ons lewe baklei het nie.” (“One must just never interrupt her when she speaks – she then stops talking. We argue, we fight as never before in our lives”) [Appendix G; Section D; Question 1c & 1d; Participant 9]  
- “Ek los maar, want sy vererg haar as ek haar in die rede val.” (“I just ignore it because she takes exception when I interrupt her.”) [Appendix G; Section E; Question 7b; Participant 9]  
- “Ek laat so nege van dit gaan, maar op ’n stadium raak dit bietjie erg….dan sal ek iets sê en dit gee gewoonlik ’n bakleery af, want hy besef dit glad nie.” (“At the start I ignore it, but when it gets to be too much I cannot keep ignoring it and berate him, which usually ends in a confrontation as he doesn’t realize it himself.”) [Appendix G; Section E; Question 1b; Participant 7]  
- “Never criticize, just stay patient and let it go. From the beginning I realized I should not belittle her.” [Appendix G; Section D; Question 5b; Participant 4]  
- “If I got cross, she would burst into tears and become stressed. What I discovered do not show any negativity or annoyance, because she becomes stressful.” [Appendix G; Section F; Question 1; Participant 4]  
- “He gets angry quickly, he snaps just like that. It is sometimes scary.” [Appendix G; Section F; Question 1; Participant 6] |
4 PHASE 1: DISCUSSION OF RESULTS

Results regarding the communication problems that caregivers observe and experience during interaction with the individual with severe TBI showed that the conversational messages of the individuals with severe TBI were in the first place insufficient regarding the quantity and quality of the informational content. These problems included difficulties with word finding, errors in the accurate transfer of information, and a decreased response adequacy, and contributed to their poor ability to produce proficient conversational discourse. The reported results confirm findings that have been reported in the literature (Coelho et al., 2005; Coelho, 2007; Kilov et al., 2009) Secondly, some conversational messages were described as inappropriate in terms of context, timing, and relevancy. The language use of the individuals with severe TBI is reportedly characterized by irrelevant utterances that do not make sense, difficulty inhibiting inappropriate utterances, poor turn taking, and difficulty in ordering words and propositions. Thirdly, the lucidity of conversational messages was influenced by the limited use of prosodic aspects of communication to express emotion and attitude during communication interaction. Most of the caregivers experienced this as one of the most challenging and confusing communication problems. Neumann (2010) found that the decreased capacity of individuals with severe TBI to participate in emotions resulted in inappropriate, inadequate, or sometimes confusing responses and that these problems have a negative impact on relationships.

Reports of caregivers also showed that the limited ability of individuals with severe TBI to interpret non-verbal communication behaviour of others accurately contributed to inappropriate communication behaviour. The caregivers reported deficits in understanding facial expressions and body postures, and delayed responses from their communication partner. Such difficulties contribute to a diminished capacity to function successfully in the community and form social relationships. Several studies have revealed that the impaired ability to interpret non-verbal communication behaviours accurately is one of the reasons individuals with severe TBI reflect social and communication difficulties (Jackson & Moffat, 1987; Karrow & Conners, 2003; Spell & Frank, 2000; Watts & Douglas, 2006).
Results regarding communication interaction problems showed furthermore that the nature of the conversational context and conversational partners influenced the occurrence of specific communication interaction problems. Problems include control over the loudness of voice, inappropriate comments, and the ability to adapt their communication interaction behaviour appropriately within a particular conversation. These problems had a negative impact on the individual with severe TBI’s ability to engage successfully in social communication with various communication partners and in various settings. In the literature a pattern of decline in inter-personal relationships, especially with those people outside the family network, was reported as a consequence of severe TBI (Shorland & Douglas, 2010; Struchen et. al., 2011). Part of returning to the community is resuming and sustaining pre-existing personal relationships, but also forming meaningful new relationships (Perkins, 1999). From the caregivers’ responses it was clear that the individuals with severe TBI are not exposed to communication interaction situations outside their comfort zone amongst family and close friends. This can partly be ascribed to limited social communication abilities, but also serves to indicate that the caregivers are not aware what integration into the community involves and how crucially important it is to return these individuals to full participation in the community.

The results regarding how individual caregivers deal with communication problems and the strategies they have developed to assist the persons with severe TBI to communicate more effectively were rather diverse. Five of the ten caregivers chose to make the individual with severe TBI aware of his/her communication interaction problems, while the other five caregivers chose not to. The caregivers who chose to make the individual with severe TBI aware of communication interaction problems either used a subtle approach to raise awareness or directly confronted the individual with severe TBI. Caregivers who chose to overlook the communication problems did it to keep the individual in the conversation or to avoid eliciting negative reaction from the individual with severe TBI. These results demonstrate that the heterogeneity of this population is not only evident in the manner in which individuals with severe TBI present with communication problems, but also the manner in which it is dealt with by caregivers.
5 PHASE 1: CONCLUSION

The analysed data of the semi-structured interviews showed that certain communication problems perceived and experienced as interfering with interaction with the individual with severe TBI are fairly obvious and easily perceptible. Caregivers were able to describe these difficulties in detail; how they experience these problems, to what degree, in which conversations the problems occurred and the impact it had on communication interaction with others. The majority of the caregivers experienced these challenges in various settings during communication interaction with individuals with severe TBI. The problems included insufficient quantity of information being conveyed, use of inaccurate words, poor turn taking and inappropriate comments. Moreover, the results showed that it is with regard to these obvious problems that caregivers have developed management strategies. It was interesting, however, to see how these strategies vary amongst caregivers. To deepen the understanding of how caregivers dealt with communication interaction difficulties, these management strategies were discussed in more detail during the focus group discussion.

There were also communication interaction challenges that the caregivers found difficult to describe. The results showed that caregivers are troubled by the decreased capacity of the individuals with severe TBI to show emotions appropriately during conversation, and by their impaired ability to interpret non-verbal communication behaviour accurately, but their explanation of the nature of these difficulties was vague. The reason for this might be that caregivers do not understand these problems completely in terms of the nature of pragmatic competence and the important role it plays during communication interaction. The results clearly showed that these problems frequently caused confusion and in some cases even conflict between communication partners. These aspects were discussed during the focus group discussion to deepen the understanding of the nature of these problems and how they can be dealt with to contribute to more effective communication interaction.

Finally the results showed that the communication interaction problems perceived by caregivers restricted the ability of the individuals with severe TBI to meet the social communication demands within the bigger community. Caregivers did not identify community reintegration as a problem. Their responses clearly indicated, however,
that the individuals with severe TBI are exposed to communication interactions that mostly involve family and close friends. People in this close circle of family and friends know and understand what happened to them. They are familiar with the communication problems the individual with severe TBI display and are therefore more ‘forgiving’, making allowance for most of the problems that occur. According to the literature, limited exposure to the bigger community results in communication participation that is less diverse, restricted to the home setting, and involves fewer social relationships (Law, 2002). In the revised version of the ICF framework by WHO in 2001, the terms ‘disability’ and ‘handicap’ were replaced by ‘activity limitation’ and ‘participant restriction’, respectively. Activities are defined as the nature and extent of functioning at the level of the person. According to WHO (2001) activity limitation is associated with actions of everyday life and relates to the actual performance of an action. Regarding individuals with severe TBI, the nature and extent of their communication functioning level has been decreased due to the brain injury. These communication interaction constraints contribute to activity limitations. Participation restriction refers to the extent to which the individual with severe TBI’s involvement is restricted in life situations due to his/her communication interaction problems. “Participation is classified according to ‘domains’ of life experience, which enables the identification of facilitators and barriers to participation” (Snow & Douglas, in McDonald, Togher & Code, 1999: 274). The limited communication participation within the bigger community might indicate that the participants are unaware that the communication interaction problems of the individual are a barrier to his/her communicative participation with others outside the close circle of friends and family. This points to a gap in the caregivers’ understanding of community integration and how to implement the process of integration successfully.

During the focus group discussion aspects of integration into the community were discussed in more detail. The pragmatic and discourse problems, which are characteristic of individuals with severe TBI, were shown to have a negative impact on communication interaction with their caregivers and other persons with whom they come into contact. Caregivers had different strategies to handle some of these problems, but it became clear that interaction with these individuals remained a significant challenge for everybody involved.
6 PHASE 2: SUB AIM 3

The aim of Phase 2 was to deepen the understanding of the researcher of the findings from Phase 1 by conducting a focus group discussion with the participants of the semi-structured interviews (sub-aim 3). Participants who took part in the focus group discussion comprised Participants 1 to 6 as captured in Table 1. Collected data from the focus group discussion were divided into themes and through systematic reviewing of these themes certain sub-themes emerged that characterized each theme. The three key questions of the focus group guide provided the foundation for the three main themes. The themes are: recommendations for dealing with perceptible communication interaction problems; decreased capacity of the individuals with severe TBI to interpret and use pragmatic aspects of communication appropriately; and aspects of community integration after TBI. The sub-themes that are discussed under each theme were not pre-determined but were systematically developed as transcripts of the focus group discussion were reviewed. Table 9 presents the main themes and sub-themes of the focus group discussions.

6.1 Sub aim 3: Description of results

6.1.1 Theme 1: Recommendations for dealing with perceptible communication interaction problems

Participants had contradictory recommendations regarding how to deal with perceptible communication interaction problems. Three participants recommended making the individual with severe TBI aware of inaccurate/inappropriate communication interaction problems that are more obvious, and three participants recommended refraining from such action. The following sub-themes were identified as considerations that determined their choice of management strategy.

- Reaction of the individual with severe TBI when made aware of inaccurate/inappropriate communication interaction behaviour.
- Influence on the emotional wellbeing of the individual with severe TBI when made aware of inaccurate/inappropriate communication interaction behaviour.
- Reaction of and impact on others taking part in the interaction.
Timing of action taken to make the individual with severe TBI aware of inaccurate/inappropriate communication interaction behaviour.

Table 9: Themes and sub-themes in the results of the focus group discussion

<table>
<thead>
<tr>
<th>Theme 1: Recommendations for dealing with perceptible communication interaction problems.</th>
<th>Sub-theme 1: Reaction of the individual with severe TBI when made aware of inaccurate/inappropriate communication interaction behaviour.</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Sub-theme 2: Influence on emotional wellbeing of the individual with severe TBI when made aware of inaccurate/inappropriate communication interaction behaviour.</td>
</tr>
<tr>
<td></td>
<td>Sub-theme 3: Considerations in making the individual with severe TBI aware of inappropriate behaviour.</td>
</tr>
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<td></td>
<td>Sub-theme 4: Timing of action taken to make the individual with severe TBI aware of inaccurate/inappropriate communication behaviour.</td>
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</tbody>
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<tr>
<th>Theme 2: Decreased capacity of the individuals with severe TBI to use and interpret pragmatic aspects of communication appropriately.</th>
<th>Sub-theme 1: Considering contextual clues to interpret the message of the individual with severe TBI because of the decreased ability to use prosodic aspects of communication effectively.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sub-theme 2: The limited ability of the individual with severe TBI to accurately interpret the conversational context and the intended meaning of the conversational message of others taking part in the conversation, frequently leads to inappropriate emotional outbursts.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 3: Aspects of community integration after severe TBI</th>
<th>Sub-theme 1: The importance of community integration</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sub-theme 2: Role of acceptance during community integration</td>
</tr>
<tr>
<td></td>
<td>Sub-theme 3: Role of confidence during community integration</td>
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<td></td>
<td>Sub-theme 4: Process of integration</td>
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Sub-theme 1: Reaction of the individual with severe TBI when made aware of inaccurate/inappropriate communication interaction behaviour.

The three participants who chose to refrain from making the individual with severe TBI aware of inaccurate/inappropriate communication interaction behaviour did so because the individual with severe TBI had a tendency to become bad-tempered. Participants did not make the individuals aware of these behaviours because they were cautious not to elicit outbursts of anger. The quotes from the original transcript are provided, together with an English translation where required, and an indication
of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “Nee, liever nie want sy word vies. Sys al vir my sê ek is nie stupid nie. Jy wys haar nie op haar foute nie. As sy hom maak dan los jy haar.” (“No, rather not because she takes exception. She’ll tell me that she’s not stupid. Don’t make her aware of her mistakes. Just leave her alone when she’s being wrong.”) [Appendix I; Question 1, Participant 3]

- “Nee weet jy, ek los hom maar. Hy is maar enetjie wat sy eie kop volg. Jy wys hom ook nie op sy foute nie.” (“No, I just leave him alone. He is truly one who follows his own head. Don’t show him on his faults.”) [Appendix I; Question 1, Participant 1]

In contrast, three participants realized that the individuals with severe TBI are not always aware of their communication interaction problems. They found that making the individuals aware of these inaccurate/inappropriate communication interaction behaviours contributes to more effective communication interaction outcomes. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “When I tell him, he says he does not realise he is doing it. He appreciates it though, because he does not know he is doing it.” [Appendix I; Question 1, Participant 6]

- “Afterwards, outside that environment; I will discuss it with her and tell her what she did. And how it is making it difficult in the situation and that we are trying to help her. It has had a response; then she realizes we are giving up a huge amount to help her. It seems she would be more careful, because she does not want to put us in a difficult position, not necessarily because she thinks she is wrong.” [Appendix I; Question 1, Participant 4]

Sub-theme 2: Influence on the emotional wellbeing of the individual with TBI when made aware of inaccurate/inappropriate communication interaction behaviour.

Several participants agreed that the reason they decided to refrain from making the individual with severe TBI aware of inappropriate/inaccurate communication interaction behaviours is because of the impact it had on the mood, motivation, and participation of the individual with severe TBI during interaction with others. The
quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “I specifically have chosen to let her go and just to continue, I found it is important to allow people to continue to progress. If you criticize or put them under pressure, they withdraw and lose the progress.” [Appendix I; Question 1, Participant 4]
- “The trauma was so big, you do not want to see them unhappy, so if she goes on and on and on in a conversation we just let her. We leave her, she needs to express herself.” [Appendix I; Question 1, Participant 2]
- “When I was critical or became cross, even with myself. She bursts out in tears. What I found is not to show irritation or negativity, it becomes very stressful for her and hinder her progress. I try always to be moving forward.” [Appendix I; Question 1, Participant 4]
- “My daughter is exactly the same. When one makes her aware of being wrong, she pulls back.” (“My daughter is much the same. When one makes her aware of being wrong, she pulls back.”) [Appendix I; Question 1, Participant 3]

Sub-theme 3: Considerations in making the individual with severe TBI aware of inappropriate behaviour.

In conversations where inaccurate/inappropriate communication interaction behaviours of the individual with severe TBI may be offensive to other communication partners or cause embarrassment to the individual with severe TBI, participants all make the individuals aware of these behaviours. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “In my son’s case, I would tell him, ‘If you do something wrong I’ll tell him it isn’t right. I would want him to do the right thing and behave well when with other people. I don’t want him to embarrass himself.”
That is why I show him what is correct and tell him how to behave.”) [Appendix I; Question 1, Participant 5]

- “My husband can make very inappropriate remarks; I make him aware of it. No, I have to, he makes everybody feel very uncomfortable” [Appendix I; Question 1, Participant 6]

- “As ek nou sien hy sal nou heel te mal die gesprek oorneem. Of dit gaan nou bietjie rof. Jy weet as hy nou agressief kwaad raak, dan sal ek vir hom sê dat dit nou nie hele mal reg is nie en help ek hom reg.” (“When I see he is totally patronizing a conversation or when he might become aggressively angry, then I would step in and tell him that it is not totally acceptable to do so, and guide him the right way.”) [Appendix I; Question 1, Participant 1]

Sub-theme 4: Timing of action taken to make the individual with severe TBI aware of inaccurate/inappropriate communication interaction behaviour.

Participants who did make individuals with severe TBI aware of inaccurate/inappropriate communication interaction behaviour carefully chose their timing and manner to do so. In terms of inappropriate turn taking, participants would interrupt the individual immediately within the conversation and make him/her aware that they should wait their turn. In some cases participants made gestures with their eyes or hands, to avoid interrupting the flow of conversation. In most cases this had a positive outcome, because most of the time the individual with TBI did not realize that he/she was interrupting somebody else. When the individuals used inappropriate comments or misinterpreted a conversation, participants tend to discuss it afterwards privately with the individual with severe TBI. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “I correct him immediately, in a nice way, not to put him in a disposition.” [Appendix I; Question 1, Participant 6]

- “Now, I don’t always have to say something, I will just look at him like this….. and he knows.” [Appendix I; Question 1, Participant 6]

- “I usually discuss the situation afterwards with her, and explain to her why her comments were inappropriate.” [Appendix I; Question 1, Participant 2]
6.1.2 Theme 2: Decreased capacity of the individuals with severe TBI to use and interpret pragmatic aspects of communication interaction appropriately.

