An exploration of the common pain-related vocabulary typically developing children use: Implications for children who use augmentative and alternative communication

by

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> *"For I know the plans I have for you," declares the* L*ORD*, *"plans to prosper you and not to harm you, plans to give you hope and a future."* – Jeremiah 29:11

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ABSTRACT

When children with significant communication difficulties experience pain, they are in dire need of an appropriate means to communicate their pain in order to receive appropriate treatment. Self-report – the first step in the hierarchy of pain assessment – may be problematic for these children. However, augmentative and alternative communication (AAC) can assist children with significant communication difficulties to communicate their pain. The main aim of this research study was to develop a list of pain-related vocabulary by using typically developing children, parents and teachers to suggest children's vocabulary and then to socially validate the list by means of a stakeholder review. A sequential exploratory mixed methods design with four phases was employed: In Phase 1 (Qualitative phase), 50 children aged 4;0 to 12;11 years old participated in focus groups to discuss their experiences related to pain. The thematic analysis of the qualitative data in Phase 1, revealed themes that were used in Phase 2 to develop the instrument, a set of hypothetical physical pain scenarios (HPPS). The HPPS was also pilot-tested and adapted in Phase 2 (Measuring Instrument Development phase). In Phase 3 (Quantitative phase), a total of 74 children, 61 parents and 56 teachers participated to suggest vocabulary that children from two age groups (6;0–7;11 and 8;0–9;11 year-olds) would use to communicate their pain. Participants provided 629 pain-related words and/or phrases, that spread over in seven pain-related categories and 23 pain-related sub-categories. A composite list of 87 frequently occurring pain-related vocabulary items as used by children was compiled. In Phase 4 (Social Validation phase), the composite vocabulary list was socially validated by means of a stakeholder review by three literate adults who use AAC. Based on the results of the study, a model for the selection of vocabulary for sensitive topics is proposed.

Keywords: augmentative and alternative communication; AAC system; hypothetical scenarios; pain; pain-related vocabulary; sensitive topic; significant communication difficulties; vocabulary items; word list.

OPSOMMING

Wanneer kinders met beduidende kommunikasieprobleme pyn ervaar, het hulle ʼn ernstige behoefte om op 'n gepaste manier hul pyn te kommunikeer ten einde toepaslike behandeling te kan ontvang. Self-rapportering – synde die eerste vlak in die hiërargie van pynassessering – kan problematies wees vir hierdie kinders. Aanvullende en alternatiewe kommunikasie (AAK) kan egter kinders met beduidende kommunikasieprobleme help om hul pyn te kommunikeer. Die hoofdoel van hierdie navorsing was om ‘n lys met pynverwante woordeskat te ontwikkel deur tipies ontwikkelende kinders, ouers en onderwysers te vra om kinders se woordeskat voor te stel en dan om die sosiale geldigheid van die voorgestelde items te bevestig. 'n Sekwensiële verkennende meervoudige-metode navorsingsontwerp bestaande uit vier fases is gevolg: In Fase 1 (Kwalitatiewe fase) het 50 kinders tussen die ouderdomme 4;0 en12;11 aan fokusgroepe deelgeneem om hul ervarings met betrekking tot pyn te bespreek. Die tematiese analise van Fase 1 se kwalitatiewe data het temas wat in Fase 2 gebruik kon word om die instrument – 'n stel van hipotetiese fisiese pynscenario’s (HPPS) – te ontwikkel, uitgewys. In Fase 2 (Meetinstrumentontwikkelingsfase) is die HPPS getoets en aangepas 'n Totaal van 74 kinders, 61 ouers en 56 onderwysers het aan Fase 3 (Kwantitatiewe fase) deelgeneem waartydens woordeskat voorgestel is wat kinders in twee ouderdomsgroepe (6;0–7;11 en 8;0–9;11-jariges) waarskynlik sal kan gebruik om hul pyn te kommunikeer. Deelnemers het 629 pynverwante woorde en/of frases voorgestel, wat oor sewe pynverwante kategorieë en 23 sub-kategorieë versprei is. 'n Lys van 87 pynverwante woordeskat items vir kinders is Saamgestel. In Fase 4 (Sosiale geldigheidsfase) is die saamgestelde woordeskatlys deur belanghebbendes, naamlik drie geletterde volwassenes wat AAK gebruik, sosiaal bekragtig. 'n Model vir die seleksie van woordeskat vir sensitiewe onderwerpe word voorbehou, gebasseer op hierdie studie se resultate.

Sleutelterme: aanvullende en alternatiewe kommunikasie; AAK-stelsel; beduidende kommunikasie probleme; hipotetiese scenario’s; pyn; pynverwante woordeskat; sensitiewe onderwerp; woordeskatitems, woordelys

CHAPTER 1

PROBLEM STATEMENT AND RATIONALE

"Even though I have thousands of words on my grids now, there are still ones I think of but don't have." (Pistorius, 2011, p. 138)

1.1 Introduction

This chapter presents the problem statement and contextualises the study. Next, a list of the most important terms is provided and defined; followed by an explanation of the abbreviations, brand names and South Africanisms used throughout this study. Chapter 1 concludes with an overview of the seven chapters of the thesis.

1.2 Background and problem statement

When a person is in pain and does not have the ability to communicate verbally, it could be a terrifying and stressful experience. Many children with severe disabilities have co-morbid communication difficulties that could be permanent (e.g. in the case of cerebral palsy) or temporary (e.g. in some cases of children with Developmental Apraxia of Speech). Furthermore, typically developing children who are admitted to intensive care units of hospitals may also experience a temporary communication loss due to medical interventions, such as tracheotomies or other procedures influencing their expressive and/or receptive communication abilities. All children, including those with significant communication difficulties, need ways to express their pain in order to ensure they receive effective and appropriate treatment for such pain.

The golden standard used by healthcare staff for pain assessment is to obtain self-report from their patients (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). However, self-report by children with significant communication difficulties is a challenge, as it might be difficult to determine if these children are in pain and if so, what the nature, location and intensity of the pain is. Therefore, healthcare staff members typically obtain proxy reports from these children's parents or caregivers, use observational tools, or do physical examinations when assessing pain. However, research has shown that these methods are unreliable in many cases, as healthcare staff indicated that they remained unsure about the children's pain experience, despite using these methods and strategies (Zhou, Roberts, & Horgan, 2008). Notwithstanding the implementation of all these methods, healthcare staff may also overlook the non-verbal communication attempts