During the semi-structured interviews, six out of the ten participants indicated that they often experience certain conversations with the individual with TBI as confusing. The participants noted that conversations are sometimes not only confusing for them but also for the individual with severe TBI. The participants found it difficult to describe the characteristics of these conversations and also the communication problems that contribute to the confusion. It became clear that these difficulties were related to limited pragmatic skills of the individual with severe TBI. From the results of the semi-structured interview two main aspects of pragmatic skills were identified as contributing to confusing communication interaction. First, individuals with severe TBI struggle to use prosodic cues effectively to generate pragmatic meaning during communication interaction. Secondly, they struggle to interpret the non-verbal behaviours of their communication partners. These problems were examined during the focus group discussion to deepen the understanding of the nature of the difficulties involved and how they can be dealt with to contribute to more effective communication interaction. The following two sub-themes were identified based on the responses of the participants:

- Considering contextual clues to interpret the message of the individual with severe TBI because of the decreased ability to use prosodic aspects of communication effectively.
- The limited ability of the individual with severe TBI to accurately interpret the conversational context and the intended meaning of the conversational message of others taking part in the conversation frequently leads to inappropriate emotional outbursts.

Sub-theme 1: Considering contextual clues to interpret the message of the individual with severe TBI because of the decreased ability to use prosodic aspects of communication effectively.

Participants agreed that the intended meaning of the verbal messages of individuals with severe TBI was often lost because they are not able to use certain pragmatic
aspects of communication interaction. For example, individuals with severe TBI are not able to use intonation and facial expression to infuse emotions like regret, preference, compassion and determination into their verbal message. As a result, other conversational partners may be confused about how to interpret the message and respond appropriately in a conversation with an individual with severe TBI. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “There is not enough communication, and you almost have to look at the environment that something is happening; you know is it waking up time, going to sleep time, eating time. I try to read in what should my wife be thinking about, where is she, is she hungry or what should she be doing. I don’t think their verbal communication that they are using is a good mechanism to express themselves and what they are feeling. There is a gap between the need and the speech. Speech is not being used the way it is meant to.” [Appendix I; Question 2, Participant 4]

- “As my seun nie lekker voel nie kom ek dit dadelik agterkom in sy spraak. Dit word baie stadiger.” (“When my son doesn’t feel well I can immediately detect it in his speech production. It becomes much slower.”) [Appendix I; Question 2, Participant 5]

- “Jy gaan dan baie meer na ander liggaams gedrag moet kyk, of hulle afsydig raak of kwaad lyk. My dogter begin baie sag praat.” (“You will then become more aware of body language…. My daughter starts speaking very softly.”) [Appendix I; Question 2, Participant 3]

- “As soon as my husband walks in the door I know what kind of mood he is in and then I know how to handle him.” [Appendix I; Question 2, Participant 6]

**Sub-theme 2: The limited ability of the individual with severe TBI to accurately interpret the conversational context and the intended meaning of the conversational message of others taking part in the conversation frequently leads to inappropriate emotional outbursts.**

During the focus group discussion, the emotional outbursts in certain communication interaction situations were discussed in order to deepen the understanding of these problems. From the participants’ responses it became evident that these outbursts most frequently occurred in situations where there are children involved, but also
with people the individual with severe TBI disliked. The participants described the individual with severe TBI as being irrational, unreasonably irritated, and bad-tempered during these outbursts. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “Veral as hulle nie van iemand hou nie. My doughter is ook so, sy sal sommer misluk wees of aspris iets doen wat daardie persoon irriteer.” (“Yes, and also when they do not like somebody. My daughter would behave badly or do things on purpose to irritate that person.”) [Appendix I; Question 2, Participant 3]
- “As sy met goed te doen kry wat sy nie meer kan doen nie, kom die agressie uit en dan baklei sy met die kinders of wie ook al.” (“I have also experienced that if she come across anything she cannot do anymore, all her aggression comes forward and she will confront anyone or fight with the children or somebody.”) [Appendix I; Question 2, Participant 3]
- “My sister can't stand to be around little kids, she is very quick to anger, very quick.” [Appendix I; Question 1, Participant 2]

6.1.3 Theme 3: Aspects of community integration after severe TBI.

Results of the semi-structured interview showed that a major gap exists between the participants’ understanding of the importance of community integration on the one hand, and how to implement integration on the other. The aspect of community integration after a severe TBI was discussed during the focus group discussion. The participants were asked what their thoughts were on community integration and the following sub-themes were identified under this theme:

- The importance of community integration
- The role of acceptance during community integration
- The role of confidence during community integration
- The process of integration
Sub-theme 1: The importance of community integration.

During the focus group discussion it was clear that the participants are aware of the importance of community integration. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “Ek dink jy moet hulle meer blootstel” (“They definitely need more exposure.”) [Appendix I; Question 3, Participant 5]
- “I think you need to do that to help them keep improving.” [Appendix I; Question 3, Participant 2]
- “It is absolutely essential for them to be integrated, it will give them confidence.” [Appendix I; Question 3, Participant 4]
- “On a one-on-one she is fine, or when she is with the family we know her. But out there people will be offended and she will be misinterpreted. That is also why we decided to push her to interact more outside her comfort zone so that she can learn through experience.” [Appendix I; Question 2, Participant 2]

Sub-theme 2: The role of acceptance during community integration.

Participants found that acceptance plays a significant role during the process of integration. From their discussions it was clear that it was not only important for the individual with severe TBI to accept the changes as a result of the TBI, it was also important for the caregiver to accept how both the individual with severe TBI and the circumstances have changed. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “Ek het agtergekom aan die begin dat my kind baie kwaad in hom gehad het. Wanneer sy neefs by ons kuier sal hy sommer op hulle skree en lelik wees. Tot ek eendag met hom gepraat het en gevra het of hy al vrede gemaak met homself. Dit help nie om te vra wie se skuld dit is nie, dit gaan daaroor of het hy al vrede gemaak, het hy al vergewe? Van daar af het dit regtig baie beter gegaan.” (“I realized in the beginning that my child had a lot of anger in him. When his small
cousins visited us, he would shout at them and behave badly. Until one day I asked him whether he had made peace with himself. Asking whose fault it was won’t help. It is all about making peace with his condition. Has he forgiven himself? From thereon it definitely improved.” [Appendix I; Question 2, Participant 5]

- “She has changed a lot. We needed to accept that and go on with life. Only there after we did come to the conclusion as a family that she needs to get out more, so that she can practice her communication outside the family environment. We are only now starting to make her aware of things, before we left it because everybody in the conversation knew.” [Appendix I; Question 3, Participant 2]

Sub-theme 3: The role of confidence during community integration

A number of the participants believed that when individuals with severe TBI return to the community in terms of going back to work, handling personal affairs, and socializing with others, it gives them the ability to communicate and interact with more confidence. This confidence plays an important role in their motivation to participate even more in activities of the community. In contrast, other participants experience that the integration process is frequently inhibited because of a lack of confidence. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “Ek dink jy moet hulle meer blootstel. Wat my seun bvoorbeeld doen as hy met vreemde mense praat is om vir hulle te sê, as julle nie verstaan wat ek sê nie, sê dit vir my sodat ek weer vir julle kan probeer verduidelik. Hy glo dan dat almal hom verstaan – en dit bou sy self vertroue.” (“I think they need to have more exposure. My son for example, now tells people that they should let him know if they don’t understand what he says so that he can try to explain it again. He believes that everybody understands him – this builds and improves his self-confidence.”) [Appendix I; Question 3, Participant 5]

- “Definitely confidence is a big thing. My husband going back to work was the best thing for him. When he was at home with me he was like a little brittle leaf. It took him a long time to get confidence. It was definitely the best thing for confidence.” [Appendix I; Question 3, Participant 6]
“It is absolutely essential for them to be integrated, it will give them confidence. It is a step-by-step process. After eight months she still does not have the confidence to go to the bank and discuss something. The caregiver is imperative to take those integration steps.” [Appendix I; Question 3, Participant 4]

Sub-theme 4: The process of integration.

All participants agreed that the process of integration is very slow, and emphasised that individuals with severe TBI should be exposed to new communication interaction environments gradually. They also acknowledged that it is the responsibility of the caregiver to initiate the process of integration. The quotes from the original transcript are provided, together with an English translation where required, and an indication of the source (the relevant Appendix and section, the particular question, and the individual participant) from which each quote was derived.

- “Ek het maar so stelselmatig haar begin blootstel aan nuwe mense en omgewings en ook meer en meer haar alleen begin los. Aan die begin het ek alles gedoen want sy was bang, maar ek het later gese dat sy self die goed moet begin doen en dit was goed vir haar want sy het gesien sy kon en dit het haar self vertroue gegee.” (“I have systematically introduced her to new people and environments and also at times left her on her own. At first I did everything for her because she was afraid. Later I told her that she would have to start doing things on her own which was good for her. She started realizing that she could, which gave her confidence.”) [Appendix I; Question 3, Participant 3]
- “It is a step-by-step process. After eight months she still does not have the confidence to go to the bank and discuss something. The caregiver is imperative to take those integration steps. If you take them too early it may result into rejection from outside, go back into their shells. You must judge yourself, It is a tremendous responsibility of the caregiver to make judgments especially when thy do not have guidance.” [Appendix I; Question 3, Participant 4]
- “Yes it is a long process. It is now two years after the accident and she went yesterday for the first time to apply for a loan on her own at the bank.” [Appendix I; Question 3, Participant 3]
- “You use a different type of approach on a different time in the journey.” [Appendix I; Question 3, Participant 4]
7 PHASE 2: DISCUSSION OF RESULTS

Theme 1: Recommendations for dealing with perceptible communication interaction problems.

From the focus group discussion it was clear that several factors determine whether or not the caregiver will make the individual with severe TBI aware of inaccurate/inappropriate communication behaviour. The reaction of the individual with TBI when made aware of inaccurate/inappropriate communication interaction behaviour was an important determining factor, but also the influence on the emotional wellbeing of the individual with severe TBI and the reaction of and impact on others taking part in the interaction.

Even though some of the participants chose to refrain from making the individual with severe TBI aware of the communication interaction problems they perceived, all the participants agreed that to be an effective communicator, a communication partner should always be alert to the informational needs of those taking part in the conversation (Owens, 2001). It is regarded as important and necessary, therefore, to make the individual with severe TBI aware of inaccurate/inappropriate communication behaviour because most of the time these individuals are not aware of their behaviours (Dahlberg, et. al., 2006). Making them aware of these challenges may contribute to more effective communication interaction outcomes. All the participants agreed that feedback regarding inappropriate or inadequate communication interaction to the individual with TBI should be positive and constructive but most of all context-sensitive; therefore careful observation of all the aspects contributing to the communication situation is crucial (Feeney, 2010).

Participants recommended different approaches to make the individual with severe TBI aware of communication interaction problems. These included subtle approaches, addressing the problem directly, addressing the problem within the conversation or afterwards. The best general approach could not be identified during the focus group discussion because each participant had a different motivation for using a certain approach. A possible explanation for this may be that the participants of the focus group discussion stood in various relationships to the individuals with severe TBI. These relationships included: mothers taking care of a son or daughter,
a sister taking care of a sister, and wives taking care of husbands and vice versa. Although various relationships were represented, there were not enough members of each category to draw a conclusion on how a specific relationship might impact on each determining factor.

**Theme 2: Decreased capacity of the individuals with severe TBI to use and interpret pragmatic aspects of communication interaction appropriately:**

Responses of the participants during the discussion of the pragmatic aspects of communication gave the impression that the participants did not understand the full extent of these behaviours. From the discussion it was clear that the participants found it challenging to describe in detail the impact of these behaviours on the communication interaction of the individual with severe TBI. For this reason it was difficult to compare their responses accurately to existing research findings.

Participants said that they often experienced the individual with severe TBI as ‘monotone’, without emotion, during conversations. This made it difficult for the participants to determine certain emotions for example whether their charges were tired, sad, or excited. A comprehensive study regarding communicative abilities after TBI (Angeleri et al., 2008) found that individuals with severe TBI demonstrated pronounced impairment in using pragmatic aspects of communication, with the tendency to express only the linguistic content of their message, neglecting the emotional meaning expressed through other modalities, for example prosody (Angeleri et al., 2008).

Participants further found that individuals with severe TBI often displayed their emotional status through the manner of speech production or behaviour. For example, the individuals will speak slower when they are not feeling well, they will speak more softly in conversation with unfamiliar persons, or they will withdraw from a conversation when they feel others in the conversation do not understand them. Through close observation of the individual with severe TBI, participants started realizing which interaction behaviours are associated with which emotion and used it to understand the individual better.
During the discussion the participants came to the conclusion that the context of conversation, especially in terms of others taking part in the conversation, frequently had a negative influence on how the individual with severe TBI interpret and subsequently reacts to the conversation. This observation implies that the individuals with severe TBI show impairment in adjusting their communication acts to the particular context. In the literature it is suggested that individuals with severe TBI have difficulty inferring the intended meanings of verbal and non-verbal behaviour in certain conversational contexts (Angeleri et al., 2008; McDonald & Flanagan, 2004). Milders and colleagues (2006) found that individuals with severe TBI have increased difficulty with interpersonal relationships because they had greater difficulty recognizing facial affect and prosody. According to the participants of the present study, they particularly experienced problems with the individual being unreasonable, impatient, and bad-tempered in conversations with young children or in conversational contexts that were noisy. These results confirm research showing that the changes in the social and emotional behaviour of an individual following TBI includes self-focused speech, insensitivity, inappropriate intimacy and disclosure, and talking out of turn (Crosson, 1987; McDonald, 1992; Prigatano, 1986). In research these changes have emerged as one of the major barriers to successful post-injury reintegration into family, community, and work environments (Brooks & McKinlay, 1983; Lezak, 1987; Thomsen, 1984).

**Theme 3: Aspects of community integration after TBI.**

Participant responses showed that they strongly believe returning to the community plays an important role in the progress of the individual with severe TBI, although most of them acknowledged that they have not really initiated this process yet. Successful community integration has come to be recognized as a primary goal of rehabilitation for individuals with TBI (Sander et al., 2010).

Participants could not recommend a clear timeframe in which it is best to start the process of community integration; in general, they were guided by the degree to which the individual with severe TBI and the caregiver have accepted the changes regarding the brain injury. From the responses of the participants and the background information the conclusion was drawn that the process is influenced by various factors such as the age of both the caregiver and the individual with TBI,
their lifestyle, the culture of the community to which they are exposed, and the extent to which the communication abilities of the individual with severe TBI have been compromised. According to Corrigan (1994), the meaning of community integration is different for different groups, including individuals of different ages and those of different backgrounds. To be successful, the process of community reintegration must address each individual’s priorities (Sander et al., 2010).

The participants who did believe the individual with severe TBI that they are caring for has returned to the community, were very positive regarding the integration process. According to these participants, the process of integration helped the individual with severe TBI to keep on improving his/her communication interaction skills. The reason for this may be that family members and close friends often started to accept the communication interaction problems and overlooked them. Unintentionally this may cause the individual with severe TBI to reach a plateau in terms of their communicative progress if they are only exposed to interactions in which they do not have to meet the demands of a conversation. Participants experienced improvement in turn taking skills and management of the topic of conversation following increased integration. in addition, these participants experienced integration as encouraging because it gave the individual with severe TBI confidence. In contrast, participants who have not yet initiated the process of community integration believe that it is because of a lack of confidence that they are hesitant to start the process.

Participants were not able to describe in concrete steps when and how the process of community integration should take place. This is understandable because of the uniqueness of the process for each person and also because so many factors have to be considered. Participants agreed that it is a gradual process, which takes a great deal of time. Participants further described the process as one of trial and error, an experimental process.

8 CONCLUSION

Even though there is a great deal of information available regarding the effects of severe TBI on communication interaction abilities, the heterogeneous nature of this population highlights the necessity to address each individual case independently.
Caregivers, who have knowledge of the individual’s pre-morbid functioning, are well placed to evaluate post-injury change in communication ability and do so from within the same socio-demographic context as that of the individual with severe TBI (Bracy & Douglas, 2005; Douglas et. al., 2007). Results of the present study clearly showed that each caregiver experiences different communication interaction problems in different contexts. For this reason it is vital to continuously consider their insights regarding these problems, especially during the chronic stage of the injury, after the individual with severe TBI has returned home. The study showed that there are limitations in terms of the caregivers’ understanding of certain aspects of communication, for example, non-verbal communication behaviour, the influence of the conversational partners and context, as well as the aspect of community reintegration.

Caregivers experienced communication interaction problems that had a direct impact on a conversation; these difficulties were easily detected and describable. The problems included insufficient quantity of information being conveyed, use of inaccurate words, poor turn taking, and inappropriate comments. The results also revealed that caregivers experience communication interaction challenges that are more difficult to detect and describe. These problems relate to certain pragmatic aspects of interaction such as prosody and non-verbal communication behaviours. Finally the results showed that caregivers do acknowledge the importance of community reintegration, although they are very unsure what exactly the process involves and how to address it. Research has shown that when the persons who experienced TBI returns home, the primary support persons identified a significant need for guidance (Rotondi et. al., 2007). This included the need to have someone to turn to for advice and guidance, to know how to care for their relative and facilitate recovery, to know how to respond to the behaviours and emotions of the person who experienced TBI, and to have help solving the day-to-day practical problems that arose. During this stage, primary family caregivers often experienced great anxiety about having their loved one home from the hospital (Rotondi et al., 2007). The participants of the present study also confirmed that they felt unprepared for the complexity and uncertainty of homecare, the associated tasks, and how to best facilitate continued improvement.
To date there is limited information available that caregivers can use to guide them in these situations. The aim of the present study was to determine how caregivers manage the communication interaction problems and what recommendations they have to offer in this regard. The results of this study provide some suggestions for managing these communication interaction problems. Caregivers recommended making the individual with severe TBI aware when these problems occur, especially because the individual is unaware most of the time of making these mistakes. They highlighted the significance of considering certain factors regarding when and how to make the individual with severe TBI aware of problems that may occur. Caregivers also mentioned that close observation of the individual with TBI is very important in order to understand the motivation for acting in a certain way, but also to know how to guide the individuals’ behaviour. Practical recommendations for improving effective communication interaction after severe TBI, proposed by caregivers, are discussed in more detail in Chapter four.

9 SUMMARY

Chapter 3 consists of the results of the present study, including the semi-structured interviews as well as the focus group discussion. The results were organized, analysed and discussed in accordance with the sub-aims of the present study. The chapter is rounded off with a conclusion.
CHAPTER 4
CONCLUSIONS

1 INTRODUCTION

Chapter 4 consists of the conclusions and implications drawn from the present study, as well as recommendations for further research and an evaluation of the study.

2 CONCLUSIONS

The aim of the present study was to determine the nature of pragmatic and discourse problems during the chronic stage after severe TBI, from the perspective of family caregivers, and their ways of dealing with such problems in a natural environment. The following conclusions were drawn based on the results of this study:

- Caregivers perceived pragmatic and discourse problems during interaction with individuals with severe TBI. These problems have a negative impact on communication interaction and may lead to frustration for the caregiver as well as the individual with severe TBI.

- The perceived communication interaction problems can influence relationships adversely. Caregivers reported that they experienced their own relationship with the individuals with severe TBI to be extremely challenging in the beginning after these individuals returned home, because their way of communication had changed so much. Some of the mothers acting as caregivers still experience conflict with their children who had a severe TBI, even after several months at home. Regarding relationships with others, caregivers are struggling to handle communication interaction problems and to maintain good relationships between the individual with severe TBI and the broader community.

- Caregivers noted that the individuals with severe TBI are not always aware of their pragmatic or discourse problems.
Caregivers have different ways of managing the communication interaction problems. Some caregivers make the individual with severe TBI aware of inappropriate/inaccurate communication interaction problems directly within a conversation, while others discuss the communication problems afterwards with the individual with severe TBI. Some caregivers prefer to refrain from addressing these problems.

There is a major gap between the caregivers’ understanding of the importance of community integration and their ability to implement integration strategies. This conclusion was important because it highlighted the need to educate caregivers on the aspects of community reintegration in order to help them implement the process successfully.

Caregivers found it difficult to describe certain communication interaction problems in detail. The reason for this may be that they do not have extensive knowledge of all the different aspects of communication. This was an important inference, because it highlighted the fact that caregivers need to be educated regarding the different aspects of communication in order to help them understand, identify, and deal with each communication problem more efficiently.

The speech-language therapist should be aware of the communication interaction problems following a TBI and how difficult it is for caregivers to manage these problems at home. The SLP should discuss these issues with family members and caregivers before the individual with severe TBI is discharged from in-patient rehabilitation.

The present study collected valuable guidelines regarding the communication interaction problems caregivers may experience. For that reason these guidelines will be discussed separately in more detail.
3 PRACTICAL RECOMMENDATIONS, PROPOSED BY CAREGIVERS, TO IMPROVE EFFECTIVE COMMUNICATION INTERACTION AFTER SEVERE TBI

During the semi-structured interviews and the focus group discussion caregivers proposed some practical recommendations to improve effective communication interaction after severe TBI. The information is presented in a framework of behaviour intervention that can easily be integrated on a daily basis.

3.1 Important aspects to consider regarding the communication situation.

As mentioned previously, individuals with TBI are not always aware of their communication interaction problems. Therefore, making these individuals aware of their problems may contribute to more effective communication interaction outcomes. Feedback to the individual with TBI regarding inappropriate/inadequate communication interaction should be positive and constructive but most of all appropriate in the conversational situation where it occurs. Careful consideration of certain aspects of the communication situation is crucial. Aspects to consider before making the individual with TBI aware of inaccurate/inappropriate communication interaction behaviour include:

- *Consider where the person is in his/her recovery.* Caregivers experienced that the individual with TBI tends to be vulnerable and insecure when returning home after being discharged from in-patient care. Commenting on inadequate/inappropriate communication interaction during this period may contribute to feelings of disappointment, anger, incompetence, and failure. This could cause the individual with TBI to withdraw or sometimes lead to outbursts of anger. Caregivers suggest that a suitable time for making the individual aware of inappropriate/inadequate communication interaction is only after he/she has been at home for at least 3-4 months.

- *Consider time of feedback regarding inappropriate/inadequate communication behaviour.* Accurate timing of feedback on inappropriate/inadequate communication interaction is essential. It plays an important role in how the individual with TBI perceives, and then reacts to the feedback.
Consider the relationship with the individual with severe TBI, conversational situation, and age. Differences in relationship, age, and conversation situations may act as indicators for a caregiver to either confront the individual with TBI’s communication interaction problems, or to refrain from doing so. It is important to remember that there will always be personal differences in how caregivers choose to handle communication interaction problems. In general, though, caregivers recommended that one should be cautious in the following instances when making the individual with severe TBI aware of inappropriate or inadequate communication behaviour.

Consider age and independence issues.

- Older spouses (acting as the caregiver) of the individual with TBI need to exercise caution when providing guidance. Spouses older than 50 years, living on their own with the individual, experienced that the individuals with severe TBI tend to withdraw because they experience it as criticism, pressure, or even an indication of failure. The spouses feel that this had a negative impact on the individuals with severe TBI's progress and self-confidence. In these instances caregivers recommended the use of techniques such as implementing humour within the conversation or discussing the problems in private after the conversation.

- In a family situation where individuals with severe TBI lived independently prior to the injury, but had to return to their parents after the injury, mothers (acting as caregivers) experienced that the individual with severe TBI tends to become bad-tempered when confronted with communication problems and they (the caregivers) were cautious not to elicit outbursts of anger by these individuals. Caregivers suggested addressing the problematic communication behaviour only after interaction. They recommended being firm, but also addressing the issue in such a manner that the individual with severe TBI will be able to reflect on his/her behaviour and realize that it was inappropriate/inadequate.
- It seems that spouses younger than 35 years, and family members who live in an environment where there are other people (e.g. young children or siblings of the individual with severe TBI) in the house as well, choose to make the individual aware of communication interaction problems because they feel the need to protect the individual from social ridicule (mockery). These caregivers want the individual with severe TBI to be more independent within a social environment and they feel the need to be assured that he/she will act appropriately in a situation where the caregiver might not be present. In these circumstances, caregivers recommended that problematic behaviours should be addressed directly and firmly within the conversation, especially in terms of behaviours such as inappropriate turn taking and inappropriate comments. They also felt it was important to discuss the behaviour again after the conversation, to ensure that the individual with severe TBI understands the significance of the matter.

- Consider personality traits of the individual with severe TBI. As mentioned previously, communication interaction problems subsequent to TBI are often associated with personality changes, including increases in negative behaviour and awkward or impulsive communication interaction behaviour.

- Consider the conversation. The content of the conversation, conversational partners, nature of the conversation, conversation environment, and mood of conversation can be controlled to some extent. Careful consideration and manipulation of these aspects can promote effective communication interaction.

- Consider the impact of the communication interaction problem on the effectiveness of the conversation. To improve effective communication interaction the caregiver should evaluate the impact of the communication interaction problem on the effectiveness of the conversation and assist the individual with severe TBI to ensure a successful transmission of intended meanings. The impact can be determined by close observation of the non-
verbal cues and body language of all the partners participating in the conversation, including the individual with severe TBI.

3.2 Recommended guidelines for dealing with communication interaction problems associated with severe TBI.

Table 10 presents the recommendations for improving effective communication interaction after TBI that were formulated together with caregivers and in accordance with communication interaction problems experienced by caregivers. It is important to remember that careful consideration of the communication situation should always precede implementation of a chosen recommendation.
### Table 10: Recommended management strategies

<table>
<thead>
<tr>
<th>Communication problem experienced by caregiver</th>
<th>Recommended management strategies</th>
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<tr>
<td>Caregivers experienced problems with the use of inaccurate words, interruptions (delayed or incomplete responses), and inappropriate amount of information being conveyed during conversation interaction. These problems had a negative impact on the effectiveness of the individual with TBI's conversational message because it sometimes led to confusion or misunderstandings by other participants in the conversation. Caregivers frequently experienced the following communication interaction problems:</td>
<td>• Help the individual with TBI to fill in the information gaps.</td>
</tr>
<tr>
<td>• Inappropriate comments and</td>
<td>• Repeat important information systematically and inconspicuously within a conversation.</td>
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<tr>
<td>• Inappropriate turn taking skills.</td>
<td>• Ask questions to confirm accuracy of information given by the individual with TBI.</td>
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<td>• Lack of sensitivity (unintentionally) towards others taking part in the conversation.</td>
<td>• The use of notebooks/written reminders is a useful strategy in more structured communication interaction situations for, example, work meetings.</td>
</tr>
<tr>
<td>• Short temper, especially in busy, noisy conversation environments.</td>
<td>• Allow the individual with TBI more “speaking time”, giving him/her the opportunity to explain their message to their full potential.</td>
</tr>
<tr>
<td>• Unawareness of these problems on the part of the individual with severe TBI.</td>
<td>• When possible, keep conversations within a quiet environment, with less background noise and movement (individuals with TBI show low tolerance for noisy/ busy conversational environments).</td>
</tr>
<tr>
<td>• The individual with TBI tries to convince others that he/she is the same person as before the brain injury and therefore tends to over-compensate with conversation interaction behaviour.</td>
<td>• Feedback to the individual with TBI should be positive and constructive.</td>
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<td></td>
<td>• Choose the timing for confronting the individual’s behaviour carefully:</td>
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<td></td>
<td>- Try to be inconspicuous and discreet during conversations, use humour or try to redirect the attention from the topic or the individual’s communication behaviour.</td>
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<td></td>
<td>- When discussing the situation or behaviour afterwards with the individual with TBI, do it in a quiet environment; be direct and firm to ensure the individual understands the impact of his/her communication behaviour on the conversation.</td>
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<tr>
<td>Communication problem experienced by caregiver</td>
<td>Recommended management strategies</td>
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<td>Caregivers found that when individuals with TBI understand that the caregiver is as much part of the recovery process as themselves and that the caregiver is placed in an uncomfortable position during these conversations, the individuals with TBI attempt to control their behaviour because they feel a responsibility towards the caregiver.</td>
<td>Make the individual with TBI aware of the slower speech production or distortions. According to caregivers the individuals are in general able to use the feedback constructively and adapt the rate of their speech production.</td>
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<tr>
<td>Caregivers experienced that the rate of speech production is closely related to how individuals with TBI are feeling. The individuals often tend to speak more slowly when they are tired or when they are ‘having an off day’. This behaviour not only depends on the mood of the individual with severe TBI, but can also be seen when the individual is tired, hungry, or doing something out of routine. Together with the slower speech productions, distortion as well as slight disfluency may occur.</td>
<td>- Always keep the background information in mind while the individual with TBI is communicating. For example, is he/she telling you about something that made him/her cross, happy, sad, or proud?</td>
</tr>
<tr>
<td>Caregivers indicated that monotone speech production frequently occurs during communication interaction. The frequency of occurrence of the monotone speech varies from almost always to only when the individual with TBI is tired. The lack of intonation may lead to confusion during communication interaction. Managing this problem is rather difficult and although there is not an actual strategy to decrease monotone speech production, strategies were formulated that might decrease the confusion caused by monotone speech production during conversation.</td>
<td>- Try to guide the individual with TBI in an inconspicuous fashion to be more descriptive regarding his/ her feelings, by asking questions relating to feelings that may be relevant in a particular conversation.</td>
</tr>
<tr>
<td>Caregivers acknowledged that because the individual with TBI shows limited emotion during conversation, the listener tends to respond with limited emotion. Caregivers found that this caused confusion for the individual with TBI, leaving the individual with TBI unsure whether he/she was able to convey emotion. Caregivers suggested trying to determine how the ‘story’ is making the individual with TBI feel (happy, sad, frustrated or proud) and then responding accordingly with appropriate emotion/attitude.</td>
<td>- Caregivers acknowledged that because the individual with TBI shows limited emotion during conversation, the listener tends to respond with limited emotion. Caregivers found that this caused confusion for the individual with TBI, leaving the individual with TBI unsure whether he/she was able to convey emotion. Caregivers suggested trying to determine how the ‘story’ is making the individual with TBI feel (happy, sad, frustrated or proud) and then responding accordingly with appropriate emotion/attitude.</td>
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### Table 10 continued

<table>
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<tr>
<th>Communication problem experienced by caregiver</th>
<th>Recommended management strategies</th>
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</table>
| Caregivers experienced problems with the ability of individuals with severe TBI to control their voice intensity during specific interactions. | • When possible, adjust the conversational environment to make it less noisy or busy.  
• Make the individual with severe TBI aware of inappropriate voice loudness/intensity. |
| Problems with the individual with TBI’s ability to interpret non-verbal communication accurately occurred frequently. The individual is either oversensitive or insensitive to non-verbal communication messages and it usually results in misperceptions. | • When confusions occur, act in a controlled manner and put things into perspective for the individual with TBI.  
• Set the scene for individuals with TBI, so that they understand why the caregiver (or other communication partner) is acting the way he/she does. Make individuals with TBI aware that an awkward situation is not necessarily caused by their actions or presence. |
| Caregivers admitted that interaction is mostly restricted to close family and friends as these people understand the circumstances and are more accepting. They did indicate that they are aware of the need for reintegration into the broader community. | • Carefully consider the timing to start the integration process; both the individual with TBI and the caregiver must be ready.  
• The process of integration is always a trial-and-error procedure, and continuous evaluation during the integration process is very important.  
• Systematically introduce different conversational environments, partners, and types of conversations. Gradually increase the complexity of these factors.  
• Steadily allow the individual with TBI to become more independent in different conversation interaction situations.  
Be patient, it is a long process. |
4 IMPLICATIONS OF THE STUDY

The following implications applicable to the clinical practice can be deduced from the results of the present study:

- Caregivers indicated the reality of communication interaction problems and the need for information about the problems they might experience. They furthermore indicated the need for guidelines regarding the management of these problems. Clinicians need to realize and take on their responsibility in this regard.
- At the present time limited resources are available to help the family caregivers cope with both the short- and long-term challenges associated with brain injury (Boschen, Gargaro, Gan, Gerber and Brandys, 2007; Wood & Alderman, 2011). In part 2.1 of this chapter some practical recommendations, proposed by caregivers, were formulated to assist others involved with individuals with TBI in dealing with communication interaction problems.
- Caregivers expressed themselves strongly on their need for guidance regarding the process of community reintegration. Speech-language therapists need to work with the caregivers of individuals with TBI and focus their long term intervention programmes on assisting them in community re-entry, and on maintenance of everyday skills in the life of the individual with TBI (Björkdahl, 2010; Shorland & Douglas, 2010; Snow & Douglas, 1999).

5 EVALUATION OF THE STUDY

The critical evaluation of a research project is crucial for the appropriate interpretation of the results within a framework of strengths and limitations (Mouton, 2001:125).

- The main limitation of the present study was that only ten participants were available for this research. Their relationships to the individuals with severe TBI, and the age of both the participants and the individuals with TBI, varied considerably. It is possible that relationships and age may impact on coping strategies. The lack of consistency in participant characteristics may limit the potential for the results to be generalised to a larger population.
• Only six of the participants were able to attend the focus group discussion. A larger group may have contributed more extensively to the guidelines for managing communication interaction problems.

• Only one focus group discussion could be arranged due to busy daily schedules of the participants. A series of focus group discussions may contribute towards comprehensive guidelines regarding handling strategies.

• From a methodological perspective, the use of the same participants of the semi-structured interviews for the focus group discussion allowed the researcher to investigate certain aspects in more detail and clarify any uncertainties that may have occurred during the semi-structured interviews.

• The main value of the study lies in the recommendations that were formulated in collaboration with caregivers to improve effective communication interaction after TBI.

6 RECOMMENDATIONS FOR FURTHER RESEARCH

The results of the present study furthermore have implications for future research:

• In future research the effect of age, of both the caregiver and the individual with TBI, and the effect of relationship on interaction problems can be further explored.

• Critical application to South African individuals and caregivers from multilingual, multicultural, and diversesocia-economic contexts is necessary.

• Another topic to explore is the effect of change with regard to living conditions and co-habitation after the TBI on interaction, and the most appropriate management strategies in such altered situations.

• It will be of service to the profession to evaluate how useful and appropriate the recommendations are which were proposed by caregivers to improve effective communication interaction after severe TBI.
7 FINAL CONCLUSION

According to the American Speech-Language-Hearing Association one of the main objectives of speech-language pathology services is “to optimize individuals’ ability to communicate in natural environments, and thus improve their quality of life. Speech-language pathologists serve individuals, families, groups, and the general public through a broad range of professional activities” (American Speech-Language-Hearing Association, 2001:26 & 29). It is a primary role of the speech-language therapist, therefore, to treat the communication problems associated with the severe TBI, but also to educate caregivers and family members involved with these individuals in all aspects of communication in order to assist them in dealing with associated problems. Significant benefit may be added to the everyday lives of individuals with severe TBI by empowering caregivers and family members with practical recommendations to improve communication interaction outcomes. The guidelines proposed in this study are a preliminary contribution that can be used to assist caregivers and family members in managing pragmatic and discourse problems during the chronic stage after severe TBI.

8 SUMMARY

In Chapter 4 conclusions were drawn based on the results of this study. Important aspects to consider regarding the communication situation were discussed in detail and recommended guidelines for dealing with communication interaction problems associated with severe TBI were compiled. Implications and evaluation of the study were explained followed by recommendations for further research. The chapter was rounded off with a final conclusion.
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Appendix A: Letter requesting permission to access patient records from rehabilitation centre
November 2009

The Superintendent
Riverfield Lodge Rehabilitation Centre
Southernwoods Road,
Nietgedacht,
P.O. Box 67372
Bryanston
2021

Dear Ms. S. Lategan

CONSENT TO APPROACH DISCHARGED PATIENTS TELEPHONICLY

I am currently a Master’s student in Speech-Language Pathology (M. Communication Pathology) at the Department of Communication Pathology at the University of Pretoria. In order to complete my degree, I am conducting a research project to determine: The nature and management of pragmatic- and discourse abilities after severe TBI, from the perspective of close relatives.

Information will be gathered from an interview with participants, who are a close relative of an individual who suffered severe traumatic brain injury (TBI). This information will provide us (speech-language pathologists) with a better understanding of how communication abilities are affected after a severe traumatic brain injury, as viewed by a close relative. We would gather information regarding communication with the individual affected by severe TBI and in future be better able to provide relevant and appropriate services to family members and other professionals.

With the aim of selecting suitable participants it is necessary that I am granted access to patients’ records. I need to obtain contact numbers and the medical history of patients who suffered a severe TBI. Patients’ records will only be used for the purpose of my study. Once I have identified possible participants, I will contact them...
telephonically and ask if they would be prepared to take part in the study. Participants will be provided with an information letter in which the study is explained. They first need to grant written informed consent before the interview commences.

All information will be treated as confidential, and no names or any other identifying information of the participants will be revealed. Please note that the person with the TBI is not seen as participants and the focus of this study is on the close relative.

I hereby respectfully request your assistance in sourcing the research participants. I trust that my request will be favourably received.

For any further queries, please do not hesitate to contact me on 083 404 5457 or my research supervisor Prof Anita van der Merwe, at the Department of Communication Pathology on (012) 420 5762.

Your willingness to assist me with this research project is greatly appreciated.

Yours sincerely

[Signature]

Cecilia Fourie
Speech Language Pathologist and Audiologist

[Signature]

Prof. Anita van der Merwe
Research supervisor
Department of Communication Pathology
University of Pretoria

[Signature]

Dr. Maggi Soer
Acting Head: Department of Communication Pathology
University of Pretoria
Appendix B: Letter from rehabilitation centre granting written consent to access patient records
5 November 2009

Dear Cecilia,

Life Riverfield Lodge is in support of training initiatives and of academic development, which will not only be of benefit to you as professional, but will enhance the value of the rehabilitation process for the patient as well as for the family.

Your research project will undoubtedly contribute and add value to the dynamic development of the rehabilitation model.

I take note of you request and wish to stress the importance to adhere to the guidelines and principles as prescribed by section 53 (1) of the promotion of access to information Act, 2000 (Act no 2 of 2000). Clinical standard document attached.

I am exited about your research project and wish you every success.

Sincere regards

Dr Marinda Overbeek
Hospital Manager
Appendix C: Ethics approval letter
16 September 2010

Dear Prof van der Merwe

Project: Pragmatic and discourse problems after severe traumatic brain injury from the perspective of caregivers
Researcher: C Fourie
Supervisor: Prof A van der Merwe
Department: Communication Pathology
Reference number: 23158990

Thank you for your response to the Committee’s correspondence of 27 August 2010.

I am pleased to be able to tell you that the above application was approved by the Postgraduate Committee on 17 August 2010 and by the Research Ethics Committee on 15 September 2010. 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.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely


[Signature]

Prof. John Sharp
Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: john.sharp@up.ac.za

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Appendix D: Informed consent letter
May 2010

Dear Participant

CONSENT TO PARTICIPATE IN RESEARCH PROJECT

I am currently a Master's student in Speech-Language Pathology (M. Communication Pathology) at the Department of Communication Pathology at the University of Pretoria. To complete my degree, I am conducting a research project titled Pragmatic- and discourse problems after severe traumatic brain injury from the perspective of caregivers.

For the research project I will be collecting information from caregivers of individuals who suffered a severe traumatic brain injury (TBI). This information will provide us (speech-language therapists) with a better understanding of how communication abilities are affected after a severe traumatic brain injury.

The study further aims to formulate guidelines, rooted in the experiences and perspectives of caregivers, which could be used to overcome communication difficulties associated with a TBI. Such guidelines will enable speech-language therapists to provide relevant and appropriate services to family members and other professionals.

Previous research has shown that the observations of caregivers and significant others, have boundless natural validity, since it is based on the TBI patient’s communication behaviour in the real world (Bordone, Seyranian & Ruff, 1997). Furthermore most caregivers knew the individual who suffered a TBI before the injury occurred and can provide truthful and valuable information regarding post-injury communication abilities relative to pre-morbid communication abilities. Please note that the person with the TBI is not seen as participant. The focus of this study is on you, the caregiver.

Your participation will be greatly appreciated and highly regarded. The study will require an interview of approximately one hour with you. The interview will be recorded on tape and you will be asked questions regarding your perception of the communication skills of the individual with the TBI before and after the accident. You will also be asked questions regarding your strategies for coping with any communication problems. For the second phase of the study all the participants will be asked to gather as a group and assist me to formulate guidelines for communicating effectively with individuals with TBI. This gathering will be at a time that suits you and will not last longer than 90 minutes.
I understand my rights as participant, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

Participant's name: ______________

Participant's signature: ______________

Signature of researcher ______________

Date: ______________
Appendix E: Semi-structured interview questionnaire (English)
Section A: Biographic information

- Tell me about the cause of the brain injury?
- When did the injury happen?
- Was the person in a coma after the incident?
- For what period of time was the person in the coma?

Section B: Communication interaction of the individual with severe TBI

- Tell me about his/her communication before the injury.

Section C: Communication problems regarding the content of the conversation

**Quantity**

**Question 1**

a) During a conversation do you experience that the person is giving too much or maybe too little information?

b) Can you describe to me why you say this?

c) Do you make the person aware of this?

d) How do you generally deal with this problem when you are having a conversation with the person?

**Quality**

**Question 2**

a) Do you experience that the person gives inaccurate or ambiguous information during conversation that influence the clarity of his/her message?

b) Can you tell me about these words and give a few examples?

c) How do you generally deal with this when you are having a conversation?

Section D: Pragmatic competence

**Prosody during communication interaction**

**Question 1**

a) Do you experience long silences during conversation that may disrupt the flow of the conversation?

b) Tell me about the disruptions you are observing?

c) Do you make the person aware when this kind of disruptions occurs?

d) How do you generally deal with this?
Question 2
   a) How would you describe the intensity of the person’s voice during conversation, for example, is it too loud or too soft?
   b) Do you make the person aware of this?
   c) How do you generally deal with this?

Question 3
   a) How would you describe the rate of his/her speech production during conversation?
   b) Do you make the person aware of this?
   c) How do you generally deal with this?

Question 4
   a) How would you describe his/her ability to adequately use voice production to express emotion and attitude?
   b) How does this impact on conversations?
   c) How do you generally deal with this?

Turn taking

Question 5
   a) In conversation is the person able to wait appropriately for a speaking turn?
   b) Do you make the person aware that he/she is not appropriately waiting for a speaking turn?
   c) How do you generally deal with this?

Non-verbal communication: Use

Question 6
How would you describe the person’s use of gestures during conversation?

Question 7
Would you describe his/her facial expressions as appropriate during conversation?

Question 8
   a) Does the person make meaningful eye contact during conversation?
   b) And is he/she able to maintain eye contact appropriately?
Non-verbal communication: Interpretation

Question 9:
   a) Do you experience that the person finds it difficult to accurately interpret non-verbal communication behaviours?
   b) How does this influence the conversation?
   c) How do you generally deal with this?

Section E: Conversational competence

Inappropriate comments

Question 1
   a) Does the person ever give inappropriate comments during a conversation?
   b) How do you generally deal with this?

Management of topic of conversation: Initiating

Question 2
   a) Does the person need encouragement to start a conversation?
   b) How do you encourage him/her to start a conversation?

Management of topic of conversation: Maintaining

Question 3
   a) Would you say the person is able to maintain the topic of conversation adequately?
   b) Tell me more about the problems you are experiencing regarding topic maintenance.
   c) Do you refer the person back to the topic of conversation?
   d) How do you generally deal with this?

Management of topic of conversation: Expanding

Question 4
   a) Would you say the person is able to adequately expand on a conversational topic?
   b) How do you generally deal with this?

Management of topic of conversation: Shifting

Question 5
   a) When a particular topic of discussion has been closed and the conversation is moving on to another topic, is the person able to move on to the new topic?
   b) Do you make him/her aware of the fact that the conversational topic has changed?
   c) How do you generally deal with this?
Management of topic of conversation: Termination

Question 6
a) Is the person able to appropriately end a conversation?
b) Tell me why you say he/she is not able to end a conversation appropriately?
c) Do you make the person aware that the conversation has ended?
d) How do you generally deal with this?

Cohesion and coherence

Question 7
a) How would you describe the overall organization of a conversation and the logical sequencing of ideas of the person?
b) How do you generally deal with this?

Section F: Conversational settings

Question 1

In view of the possible communication problems you have identified, how do different conversational settings impact on his/her communication?

- One-to-one communication situation?
- In a conversation where a few people are present?
- In a public place where many people are present?
- Conversations with familiar people vs. strangers
- Conversation in different environments for example on the telephone or in motor vehicle.
Appendix F: Semi-structured interview questionnaire (Afrikaans)
Afdeling A: Biografiese inligting
- Vertel vir my van die oorsaak van die breinbesering?
- Hoe lank terug was die besering?
- Was die persoon in 'n koma na die besering?
- Kan u onthou vir hoe lank was die persoon in 'n koma?

Afdeling B: Kommunikasie interaksie van die individual met ernstige TBB
- Vertel vir my van sy/haar kommunikasie voor die besering.

Afdeling C: Kommunikasie probleme ten opsigte van die inhoud van die gesprek.

Kwantiteit
Vraag 1
a) Tydens 'n gesprek kom u agter dat die persoon soms te veel of dalk te min inligting gee?
   b) Kan u vir my beskryf hoekom u so sê?
   c) Maak u die persoon bewus daarvan?
   d) Hoe handteer u dit gewoonlik in 'n gesprek situasie?

Kwaliteit
Vraag 2
a) Ondervind u dat die person onakkurate of onduidelik inligting gee tydens gesprekvoering wat die duidelikheid van sy/haar boodskap beinvloed?
   b) Kan u vir my miskien 'n paar voorbeelde hiervan gee?
   c) Hoe handteer u dit gewoonlik in 'n gesprek?

Afdeling D: Pragmatiese Vaardighede

Prosodie gedurende kommunikasie interaksie
Vraag 1
a) Ervaar u onnodig lang stiltes tydens gesprekvoering wat die vloei van die gesprek onderbreek?
   b) Kan u dalk vir my meer vertel van hierdie onderbrekings?
   c) Maak u die persoon bewus van hierdie onderbrekings?
   d) Hoe handteer u dit gewoonlik in 'n gesprek?

Vraag 2
a) Hoe sou u die intensiteit van die persoon se stem beskryf tydens gesprekvoering, is dit byvoorbeeld te hard of miskien te sag?
b) Maak u die persoon bewus daarvan?

c) Hoe handteer u dit gewoonlik in ´n gesprek?

Vraag 3
a) Hoe sou u die persoon se tempo van spraakproduksie beskryf tydens gesprekvoering?
b) Maak u die persoon bewus daarvan?
c) Hoe handteer u dit gewoonlik in ´n gesprek?

Vraag 4
a) Hoe sou u sy/haar vermoeë beskryf om stemtoon te gebruik om emosies uit te druk?
b) Watter impak het dit op die gesprek?
c) Hoe handteer u dit gewoonlik in ´n gesprek?

Beurtname
Vraag 5
a) Is die persoon om instaat om toepaslike beurtname toe te pas gedurende gesprekvoering?
b) Maak u die persoon daarvan bewus as hy/sy dalk uit sy/haar beurt praat?
c) Hoe handteer u dit gewoonlik in ´n gesprek?

Nie verbale kommunikasie: Gebruik
Vraag 6
Hoe sou u die persoon se gebruik van gebare tydens gesprekvoering beskryf?

Vraag 7
Sal u sy/haar gesigsuitdrukkings as toepaslik beskryf tydens gesprekvoering?

Vraag 8
a) Maak die persoon betekenisvolle oogkontak tydens gesprekvoering?
b) Is hy/sy instaat om oogkontak te behou tydens gesprekvoering?

Nie verbale kommunikasie: Interpretasie
Vraag 9
a) Ervar u dat die persoon soms nie-verbale kommunikasie gedrag onakkuraat interpreteer?
b) Hoe beinvloed dit die gesprek?
c) Hoe handteer u dit gewoonlik in ´n gesprek?
Afdeling E: Gesprekvoeringsvaardighede

Ontoepaslike kommentaar

Vraag 1

a) Gee die persoon soms ontoepaslike kommentaar tydens gesprekvoering?
b) Hoe handteer u dit gewoonlik?

Handtering van gespreksonderwerp: Inisiëring

Vraag 2

a) Het die persoon aanmoediging nodig om ’n gesprek te begin?
b) Hoe moedig u hom/haar aan om ’n gesprek te begin?

Handtering van gespreksonderwerp: Handhawing

Vraag 3

a) Sou u sê dat die persoon instaats is om toepaslik by die gespreks onderwerp te hou?
b) Vertel vir my meer oor die probleme wat u ervaar tov die handhawing van ’n gespreksonderwerp.
c) Sal u die persoon terug verwys na die onderwerp van die gesprek?
d) Hoe handteer u dit gewoonlik?

Handtering van gespreksonderwerp: Uitbreiding

Vraag 4

a) Sou u sê dat die persoon is om toepaslik uit te brei op ’n bepaalde gespeksonderwerp?
b) Hoe handteer u dit gewoonlik?

Handtering van gespreksonderwerp: Verander/Skuif

Vraag 5

a) Wanneer ’n bepaalde onderwerp van ’n gesprek afgesluit is, en dit gesprek het aanbeweeg na ’n volgende onderwerp, is die persoon instaats om aan te beweeg na die nuwe onderwerp?
b) Maak u hom/haar bewus daarvan dat die onderwerp van die gesprek verander het?
c) Hoe handteer u dit gewoonlik?

Handtering van gespreksonderwerp: Afsluiting/Be-einding

Vraag 6

a) Is die persoon instaats om ’n gesprek toepaslik af te sluit?
b) Vertel my hoekom u sê dat hy/sy nie ’n gesprek toepaslik kan afsluit nie?
c) Maak u die persoon daarvan bewus dat die gesprek ge-eindig het?
d) Hoe handteer u die gewoonlik?
Cohesion and coherence
Vraag 7

a) Hoe sou u die persoon se gesprek beskryf in terme van algemene organisering en die logiese volgorde van idees?

b) Ondervind u ‘n gebrek aan aaneenlopendheid tydens gesprekvoering?

Afdeling F: Gesprek opset
Vraag 1

In die lig van die verskillende probleme wat ons nou bespreek het, watter invloed het opset van verskillende gesprekke op die persoon se kommunikasie interaksie vaardighede?

- Een tot een gesprekke?
- In gesprekke waar daar min mense teenwoordig is?
- In publieke gesprekke waar daar baie mense is?
- Gesprekke met bekende mense teenoor gesprekke met vreemde mense
- Gesprekke in verskillende omstandighede bv. in die motor of oor die telefoon
Appendix G: Transcriptions of Semi-structured interviews
Transcriptions of semi-structured interviews

Section C: Communication problems regarding the content of the conversation

**Quantity**

<table>
<thead>
<tr>
<th>Question 1</th>
<th>b) Can you describe to me why you say this?</th>
<th>c) Do you make the person aware of this?</th>
<th>d) How do you generally deal with this when you are having a conversation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) During conversation do you experience that the person is giving too much or maybe to little information?</td>
<td>She can tell you a story from beginning to end in more detail that you need to know and also her memory is amazing, is almost the only thing she can hold on to. Very yappie-yappie</td>
<td>In the beginning we used to leave her but now we kind of tell her in a joky way that she is talking too much. And she laughs you off.</td>
<td></td>
</tr>
<tr>
<td>2 Too much: Oh yes definitely.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Nee nie regtig nie.</td>
<td>Die ding is die meeste mense waarmee sy te doen kry weet wat met haar gebeur het. Sy brei nooit uit nie. Baie min vreemde mense.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Ja, ja, ja. Vreeslik baie inligting.</td>
<td>(Gee voorbeeld van bouwerk).</td>
<td>Ag weet jy wat, aan die begin is dit verskriklik frustrerend, maar jy raak dit gewoond. Maar jy kom op so stadium dat jy net bietjie afswitch, anders sal dit jou mal maak. As jy ook kritiseer dan vat hulle dit half verkeerd op. Hy is nie goed met kritiek nie. So dit is beter om dit te ignoreer.</td>
<td></td>
</tr>
<tr>
<td>5 Ek kan nie regtig vir jou sê nie, maar ek sal eerder sê te min inligting.</td>
<td>Hy is nie meer so gretig om te praat nie. Hy praat net die nodige, maar sal nie bietjie uitbrei nie. Hy sukkel nog met onthou.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Ek sal sê eerder te veel.</td>
<td>Hy sal nogal praat en praat oor ´n punt.</td>
<td>Ag, entertain hom maar. Ons gesels maar daaroor tot hy klaar daaroor gesels het.</td>
<td></td>
</tr>
<tr>
<td>4 I think it is pretty balanced.</td>
<td>There is a slight tendency to go of on a tangent.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 Ja, ag weet jy dis moeilik.</td>
<td>Ons gesels oor dinge, maar as jy nou vir hom iets sê dan later vergeet hy weer... Hy self kom dit nie agter in gesprekke nie, hy dink om iets te sê maar dan vergeet hy. Sy probleem is hy vergeet baie maklik.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 He probably gives to little information,</td>
<td>He forgets quite a lot.</td>
<td>I ask, I am very inquisitive</td>
<td></td>
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</tbody>
</table>
### Transcriptions of semi-structured interviews continued

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<thead>
<tr>
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<tbody>
<tr>
<td>10</td>
<td>Ja te veel,</td>
<td>byvoorbeeld hy sal 'n storie by 'n storie las om by die antwoord uit te kom, te veel.</td>
</tr>
<tr>
<td>9</td>
<td>Te min.</td>
<td>Sy is absoluut baie privaat. Sy vergeet goed, dit is waar die verwarring in kom. Dit veroorsaak konflik</td>
</tr>
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</table>

### Quality

<table>
<thead>
<tr>
<th>Question 2</th>
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<tbody>
<tr>
<td>a) Do you experience that the person uses inaccurate or gives ambiguous information during conversation that influences the clarity of his/her message?</td>
<td>b) Can you tell me about these words or give a few examples?</td>
</tr>
<tr>
<td>c) How do you generally deal with this when you are having a conversation?</td>
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<tr>
<td>2</td>
<td>Yes, Yes. She is not very clear.</td>
</tr>
<tr>
<td></td>
<td>She struggles to find words to describe what she is trying to say.</td>
</tr>
<tr>
<td></td>
<td>Well, at first we try to describe it ourselves and ask her to think about it. In the beginning we felt that we did not want to put too much pressure on her and we just told her the word, now it is different. We let her make up her own thing. I will prompt her to describe it in a different way…. to think of other words to describe something.</td>
</tr>
<tr>
<td>5</td>
<td>Ja, ja dit gebeur dikwels</td>
</tr>
<tr>
<td></td>
<td>Hy raak deurmekaar en gebruik dan verkeerde woorde of hy sukkel om op die regte woord te kom.</td>
</tr>
<tr>
<td></td>
<td>Dan sal ek hom vra, maar wat spesifiek en sal hy probeer uitbrei. As ons nie regkom nie gaan wys hy vir my.</td>
</tr>
<tr>
<td>7</td>
<td>Ja</td>
</tr>
<tr>
<td></td>
<td>Hy sal party keer die verkeerde naam sê. Hy ruil partykeer goeters om byvoorbeeld name.</td>
</tr>
<tr>
<td></td>
<td>Ek help hom reg deur te sê nee man dit is mos …….</td>
</tr>
</tbody>
</table>
Transcriptions of semi-structured interviews continued

|   | Yes | I can’t think of anything specific. But sometimes when we are in a conversation, I will not always understand what he is saying. There will be misunderstandings, he will explain something and at the end I realize that I have no clue. Maybe that is because he is not giving me accurate information. | I do some times get irritated. And then we will have to go though the conversation to make sure we understand each other |
|---|---|---|
| 6 | No | Yes |
| 10 | Absoluut, hy doen dit baie maal. | Ek kan nie nou aan ‘n voorbeeld dink nie. | Ek sal vir hom vra watter ding. So ek probeer dat hy meer van die werk doen. En ek moedig hom aan om meer akkurate woorde te gebruik. Soms kry hy dit glad nie reg nie, dan los ek hom tot later en dan kom hy tog op die regte woord. (Herlei amper sy aandag) |
| 9 | Ja verseker | ek kan nie dink aan ‘n voorbeeld, maar kommunikasie is baie moeiliker |

Section D: Pragmatic competence

*Prosody during communication interaction*

<table>
<thead>
<tr>
<th>Question 1</th>
<th>a) Do you experience long silences during conversation that may disrupt the flow of the conversation?</th>
<th>b) Tell me about the disruptions that you are observing?</th>
<th>c) Do you make the person aware when this kind of disruptions occurs?</th>
<th>d) How do you generally deal with this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Sometimes yes</td>
<td>She will start a sentence and jump to something else.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Ja,</td>
<td>Jy sal agterkom hy is nogal stadig om te antwoord. jy kan sien hy is nog nie seun wat hy was nie. Soos met die vergeet. Hy loop baie, hy is verskriklik lief vir loop. Hy vergeet nogal baie belangrikke inligting.</td>
<td>Weet jy, ons het al so opgelet met hom. Soos met die sin klaarmaak sal ek vir hom se:” is daar iets wat jy wil sê?” Sodat hy onthou, maar net so in die omtrek sodat hy nie agter kom nie.</td>
<td></td>
</tr>
</tbody>
</table>
**Transcriptions of semi-structured interviews continued**

<p>| | | |</p>
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<tr>
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</thead>
<tbody>
<tr>
<td><strong>10</strong></td>
<td>Dikwels.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hy onderbreek homself want dan kan hy nie onthou waaroor die gesprek verder gaan nie, dan kan hy nie onthou hoekom hy dit begin nie.</td>
<td>Baie mense sê hy is nie 'n kind nie, ek weet hy is nie 'n kind nite. Maar baie moet jy hom hanteer as 'n kind. En die sinne uitspreek soos 'n kind. Dan verstaan hy beter. Dit hang baie van sy gemoedstoestand af, Ek kan nie vir jou sê wat doen ons môre nie. Ek kyk hoe is hy as hy wakker word en dan vat ons dit van daar af. Daar is dae wat hy 'on top of the world' is maar daar is dae, soos spesifiek vandag is hy af, hy is op 'n plato. Dan verstaan hy dinge nie en hy kan nie uitspreek wat hy wil hê nie. Maar dan gaan ek op 'n makliker manier in.</td>
</tr>
<tr>
<td><strong>9</strong></td>
<td>Nee, sy word net geweldig vinnig kwaad.</td>
<td>Mens moet haar glad nie in die rede val as sy praat nie, want dan hou sy net op. Ons stry, ons baklei soos ons nog nooit in ons lewe baklei het nie.</td>
</tr>
</tbody>
</table>

**Intensity of voice production**

<table>
<thead>
<tr>
<th></th>
<th>Question 2</th>
<th></th>
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<tbody>
<tr>
<td><strong>a)</strong></td>
<td>How would you describe the intensity of the person's voice during conversation, for example, is it too loud or to soft?</td>
<td>b)</td>
</tr>
<tr>
<td><strong>c)</strong></td>
<td>How do you generally deal with this?</td>
<td></td>
</tr>
<tr>
<td><strong>2</strong></td>
<td>She’s gone very loud suddenly, especially when she screams. When her patience is low, around - for example when there are a lot of children around. She gets irritated very quickly and shouts at them, which she never would have done.</td>
<td>In the beginning we left it, but now we are trying to teach her she does not need to scream at them like that. We do tell her, and explain that is not necessary to shout, but don’t worry it is ok. And she will say: “But they make me so angry!”</td>
</tr>
<tr>
<td><strong>3</strong></td>
<td>Sy praat net baie sag, veral oor 'n foon. Bietjie sag en baie grof. Dit maak dat jy haar nie altyd kan hoor nie.</td>
<td>Dan moet ek vir hom sê om net die radio af te sit sodat ek kan hoor. Die geringste ding trek sy aandag af.</td>
</tr>
<tr>
<td><strong>5</strong></td>
<td>Partymaal as hy opgewonde raak praat hy baie hard. Ook partymaal in die kar</td>
<td>Ek sê vir hom: “Nee, praat sagter ek sit net hier langs jou” <strong>In gesprekke waar daar meer mense is sal ek so vir hom wys – zip it!</strong></td>
</tr>
<tr>
<td><strong>4</strong></td>
<td>When she tries to shout at the dogs, her tone is very different, almost out of control.</td>
<td>No, I don't do anything, may chuckle a little.</td>
</tr>
<tr>
<td><strong>10</strong></td>
<td>As hy baie excited raak is sy stemton baie hard.</td>
<td>&quot;Dan sal ek vir hom sê:&quot; My man, jy praat nou bietjie hard’&quot;</td>
</tr>
</tbody>
</table>
Transcriptions of semi-structured interviews continued

Rate of speech production

| Question 3 | b) Do you make the person aware of this?  
| c) How do you generally deal with this? |
|---|---|
| a) How would you describe the rate of his/her speech production during conversation? | No, we leave her. We do not tell her to speak faster. It is not slower that you need to interrupt her; it is just slower that she used to be. |

| 2 | Much slower. It is clear, but is definitely slower that it used to be. And I don’t think it will get any faster. |

| 8 | Dit hang af. In die oggende sal hy o.k. wees, maar in die middag begin hy vreeslik stadig praat. Hy het ook sy af dae. Dan in die oggend al praat hy baie stadig |

| 5 | Hy trek nogal sy woorde. |

| 4 | She does speak too fast. One of the things that has been very slow. |

| 10 | Hy doen dit. Dit hang af hoe hy opstaan. As hy goeie nagrus gehad het en dit is nie bedompig nie, dan is hy baie vinnig. Sy brein is baie vinniger as sy mond. Dan struikel hy oor sy woorde of sy sin. |

Intonation during speech production

| Question 4 | b) How does this impact on conversations?  
| c) How do you generally deal with this? |
|---|---|
| a) How would you describe his/her ability to adequately use voice production to express emotion and attitude? | We know were she is coming from. It has happened before that somebody that does not know her may take offensively or as an insult. We know what she is trying to say. Everybody that she speaks to knows she has been in an accident, so they take it from where it comes. People that she has interacted with on another level or on the telephone, for instance an insurance company; there was a lot of explaining from her side. For a long time she was fine and then she snapped, and she became very irritated. I don’t know if the monotone speech impacts on the clarity of the message. |

| 2 | She is absolutely monotone. She gave her testimony in church. And one of the comments of one of the ladies that knew her is that she is completely monotone. She did not show any emotions all the way through. |

| 8 | Ja, dit is wanneer hy moeg raak. Anders is hy redelik |

| 4 | Hy moet net remind word dat hy dit nie moet doen nie, want hy vergeet. So ek sê baie keer hy moet oor begin. Hy vergeet soms waarop moet hy fokus. |

| 10 | Dan sê ek vir hom: “Haal net asem, dink mooi wat jy sê.” Dan doen hy dit, dan is dit perfek. Dan is daar dae wat dit baie stadig is, asof hy ‘n dik tong het. So hy spreek nie sy woorde baie mooi uit nie. En dan sê ek net weer vir hom dat hy nie sy woorde mooi uitspreek nie en hy moet duideliker praat. Ek voel dit is reg dat hy weet. Ek probeer sy memory terug kry om self daai dinge te doen. |

| 4 | No, we leave her. We do not tell her to speak faster. It is not slower that you need to interrupt her; it is just slower that she used to be. |

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Transcriptions of semi-structured interviews continued

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>My seun is baie stiller as wat hy was.</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>I must say, I haven’t really noticed that, or picked that up in a situation.</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Her tone is completely different. The intonation is not what it should be. Yes that is a problem.</td>
<td>I don’t criticise her or try to point out. We do exercises to help her.</td>
</tr>
<tr>
<td>5</td>
<td>Ja, ja ek kry dit. Jy kan dit nie op sy gesig sien wat is fout nie. Maar ek tel dit nogal op. Iets sal gebeur en ek weet dit moes hom kwaad of seer gemaak het, maar hy sal niks se dat jy dit agterkom nie.</td>
<td>Ek sal hom vra, en hom soms vir ’n rukkie los tot hy later na my toe kom en dan vertel wat het gebeur.</td>
</tr>
<tr>
<td>6</td>
<td>That is totally him. He is also very sensitive when you do make use of intonation.</td>
<td>It does confuse him and me.</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td>I address it immediately. This is how we overcome the problem, which works well. I feel it is correct to let him know and be aware of it…… I try to bring him to think for himself.</td>
</tr>
<tr>
<td>8</td>
<td>Dit is baie monooton. Dit is een geluid wat uitkom. As hy opgewonde is bly dit dieselfde, as hy terneergedruk is bly dit dieselfde.</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Sy praat heeltyd op een toon. Sy wys geweldig min emosie. Sy huil egter baie meer, my kind het nooit gehuil nie. Sy het soveel selfvertroue gehad.</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Turn-taking**

<table>
<thead>
<tr>
<th></th>
<th>Question 5 a) In conversation is the person able to wait appropriately for a speaking turn?</th>
<th>b) Do you make the person aware that he/she is not appropriately waiting for a speaking turn?</th>
<th>c) How do you generally deal with this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>I must say, I haven’t really noticed that, or picked that up in a situation.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Verskriklik baie, en praat onnodige goeters wat nie van toepassing is op die Ek maak so “zip it” en dan sal hy stilbly.</td>
<td>Dis daarom dat ek sorg dat ek altyd by hom is. Ek gaan saam hom kerk</td>
<td></td>
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</tbody>
</table>
Transcriptions of semi-structured interviews continued

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<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>gesprek nie.</td>
<td>toe oral. Want ek wil daar wees om vir hom te wys.</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Yes, she has never been a person of many words, and we don’t get in contact a lot with other people.</td>
<td>Never criticize, just stay patient and let it go. From the beginning I realized I should not belittle her.</td>
</tr>
<tr>
<td>6</td>
<td>He often interrupts people while they are talking. Someone will be talking and he will just talk over them.</td>
<td>I told him and he says he does not realize he is doing that, and is glad that I am telling him when he does.</td>
</tr>
<tr>
<td>10</td>
<td>Ja, hy doen dit baie.</td>
<td>Ek probeer hom wysmaak dat as daar mense is wat praat moet hy wag vir sy beurt. Want hy sal jou onderbreek.</td>
</tr>
</tbody>
</table>

Non-verbal communication - Use

None of the participants are experiencing problems regarding expression of non-verbal communication behaviour in terms of gestures, facial expressions or eye contact, although many participants had problems with limited voice intonations and intensity. Examples of these transcriptions are captured in Section D: Pragmatic competence.

Non-verbal communication – Interpretation

<p>| | | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td><strong>Question 9</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Do you experience that the person finds it difficult to accurately interpret non-verbal communication behaviours?</td>
<td>b) How does this influence the conversation?</td>
<td>c) How do you generally deal with this?</td>
</tr>
<tr>
<td>2</td>
<td>I don’t think so. I think she pretty much gets it. There have been a couple of conversations that she was able to understand body language very good.</td>
<td></td>
</tr>
</tbody>
</table>
Transcriptions of semi-structured interviews continued

| 8  | Mmmmm, Ja, hy is vreeslik sensitief. En partykeer raak dit bietjie erg. Soos as ek besig is en as hy met my praat en ek antwoord hom nie dadelik nie, is hy onmiddelik kwaad. | Gewoonlik sal ek vir hom se onthou net ek is besig met ons dogtertjie. Sy is klein, sy verstaan nie. |
| 5  | Ja, nou en dan. Met sy pa baie. | Ek sal vir hom se jou pa is nou kwaad, los dit. Hy sien die nie raak nie. |
| 4  | No, she is if anything oversensitive. She watches people very closely, and she picks it up quickly. | Yes, yes. He gets agitated for example when I raise my voice, even if I am not really. It does confuse me and him. He wants me to be monotone like him. |
| 6  | Yes, yes. He gets agitated for example when I raise my voice, even if I am not really. It does confuse me and him. He wants me to be monotone like him. | I try to explain to him to him, but he does not really understand. |
| 10 | Hy kry dit, hy is knap met dit. | Hy kry dit, hy is knap met dit. |
| 9  | Sy doen dit permanent met my. Sy vat dinge baie ernstig baie op. Dinge is baie konkret en set in stone. Dit veroorsaak verwarring en soms konflik. | Ek probeer vir haar verduidelik as ek agter kom sy het verkeerd verstaan, dit lyk tog of sy verstaan dan. |

Section E: Conversational competence

Inappropriate comments

<table>
<thead>
<tr>
<th>Question 1</th>
<th>b) How do you generally deal with this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Does the person ever give inappropriate comments during a conversation?</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Yes, definitely. Especially when she around the children. I have discussed her impatience with younger children with her several times. It is easier now, we tell her: “No, you don’t need to say that that; it might hurt some one’s feelings”. And she’ll ask why? Because she does not understand.</td>
</tr>
<tr>
<td>3</td>
<td>Sy is net vreeslik ongeduldig en veral met kinders. Ek het dit al met haar bespreek maar sy steur haar nie veel aan my nie. Ek dink nie sy dink sy is verkeerd nie.</td>
</tr>
</tbody>
</table>
### Transcriptions of semi-structured interviews continued

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>8</td>
<td>Ja, soos byvoorbeeld met sy oudste sussie, hy sal sommer met hulle seun raas en vir hom preek, soveel so dat haar man baie geïrriteer raak met hom want hy weet nie waar om op te hou nie. En hy sal sommer kommentaar lewer oor onderwerpe wat glad nie sy plek is nie, soos iemand anders se geldsake en so.</td>
<td>Dit veroorsaak soms rusie. Maar nie vir lank nie, almal weet mos nou en is dit gewoond. En die volgende dag is dit weer vergete.</td>
</tr>
<tr>
<td>5</td>
<td>Ja dit gebeur, dit is baie beter nou.</td>
<td>Aan die begin was dit baie erg, tot ek eendag met hom gepraat het en vir hom gesê het jy moet nou tot orde kom. Mens sê nie sommer goed nie, jy dink voordat jy praat.</td>
</tr>
<tr>
<td>7</td>
<td>Op die oomblik is hy baie aanvallend as hy praat oor ietsie kleins. Hy bedoel dit nie, maar hy sal op ’n lelike manier vir jou iets sê. Dit is nogal moeilik met die kinders. Hulle verstaan nie hoekom is hy so aanvallend nie. Hy is so bietjie onredelik ook. Hy word gou kwaad, en klein goedjies is vir hom groot issues. Veral met die kinders sal hy baie onredelik is.</td>
<td>Ek laat so 9 van dit gaan, maar op ’n stadium raak dit bietjie erg, veral as dit met die kinders is, sal ek iets sê, en dit gee gewoonlik ’n bakleiery af, want hy besef dit glad nie.</td>
</tr>
<tr>
<td>4</td>
<td>Yes she does. It is almost as if it is a build-up of something and then she just blurts it all out.</td>
<td>Chuckle about it with her or made a joke about it</td>
</tr>
<tr>
<td>6</td>
<td>Yes, totally. He tries to be funny, but it is not the right time and place. And it is often about sex. That is totally him. We had a work function where he said things that were very inappropriate. It is as if he wants to be funny, and let people think he is still the same person, almost as if he is trying to hard to show them that.</td>
<td>I mentioned it to him and he says he does not mean it like that</td>
</tr>
<tr>
<td>10</td>
<td>Yes dit gebeur, dit is so.</td>
<td>Maar dit sal ek later meer daaraan werk. Ons werk aan baie ander goed op hierdie stadium.</td>
</tr>
<tr>
<td>9</td>
<td>Sy is baie eerlik. Sy spaar niemand se gevoelens nie. En dit was nooit soos sy is nie.</td>
<td>Ek weet eerlik nie hoe om dit te hanteer nie. Sy het so baie verander.</td>
</tr>
</tbody>
</table>

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Transcriptions of semi-structured interviews continued

**Management of topic of conversation: Initiation**

<table>
<thead>
<tr>
<th>Question 2</th>
<th>b) How would you encourage him/her to start a conversation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Does the person need encouragement to start a conversation?</td>
<td></td>
</tr>
<tr>
<td>9 Ja, sy sal nie sommer ’n gesprek aan knoop nie, ek moet alles uit haar trek en selfs dan sê sy nie veel nie.</td>
<td>Ek het gevind dat as ek stil bly, dan gesels sy meer, dan sal sy soms iets vir my begin vertel.</td>
</tr>
</tbody>
</table>

**Management of topic of conversation: Maintaining**

<table>
<thead>
<tr>
<th>Question 3</th>
<th>c) Do you refer the person back to the topic of conversation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Would you say the person is able to maintain the topic of conversation adequately?</td>
<td></td>
</tr>
<tr>
<td>b) Tell me more about the problems you are experiencing regarding topic maintenance.</td>
<td></td>
</tr>
<tr>
<td>10 Nee, hy is nogal geneig om oor ander goed te praat as waaroor die gesprek gaan.</td>
<td>Ek los hom dat hy sy sê sê, anders voel hy uit. Maar ons gaan dan net aan met die onderwerp waarmee ons besig was.</td>
</tr>
<tr>
<td>1 Omdat hy so maklik vergeet, sal hy sommer vergeet waaroor ’n gesprek gaan en dan hou hy seker nie altyd daarby nie.</td>
<td>Dis moeilik, as ek agterkom hy vergeet dan sal ek maar vra of hom probeer herhinner sodat hy dit nie kan agterkom nie. Of ek sal sê ja, jy wou sê…..</td>
</tr>
<tr>
<td>2 She will start her own topic, in the middle of the conversation. Not realizing it has nothing to do with what we are talking about.</td>
<td>We tend to go on with hers, because you are sensitive to the situation and we don’t want her to feel left out.</td>
</tr>
<tr>
<td>8 Ja weet jy, veral as dit nie iets is waarin hy belangstel nie. Hy sal sommer net oor iets anders begin praat of vir jou sê om nie nou daaroor te praat nie.</td>
<td>Ag gewoonlik sal ek sê maar ons wil nou hieroor praat en dan gaan ons net aan.</td>
</tr>
</tbody>
</table>
Cohesion and coherence

<table>
<thead>
<tr>
<th>Question 7</th>
<th>b) How do you generally deal with this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) How would you describe the overall organization of a conversation and the logical sequencing of ideas of the person?</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Ek kom dikwels agter dat haar sinne nie verband hou nie. Dit maak dit moeiliker om haar te volg, ek weet nie of vergeet sy dalk wat sy besig is om te sê nie.</td>
</tr>
<tr>
<td></td>
<td>Ek los maar, want sy vererg haar as ek haar in die rede val</td>
</tr>
<tr>
<td>5</td>
<td>Normaal weg dink ek sy gesprekke is redelik georganiseer, maar wat ek wel agter gekom het is dat wanneer hy oor die foon praat is sy stories baie keer deurmekaar.</td>
</tr>
<tr>
<td></td>
<td>Jy kan nie veel doen nie, so ek los dit maar.</td>
</tr>
<tr>
<td>6</td>
<td>He often does not make sense. And it confuses me. I do sometimes get frustrated and I know I shouldn’t.</td>
</tr>
<tr>
<td></td>
<td>When I realize that I am not understanding him we will kind of start the conversation over, and I make sure I following him.</td>
</tr>
<tr>
<td>8</td>
<td>Dit gebeur nogal dat wanneer hy vir my iets prober verduidelik, dat ek nie mooi byhou nie, ek weet nie hoe om dit te verduidelik nie, maar hy praat half deurmekaar.</td>
</tr>
<tr>
<td></td>
<td>Ek bly eers stil, want hy sien as jy stil bly dat jy nie verstaan nie, en dan sal hy vir jou vra: ‘Vertaan jy wat ek sê?’ En dan sal ek sê: “Nee, verduidelik net weer.”</td>
</tr>
</tbody>
</table>

Section F: Conversation in different social environments

<table>
<thead>
<tr>
<th>Question 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>In view of the possible communication problems you have identified, how do different conversational settings impact on his/her communication?</td>
</tr>
<tr>
<td>- One-to-one communication situation?</td>
</tr>
<tr>
<td>- In a conversation where a few people are present?</td>
</tr>
<tr>
<td>- In a public place where many people are present?</td>
</tr>
<tr>
<td>- Conversations with familiar people vs strangers?</td>
</tr>
</tbody>
</table>
**Transcriptions of semi-structured interviews continued**

<table>
<thead>
<tr>
<th></th>
<th>Conversation in different environments (telephone, in a motor vehicle)</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Kom nie baie in aanraking met nuwe mense nie. Meeste mense weet van haar ongeluk.</td>
</tr>
<tr>
<td></td>
<td>Sy is nog nie terug by die werk nie (amper 2 jaar na ongeluk) – Ek dink sy wil net eers bietjie meer seker wees van haar self, sy wil kan sê: “Ek is terug by ‘n werk.”</td>
</tr>
<tr>
<td></td>
<td>Sy is stiller by nuwe mense, stel nie regtig belang om nuwe mense te leer ken nie.</td>
</tr>
<tr>
<td></td>
<td>Sy is skrikkerig, as sy voel iemand gaan haar te na kom sal sy terugtrek en wegbly van daardie persoon.</td>
</tr>
<tr>
<td></td>
<td>Baie onvergewensgesind, sy vergewe en vergeet nie maklik nie.</td>
</tr>
<tr>
<td></td>
<td>Haar gedrag was op ‘n stadium so, amper ‘n jaar terug, dat sy amper mense weggejaag het.</td>
</tr>
<tr>
<td></td>
<td>Sy het net nie baie vriende oor nie.</td>
</tr>
<tr>
<td></td>
<td>Die mense met wie sy kommunikeer is die wat haar ken en weet van die ongeluk, daar is baie min vreemde mense met wie sy praat.</td>
</tr>
<tr>
<td></td>
<td>Behalwe met die vriend van haar se kinders. Sy wip haar vreeslik vinnig en is ekstra streng en ekstra mislik met hulle nog voordat hulle iets gedoen het, klim sy sommer in hulle keel af.</td>
</tr>
<tr>
<td></td>
<td>Al waar sy verander het is sy gaan nie meer uit nie. Sy wil nie meer uitgaan na kuier plekke toe waar daar ‘n klomp mense is nie.</td>
</tr>
<tr>
<td></td>
<td>Al haar vriende het na die ongeluk weggeraak.</td>
</tr>
<tr>
<td></td>
<td>Sy skroom nie om te wys hoe sy voel nie.</td>
</tr>
<tr>
<td></td>
<td>Sy het op ‘n stadium vir haar vriendinne gesê ek oorheers haar, en wil haar lewe beheer. Ek het myself toe heeltemal onttrek, dat sy self moet regkom, en sy kon nie, sy het baie vinnig weer vir hulp kom vra.</td>
</tr>
<tr>
<td>10</td>
<td>Hy is gemaklik met alles. Hy kan met vreemde mense gesprekke aanknoop. Al wat ek vind is dat as ons ry is hy tjoepstil, waar voorheen kon ons baie in die kar gesels. Dis al waar daar nie meer kommunikasie is nie.</td>
</tr>
<tr>
<td></td>
<td>Ek praat met hom, ek vertel vir hom goed, maar ek vra ook vir hom goed. Hy sal antwoord, maar nie regtig uitbrei nie.</td>
</tr>
<tr>
<td></td>
<td>Oor ‘n telefoon, in ‘n groep mense, met vreemde mense hy is baie gemaklik.</td>
</tr>
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</table>
**Transcriptions of semi-structured interviews continued**

<p>| | |</p>
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<thead>
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</thead>
<tbody>
<tr>
<td>As daar baie mense is, is sy stemtoon baie hard, te hard. Maar dit is omdat hy excited is.</td>
<td><strong>9</strong> Geen telefoon persoonlikheid nie. Baie gestruktureerd en basies.</td>
</tr>
<tr>
<td>Ons hou hom deel van die gesprekke. Hy is deel van my lewe.</td>
<td>Sy wil nie terug gaan universiteit toe nie, sy wil nie meer sing nie.</td>
</tr>
<tr>
<td>Almal waarmee ons kuier is nou al gewoond dat as hy ‘inchip’ los hom dat hy klaar praat en dan gaan ons aan met die gesprek, anders vergeet hy.</td>
<td>Sy het haarsel heeltemal onttrek van sosiale interaksie, sy stel nie meer belang nie.</td>
</tr>
<tr>
<td>Dan moet ek net vir hom sê: “My man jy praat nou bietjie hard.”</td>
<td>Sy is baie eerlik, sy spaar niemand se gevoelens nie.</td>
</tr>
<tr>
<td><strong>1</strong> Stiller in die motor en in gesprekke met vreemde mense.</td>
<td><strong>1</strong> Stiller in die motor en in gesprekke met vreemde mense.</td>
</tr>
<tr>
<td>Hy is baie stiller as wat hy was en hy loop vreeslik baie. Hy sal los dat ander gesels maar dan loop hy sommer.</td>
<td>Hy is baie stiller as wat hy was en hy loop vreeslik baie. Hy sal los dat ander gesels maar dan loop hy sommer.</td>
</tr>
<tr>
<td>Hy is baie stiller as daar meer mense is en doodstil in die kar.</td>
<td>Hy is baie stiller as daar meer mense is en doodstil in die kar.</td>
</tr>
<tr>
<td>Hy is al terug by die werk, voldag. Maar nog nie by die afdeling waar hy was nie en ook nie op sy eie nie. Daar is nog heeltyd iemand wat sy werk moet dubbel check.</td>
<td>Hy is al terug by die werk, voldag. Maar nog nie by die afdeling waar hy was nie en ook nie op sy eie nie. Daar is nog heeltyd iemand wat sy werk moet dubbel check.</td>
</tr>
<tr>
<td><strong>7</strong> Hy is baie ongeduldig. Hy word gou kwaad vir klein goedjies en dan maak hy dit ‘n groot ding. Veral met die kinders is hy baie onredelik en streng.</td>
<td><strong>7</strong> Hy is baie ongeduldig. Hy word gou kwaad vir klein goedjies en dan maak hy dit ‘n groot ding. Veral met die kinders is hy baie onredelik en streng.</td>
</tr>
<tr>
<td>Hy is vreeslik social in alle plekke en met alle mense. Met sy foorn en al die dinge</td>
<td>Hy is vreeslik social in alle plekke en met alle mense. Met sy foorn en al die dinge</td>
</tr>
<tr>
<td>Ek laat so nege van dit gaan, maar soms dan kan ek ook nie meer nie. Dan is dit eers ‘n bakteley. Veral as dit op die kinders is dan sal ek iets sê</td>
<td>Ek laat so nege van dit gaan, maar soms dan kan ek ook nie meer nie. Dan is dit eers ‘n bakteley. Veral as dit op die kinders is dan sal ek iets sê</td>
</tr>
<tr>
<td><strong>6</strong> When meeting new people he lacks confidence and then he tries too hard …..trying to put on a show.</td>
<td><strong>6</strong> When meeting new people he lacks confidence and then he tries too hard …..trying to put on a show.</td>
</tr>
<tr>
<td>He often interrupts people – I try to do it afterwards, but I will in the conversation make him aware of it. Not to embarrass him, but he does it so often.</td>
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<td>His comments can be very inappropriate in social groups and especially work functions, where it is not the time and place. He is more relaxed with</td>
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Transcriptions of semi-structured interviews continued

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<td>1</td>
<td>He wants to be funny; he wants people to think he is normal, almost as if he is trying to hard. He has no patience. He gets angry quickly, he snaps just like that. It is sometimes scary.</td>
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<tr>
<td>2</td>
<td>She is not so often in unfamiliar conversations She needs prompting in conversations were there is lots of people During the day she is with my aunt and there are a lot of children around and she gets irritated very quickly and she will scream at the children. She would have never done it before. In the beginning we left her but now we are starting to tell her that she does not need to shout at them, she can just tell them. We try to do it calmly and tell her not to worry. She gave her testimony at church and one of the comments of the ladies was that she was completely monotone. She didn't show any emotion. It has happened before that somebody who does not know her may take this as an insult, but we know her and we just leave it. Because we know the background it helps to understand her better. Everybody that she speaks to pretty much knows she has been in an accident, so they take it were it comes from. She will be very honest, even with strangers, and it has happened that her comment was very inappropriate, but she does not always know when to stop. She is a bit more quiet in big groups. For example at my cousins birthday there were a lot of strangers, we had to prompt her to take part in the conversations. There is definitely a lack of confidence. But there is not a big difference in different situations, she is pretty much the same. We make her aware of it. We try to do it in a joke and not to put to much pressure. We are trying to let her interact with other people, for example she had to call the insurance company by herself to sort out some stuff. She snaps like that, her patience is very thin.</td>
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Transcriptions of semi-structured interviews continued

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<thead>
<tr>
<th></th>
<th>She frames the telephone conversation almost every time the same.</th>
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<tr>
<td>4</td>
<td>She is o.k. with meeting strangers or old friends.</td>
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<tr>
<td></td>
<td>We don’t really have a lot of contact with other people. And almost never big groups, it is always only a few, at most 4 people in a conversation. And mostly family – usually one-one. But it has happened that you’ll find she is talking about something nobody else is talking about, or butting in while my daughter-in-law is speaking.</td>
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<tr>
<td></td>
<td>Never criticise her. No I won’t ever make her aware, be patient and let it go, it may not be entirely correct.</td>
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<tr>
<td></td>
<td>If I got cross, she would burst into tears and become stressed. What I discovered do not show any negativity or annoyance, because she becomes stressful. I always try to move forward and be positive.</td>
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<thead>
<tr>
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<th>Minder effektief op diefoon</th>
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<tr>
<td>3</td>
<td>Ja, weet jy, soos veral as ons in ’n kar ry, dan praat hy verskriklik sag. Ek sit baie keer agter by ons dogtertjie, dat ek hom glad nie kan hoor nie.</td>
</tr>
<tr>
<td></td>
<td>Ek vra dan vir hom om net die radio af te sit.</td>
</tr>
<tr>
<td></td>
<td>TROUE: Hy het sommer iemand in die rede geval. Gelukkig, ek moet sê al ons familie en vriende is nou al gewoond daaraan, hulle pas daarby aan, of hulle sal net aangaan. En dan besef hy, hy het uit sy beurt gepraat en dan bly hy stil.</td>
</tr>
<tr>
<td></td>
<td>Party keer met onbekende mense veral oor diefoon, sal hy onbeskof en kort-af wees as hulle hom byvoorbeeld nie kan hoor nie.</td>
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<tr>
<td></td>
<td>Hy is vreeslik gestel dat mense hom moet komplimenter en maniere.</td>
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<tr>
<td></td>
<td>As ek by hom is sal ek na die tyd vir hom sê dat hy nie so moet praat nie, en dit lyk tog of hy skuldig voel.</td>
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Appendix H: Translated transcriptions of Semi-structured interviews
SECTION C: Communication problems regarding the content of the conversation

2) —

3) No, not really.

Most people with whom she comes into contact with know what happened to her. She never explains more about it. Very few strangers. (Section C, Question 1b)

8) Yes, oh yes. A lot of information. (Section C, Question 1a)

(Gives example of building up.)

At first it is very frustrating, but one gets used to it. One does get to a stage where one switches off, otherwise it will drive one crazy. If you dare to criticise they interpret it in a negative way. He does not exclude any criticism. Thus it is better to just ignore it. (Section C, question 1c-d)

5) I cannot really say, but I would rather choose to say too little information. (Section C, Question 1b)

He is not anymore keen to speak about it. He only speaks about the necessary without embroidering on anything. He has trouble about remembering.

7) I would say rather too much. (Section C, Question 1a+b)

He rather repeats himself over and over on a specific topic.

1) It is rather difficult.
We talk about specific things, but he forgets about it soon afterwards. (Section C, Question 16)

He will, for example, give me telephone messages. During conversation he himself doesn't realize that he forgets what he was about to say.

The problem is that he very easily forgets.

6)

10) Yes, too much. (Section C, Question 10a+b)

He'll, for example, tell a story, then add another story to get to the conclusion. This happens too often.

I would listen because I cannot interrupt him, but I feel it may cause too much harm. (Section C, Question 1c+d)

9) Too little.

She is absolutely a very private person. She forgets things, which causes her to be confused. This also causes conflict.

I have to extract everything from her. I found though that I get more information from her when I just keep quiet, which was never so before. (Section C, Question 1c+d)
Quality

5) Yes. Yes it happens often. He gets confused and uses the wrong words or struggles to find the right words about specific details. If this doesn’t work then I’ll go and show him.

7) Yes. He’ll sometimes use the wrong word. He sometimes switches his words around, for example names.

I correct him by saying, “No man, isn’t it……?”

6) Absolutely, he often does it.

I cannot immediately recall an example.

I’ll ask him to explain. Thus I try to put more responsibility on him to do the work himself. I try to pressure inspire him into using more fitting or accurate words. Sometimes he just cannot. After just letting go, then it often happens that he recalls the correct word. (Almost like leading his attention to the right answer.)

9) Yes, definitely. I cannot think of an example, but it does cause communication to be much more difficult.
SECTION D: Pragmatic competence
Prosody during communication interaction

5) Yes, yes:

I shall then say, "Talk! Tell us your story. When I ask you a question, I need an immediate answer." Before, he just talked without thinking, so we had to remind him to think what he wanted to say before he spoke. Now, again, it takes him too long to start speaking. Although, he reacts well on it when we remind him.

6) Yes.

One realizes that he is rather slow to answer. It is clear that he is no more the boy he used to be. For example, the forgetting. He also walks a lot — he is extremely keen on walking.

He forgets a lot, especially important instructions.

We have noticed it with him. At the end of his sentence I would, for example, say to him, "Do you want to say something?" It is to remind him about it without his realizing it.

10) Often.

He interrupts himself because he cannot then remember what the conversation is about. He doesn't recall why he started the topic of the conversation.
No. She just gets angry very easily. One must just never interrupt her when she speaks—she only then stops talking.

We argue, we fight as never before in our lives. (Section D, Question 1c1d)

Intensity of speech production

2)

She just speaks very softly, especially on the telephone—just softly and clear. It causes that one cannot hear what she says. (Section D, Question 2a)

(Section D, Question 2a)

8)

Yes, very softly, especially when we are driving in a car. I often sit in the back with our little daughter then it is extremely difficult to hear anything.

Then I have to tell him to please shut off the radio so that I can hear. “The smallest thing distracts his attention.”

5)

Sometimes he gets very excited then he speaks very loudly. Also in the car. (Section D, Question 2a)

I remind him to speak softer as I am sitting just next to him. (Section D, Question 2b1c)

In conversation with more people present I would just gibe him to zip it!”

4)

When excited, his tone of voice becomes very loud. I would then remind him “you are now talking a little too loudly!” (Section D, Question 2a)

(Section D, Question 2b)
Rate of speech production

8) It depends. In the mornings he would be OK, but then in the afternoons he would start speaking very slowly. He also has his on and off days, e.g. he would then sometimes speak very slowly in the mornings as well.

5) His words sometimes slur.

He would then have to be reminded that he mustn't do that, because he forgets.
I have to remind him often to start again.
He forgets sometimes on what he should focus.

4) He does it. It depends on how he wakes up.
If he has had a good night's sleep and the air is fresh, his reactions are quick. His brain is quicker than his mouth (speech). When he stumbles across two words or sentence construction.

I then have to say, "take a deep breath and think clearly what you want to say." He then does so.
It is then perfect. But then there are days when he is slow – as if his speech is thick on the tongue. He doesn't pronounce his words clearly.
I then just remind him that his words are not clear, he should pronounce them clearer.
I feel it is correct that he should know. I really try to stimulate his memory in order for him to know it himself.
5) Intonation

2) (Section D, Question 4a)

8) Yes, this is when he is tired. Otherwise he is quite normal. It is only so when he gets tired.

Oh, I don't really think so.
I just then leave him alone.

(Section D, Question 4a)

5) Yes, I get it. One cannot see on the face what is wrong. But I actually sense it.

Something would happen then I would know it must have hurt him or made him angry, but he would never say anything.

I would ask him, then leave him for a while, then he would later come to me and tell me about it himself.

4) -

17) Maarten is much more quiet than he used to be.

6) -

10) It is a lot in monotone. Only one sound is uttered. Even when he is excited or depressed it still remains the same. (Section D, Question 4a)

9) She speaks all the time in one tone of voice. She shows extremely little emotion. However, she cries more. My child never cried before. She had so much confidence. (Section D, Question 4a)
2) Turn-taking

8) Yes, like at the wedding of two sisters. We were all sitting together and talking outside when he just interrupted someone busy speaking. Yes, he chips in.

(Sec. D. Question 5a)

I usually sit next to him and give him a nudge when he does so. (Sec. D. Question 5b)

5) Very much. He also talks about unnecessary things which have no bearing on the conversation.

(Sec. D. Question 5a)

I give him the "zip it" sign and tell them keep quiet. (Sec. D. Question 5b)

That is why I see to it that I'm always with him. I go everywhere with him and also to church, because I need to show him the way to behave.

10) Yes, he does it a lot. (Sec. D. Question 5a)

I try to make him understand that when people talk, he has to wait his turn and he should not interrupt.

He now starts putting up his hand and say it is now his turn to speak. It is all like a game.
We keep him in our conversation—he has to be part of it. What he does is without realizing that he interrupts. We have now learnt a lesson, because when we make him aware of it, he doesn’t remember what he was about to say. All our friends and contacts are already used to it when he “chips in.” They just let him carry on and then continue their conversation, otherwise he forgets.

Non-verbal communication—Interpretation

8) Mmm, yes, very sensitive. (Section D Question 9a)
   Sometimes it becomes really bad. For example, when I am busy and don’t answer him immediately, he becomes angry.

8) Usually I would tell him to remember that I’m busy with our little daughter who is still small and doesn’t understand. (Section D Question 9c)

5) Yes, on and off. A lot with his father. (dad)!
   (Section D Question 9a)
   If I would say to him that his dad is angry and to leave him alone, he wouldn’t understand it.

6) -

10) He gets it. He is very adept at it.
9) She continually does it with me. She takes it very seriously. Things are extremely concrete to her, as ‘set in stone.’
   It causes confusion and sometimes conflict. (Section D Question 9b)
   I try to explain to her when she hasn’t understood correctly. Then it really seems as if she understands
Section E: Conversational Competence

(Section E, Question 1a)

2) Inappropriate comments

3) She is just very impatient, especially with children.

I've already discussed this with her, but she doesn't seem to take it to heart. I think she doesn't think she's wrong.

8) Yes, for example towards his eldest sister. He would without reason berate their son which would irritate her husband as he doesn't know how and when to stop. He would also speak his mind on topics which he has no knowledge about, for example other peoples' money matters, etc. (Section E, Question 1a)

This causes confrontation. Luckily not for long as everybody is aware of his condition and the next day all is forgotten again.

5) Yes, it does happen, but fortunately getting better now. (Section E, Question 1a)

In the beginning it was very bad until one day when I seriously spoke to him and told him to bring himself to order and take control. He should not just speak his mind without thinking before he speaks.

7) At present he is very abusive even when speaking about trivial matters. He doesn't really mean it but the way he says it is rude. (insulting)

It is especially difficult with children. They can't...
really understand why he behaves like that. He is very unfair and becomes angry about nothing which to him is a big issue, especially towards children. At the start I ignore it but when it gets to be too much, I cannot keep ignoring it and break him which usually ends on a confrontation as he doesn't realize it himself. (Section E, Question 16)

4) -

6) -

10). Yes, it happens. It's true.

I'll definitely work more on it later as we are working on many other issues at this stage.

9) - She is very open and honest. Therefore she doesn't consider anyone's feelings. This is definitely not like she used to be before. (Section E, Question 19)

I honestly don't know exactly how to handle it. She has changed such a lot.
Management of topic of conversation: Initiation.

9) Yes. She would never spontaneously start a conversation. I always have to lead her and encourage her, and even then she never says much.

I did find, however, that if I keep quiet she talks more and would even start telling me something on her own.

Management of topic of conversation: Maintaining

10) No, he is actually inclined to talk about things which are not relevant to the conversation.

I just leave him to play so that he doesn't feel left out. We just continue with whatever we've been talking about. (Section E, Question 3c+d)

1) As he forgets so easily, he doesn't remember what the topic of conversation is. That is why he cannot always keep to it.

It is difficult. If I realize that he doesn't know, I'll try to remind him in a roundabout way by prompting him, for example, with, "Yes, you wanted to say......?" (Section E, Question 3d)

2) --

8) Yes, especially when it doesn't concern him. Then he changes the topic or tells us not to speak about it.

Usually I tell him that we want to discuss whatever the topic of conversation is, then we just continue.
Management of topic of conversation: Shifting.

1) I am inclined to switch around topics when talking which makes it more difficult for her to follow. This was never so before.

She will call one's attention to it. Then I just repeat myself until she is with us again.

Cohesion + Coherence

9) I often realize that her sentences don't link or relate to any logical sequence. This makes it difficult to understand what she really wants to say. I don't know if it is just forgetfulness.

I just ignore it because she takes exception when I interrupt her. (Section E, Question 7b)

5) Normally this conversation seems to be quite organized, but I do realize that the telephone conversations are very disorganized/muddled. (Section E, Question 7a)

There is not much one can do about this, so I just ignore it.

6) 

8) It happens quite often when he tries to explain something to me. I then can't always keep track of what he wants to say. I cannot explain it, it is just very muddled.

At first I keep quiet. When he realizes this
he will actually ask if I understand what he is saying. If I still don't understand, he will then ask him to explain again.
Section F: Conversation in different social environments.

3) She doesn't often come into contact with new people (strangers). Most people know about the accident. After two years she is not back at work yet. I think she wants to move past herself and be able to say, "I am back at work."

(Section F, Question 1)

She is more quiet with new people (strangers) and isn't really interested in getting to know new people.

She is actually scared of someone being detrimental to her, so she avoids them.

Very unforgiving - she doesn't forgive or forget easily.

Almost a year back she was inclined to chase people away.

She just doesn't have many friends left.

Most people she communicates with are those who knew her and about the accident. There are very few strangers with whom she communicates (Section F, Question 1)

Except for the children of... they...

She is very easily angered, and especially strict with them, even before they even do anything. (Section F, Question 1)

What has definitely changed is that she never goes out anymore, especially to get together with many people. (Section F, Question 1)
All her friends disappeared after her accident.

She does not shy away from showing her feelings.

At a stage she told her friends that I dominate her and I want to change her life. I then detached myself to see if she could cope by herself. She couldn’t and very quickly asked for help again.

10) He is comfortable with everything. He can converse with strangers. I only find that in the car he is completely quiet. Before we used to talk a lot while driving, but now it is the only place where there’s no communication anymore.

I talk to him, tell him things and also ask him things. He’ll answer but nothing more.

He is quite comfortable on talking on the telephone, in a group of people and to strangers.

With many people in a group he is inclined to speak too loudly because he then gets very excited.

We always keep him part of the conversation. He is after all part of my life.

(Section F, Question 1)

All our friends are now used to him butting in and let him be to finish what he has to say, then we just carry on with our conversation lest he forget what he wants to say.
I then just have to say, “Daantjie, you’re talking a little loudly now.”

9) He has no telephone conversation ability, only very structural and basic. (section F, Question 1)
   She doesn’t want to go back to university, she also doesn’t want to sing anymore.
   She totally detached herself from social interaction and has lost all interest.
   She is very straightforward and spares no one’s feelings. (consider)

1) More quiet in the motor car and in conversation with strangers. (section F, Question 1)
   He cannot sit quietly when conversing, he is always stumping around. In a group of people, he will just walk out.

Martin is much more quiet than he used to be and he sometimes just leaves the company while they carry on talking.

The more people, the more quiet he is and never talks in the car.

He is back at work full time, but not at the same department where he used to be, also not on his own. There is always someone to keep an eye and control on his work.
7) He is very impatient. He is easily angered about trifling things and makes a great deal about it, especially unfair and strict to children. (Section F, Question 1)

He is very social with everyone and everywhere, even on his telephone.

I will let go for, say, 9 times, but then I cannot anymore. It then develops into a fight, especially when it concerns the children. Then I can't help saying something.

7)
6)
2)
4) Less effective on the telephone.

8) Yes, especially when driving in car, he speaks very softly. I often sit in the back with our little daughter then I totally can't hear what he says. I then only ask him to switch off the radio.

At a wedding he just interrupted someone. Back
Fortunately all our family and friends are now used to it and adapt to it. They just carry on.

He'll then realize he talked cut of turn and then keep quiet. (Section F, Question 1)

Sometimes, with strangers, especially on the telephone, he'll be rude and very curt, for example when they cannot hear him well.

He is very concerned about receiving compliments......

Afterwards I reproach him about it and it seems that his manners

The then feels guilty about it

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Appendix I: Transcriptions of Focus group discussions
Transcriptions of the focus group discussion

Key question 1

During the interviews there were different views regarding whether to make the person aware of problematic communication behaviors. I want us to discuss this in a little more in detail. Why do you make the person aware of these behaviors, or why do you choose not to?

Participant 3: Nee, liever nie want sy word vies. Sy sal vir my sê ek is nie stupid nie. Jy wys haar nie op haar foute nie. As sy hom maak dan los jy haar.


Participant 4: I specifically have chosen to let her go and just to continue, one thing that I found watching her is it is very important to allow people to continue to progress. If you criticize or put them under pressure, they withdraw and lose the progress. What I try in terms of management is to use a pulling rather than pushing style. So that, bring haar uit. Every time I put the breaks on it has had a pretty serious retarding, backward step result. When I was critical or became cross, even with myself. She bursts out in tears. What I found is not to show irritation or negativeness, it becomes very stressful for her and hinder her progress. I try always to be moving forward.

Participant 3: My dogter is baie dieselfde. Wanneer jy vir haar sê iets is verkeerd dan is dit asof sy terug trek. Ek verduidelik die situasie vir haar, en praat met haar. Dit lyk of sy verstaan, maar stem nie noodwendig saam nie.

Participant 5: In my seun se geval sal ek sê, as hy iets verkeerd doen sal ek vir hom sê: “maar seun dit is nie reg nie.” Ek voel as hy iewers kom tussen mense waar ek nie is nie, wil ek hê hy moet die regte ding doen. Ek wil nie hê hy moet homself embarrass nie. En dit is daarom dat ek vir hom wys wat is reg. Ek sal vir hom sê as hy nie reg maak nie of as hy iemand in die rede val sale k vir hom met die hand wys om te wag vir sy beurt.

Wat ek tog agterkom is dat wanneer hy ‘n teleurstelling gehad het is sy speech helemaal af. En dan sê ek vir hom: “OK, ek los vir jou tot jy reg is en dan roep jy my dan sal ons praat.” As hy reg is sal ons praat. Ek probeer dat hy verstaan dat ‘n teleurstelling niks in
die lewe is nie. Mens gaan een trap agter toe en dan gaan jy 2 trappe voren toe. So jy kan net vorentoe gaan in die lewe. Ek sal nie kritiseer nie ek sal net sê dat wat hy nou gedoen het is nie reg nie, en hy moet dit reg stel. En dit werk, hy luister en besef nou al self as hy iets nie reg doen nie.

**Participant 2:** The trauma was so big, you do not want to see them unhappy, so if she goes on and on in a conversation we just let her. We leave her, she needs to express herself. Out there she will be ridiculed and ripped to peaces. I usually discuss the situation afterwards with her, and explain to her why her comments were inappropriate. More explaining has to be done to make sure everybody is on the same page.

**Participant 6:** I correct him immediately, in a nice way, not to put him in a disposition. Sometimes I will do it within the conversation, and other times I’ll discuss it on the way home. When I tell him, he says he does not realize he is doing it. He appreciates it though, because he does not know he is doing it. Now I don’t always have to say something I will just look at him like this *****, and he knows.

**MODERATOR:** Ek kom agter dat daar iets is van beskerming, want jy wil tog daardie persoon beskerm teen sosiale uitmergeling, maar tog wil mens ook vir hulle ruimte gee en hulle nie kritiseer nie. Wat sou die grens wees, of op watter punt sal jy die persoon bewus maak van sy/haar gedrag?

**Participant 1:** Weet jy wat, wat ek altyd kyk as ons nou in 'n geselskap is. As ek nou sien hy sal nou heel te mal die gesprek oorneem. Of dit gaan nou bietjie rof. Jy weet as hy nou agressief kwaad raak, dan sal ek vir hom sê dat dit nou nie hele mal reg is nie en help ek hom reg.

**MODERATOR:** Sal mens van ander se cues gebruik maak?

**Participant 3:** As ander mense begin ongemaklik voel met wat hulle doen.

**Participant 4:** With my son and his wife we have had situations were my wife tends to burst out with stuff in a conversation up to a point were you can see my daughter- in-law becomes uneasy. Luckily my son will butt in and make a joke to break the tension. And
then afterwards, outside that environment; I will discuss it with her and tell her what she did. And how it is making it difficult in the situation for us and that we are trying to help you. And that has had a response then, she realizes we are giving up a huge amount to help her. It seems he would be more careful, because she does not want to put us in a difficult position, not necessarily because she thinks she is wrong.

Participant 6: My husband can make very inappropriate remarks; I make him aware of it. No, I have to, he makes everybody feel very uncomfortable. You need to be firm and direct – and he definitely got better.

Participant 2: My sister can’t stand to be around little kids, she is very quick to anger, very quick. She will be very blunt and honest. And I tell she should be careful not to offend somebody. And she’ll ask: “Why? I am just being honest.” It is almost as if she is not aware of the boundaries.

Key question 2

Most of you mentioned that nonverbal communication behavior is one of the most difficult problems to handle. Can you please expand on this and let us discuss how one can handle these problems.

Examples

(Several of the participants experience a lack of intonation during conversation – contributing to monotone speech production. This can be confusing. We don’t always realize how much information is hidden in the intonation of our voice. What can we do to understand the emotions this person is feeling more accurately?)

(Most of you is experiencing that the person is very sensitive to your feelings, feelings like irritation, sadness, excitement and disappointment. The person is either over sensitive or misinterprets it completely. You told me that it sometimes leads to tension of self consciousness for the person with the injury.)
Participant 5: As my seun nie lekker voel nie kom ek dit dadelik agterkom in sy spraak. Dit word baie stadiger.

Participant 4: There is not enough, the communication maybe monotone, but not necessarily directed at irritation or pain, and you almost have to look at the environment that something is happening, you know is it waking up time, going to sleep time, eating time. I try to lead in what should my wife be thinking about, where is she, is she hungry or what should she be doing. She finds it difficult to make decisions. If I give her 2 options she gets confused and she will say either. I don’t think their verbal communication that they are using is a good mecanism to express them selves and what they are feeling. There is a gap between the need and the speech. Speech is not being used the way it is meant to.

MODERATOR: It is almost as if the observation of the person becomes so much more important than before, because the usual way of communication has changed. We use other cues to help us understand.

Participant 3: Jy gaan dan baie meer na ander liggaams gedrag moet kyk, of hulle afsydig raak of kwaad lyk. My dogter begin baie sag praat. Mens word meer sensitief vir hulle en ook vir ander

Participant 2: Yes, but you get to know them so well. On a one-on-one she is fine, or when she is with the family we know her. But I think out there people will be offended and she will be misinterpreted. That is also why we decided to push her to interact more outside her comfort zone so that she can learn through experience.

Participant 6: As soon as my husband walks in the door I know what kind of mood he is in and then I know how to handle him.

Participant 6: I agree, because my husband got much better when he went back to work
Patricipant 3: Veral as hulle nie van iemand hou nie. My dogter is ook so, sy sal sommer misluk wees of aspris iets doen wat daardie persoon irriteer. Gewoonlik ontloont ons dit deur koffie te maak of haar klein sussie in die geselskap in te stuur. Net om die situasie te red.

Ek het dit met my dogter ook ervaar. As sy met goed te doen kry wat sy nie meer kan doen nie, kom die agressie uit en dan baklei sy met die kinders of wie ook al. Ons as groot mense eers met die kinders gaan praat en aan hulle verduidelik dit is omdat sy nie meer kan doen nie. Maar ons los haar vir eers. En later toe sy kalm is het ek haar gevra of was dit regtig nodig? Sy het gesê dat sy skielik besef het dat sy nie meer kan nie en dit maak haar kwaad. Ek het gesê dit gaan jou niks help nie, maak vrede.

Key question 3

What are your observations regarding community integration and how do you address it?”

During the interviews care givers frequently acknowledge that the conversational interactions the patients are exposed to mostly involve family and friends. In other word people that know and understand what happened to the patient. Family and friends are more ‘forgiving’ and allows most of the problems that have been identified.

Participant 2: I think you need to do that to help them keep improving. We as family tend to except things or not notice it any more. We did come to the conclusion that she needs to get out more, in the work place for example were she can interact with other people and learn through experience.

Participant 5: Ek dink jy moet hulle meer blootstel. Wat my seun bvoorbeeld doen as hy met vreemde mense praat is om vir hulle te se, as julle nie verstaan wat ek se nie, se dit vir my sodat ek weer vir julle kan probeer verduidelik. Hy glo dan dat almal hom verstaan – en dit bou sy self vertroue. (Advertisement) (opleiding van die gemeenskap)

Participant 6: Definitely confidence is a big thing; my husband going back to work was the best thing for him. When he was at home
with me he was like a little brittle leaf. It took him a long time to get confidence. It was definitely the best thing for confidence.

Participant 3: Ek het maar so stelselmatig haar begin blootstel aan nuwe mense en omgewings en ook meer en meer haar alleen begin los. Aan dit begin het ek alles gedoen want sy was bang, maar ek het later gese dat sy self die goed moet begin doen en dit was goed vir haar want sy het gesien sy kon en dit het haar self vertroue gee. (stelselmatig onafhanklikheid aanmoedig) (Bou van selfvertroue)

Participant 4: It is absolutely essential for them to be integrated, it will give them confidence. It is a step-by-step. After 8 months she still does not have the confidence to go to the bank and discuss something. The caregiver is imperative to take those re-integration steps. If you take them too early it may result into rejection from outside, go back into their shells. You must judge yourself. It is a tremendous responsibility of caregiver to make judgments especially when they do not have guidance

Participant 4: You use a different type of approach on a different time in the journey.

Participant 3: Yes it is a long process. It is now 2 years after the accident and she went yesterday for the first time to apply for a loan on her own at the bank.

MODERATOR: Dit is vir my amper asof daar ‘n gevoel is van versigtigheid en broosheid hier rondom?

Participant 6: In the beginning you walk on egg shells around them, because you are not sure what can you say or not.

Participant 4: I was terrified. Nobody has given me guidance in what to do. Everybody gives a wide answer. In terms of versigtigheid, jy weet nie how far I can push. Even now it is touch and feel.

Participant 2: She has changed a lot. We needed to accept that and go on with life. Only there after we did come to the conclusion as a family that she needs to get out more, so that she can practice her communication outside the family environment. We are only now starting to make her aware of things, before we left it because everybody in the conversation knew. I think we are careful because there are no clear guidelines.
Appendix J: Translated transcriptions of Focus group discussions
**KEY QUESTION 1**

Participant 3: No, rather not because she takes exception. She'll tell me that she's not stupid. Don't make her aware of her mistakes. Just leave her alone when she's being wrong. (Question 1)

Participant 1: No, I just leave them alone. He is truly one who follows his own head. Don't show him on his faults. Only when he really makes a bad mistake, I'll say, "No, son. This is now too much!" Fortunately, he then pays attention.

Participant 3: My daughter is much the same. When one makes her aware of being wrong, she pulls back.

Participant 5: In the case of my son when he does something wrong, I'll tell him that it isn't right or the correct behaviour. I would want him to do the right thing and behave well when with other people. I don't want him to embarrass himself, that is why I show him what is correct and tell him how to behave. He would later come back to me and admit that I was right. So he knows.

I realize when he's had a disappointment in any way, his speech is affected. Then I'll say I'll come back later when he's ready to talk about it. I want him to understand that a disappointment is nothing—one step forward and two back help us to go forward in life.
That is the way we go ahead in life. I don’t criticize but only show him on what’s been done is not acceptable and he should rectify it. And this works. He listens and realizes himself now when he does something wrong.

MODERATOR: I discovered that there is something of a protection against social grinding, but on the other hand one would want to give them some room to do things for themselves and not criticize them too much. So at what stage would it be best to make the person conscious of his/her behaviour?

Participant 1: (Question 1)
Do you know what I look for in a conversation? When I see him totally taking over a conversation through a patronizing way, or when he might become aggressively angry then I would step in and tell him that it not totally acceptable to do so, and guide him on the right way.

MODERATOR: Would one make use of others’ cues?
WE Rong: When people don’t feel at ease with their behaviour.
Key Question 2

2. The next topic —

Moderate: It is almost —

Participant 3: You will then become more aware of body language if when becoming withdrawn or angry. Amelia starts speaking very softly. (Question 2)

Participant 5: When Delano doesn’t feel well, I can immediately detect it in his speech. (Question 2)

It is almost —

Participant 3: One becomes much more sensitive towards them and also others. (Question 2)

... ...

3). Most of you... Let’s discuss...

Watts: ... (Question 2)

Participant 5: Perhaps it can be that as well because I realized at the beginning that my child fostered a lot of anger in him. When his cousins visit us, the would shout at them and behave badly. Until I asked him one day whether he’d made peace with himself. Asking whose fault it was won’t help. It is all about making peace with this condition. Has he forgiven himself? From there on it definitely improved.
Participant 3: Especially when they don’t like somebody. Annette is also the same. She would behave badly or do things on purpose to irritate that person. Usually we can save the situation by making some coffee or send her little sister to join them.

(Question 2)

I also experienced it with my daughter. If she comes across anything she cannot do anymore, all her aggression comes forward and she confronts anyone/anything with them. We as adults should first inform and explain to the children why she cannot do everything with them anymore. But we don’t immediately confront her. Only later, when Annette had calmed down, did I ask her if it had been necessary.

She admitted that she had suddenly realized her abilities and it made her angry. I told her that it wouldn’t help her, she should rather make peace with herself.

KEY QUESTION 3

I - INTEGRATION

During... I want to discuss...

(Question 2) (Question 3)

Participant 5: I think they need to have more exposure in order to help them to keep improving. My son, for example, now tells people that they should let him know if they don’t understand what he says so that he can try to explain it again. He believes that everybody understands him. This builds and improves his self-confidence. (Tutoring the community)

Cochran: —
Participant 3: I have systematically introduced her to new people and environments and also at times left her on her own. At first I did everything for her because she was afraid. Later I told her that she would have to start doing things on her own which was good for her. She started realizing that she could which gave her a lot of confidence. (systematic independence inspiration) (building of self-confidence)

EXPERIMENTAL

GRAdually

MODERATOR: To me it is almost as if there is a feeling of caution and fragility around this matter?

MODERATOR: Stay ....
      Health...
      Take it day by day.
      Don't plan ahead, no long term planning
      Every day brings procedure, even after 2 years

Participants start deviating from the real issue by talking about their own needs.

Caregivers ..... Information ...
When something like this happens we don't have background knowledge on brain injuries when it occurs we need...
One is so focused on the situation itself - thus written information helps as one can read it through in one's own time.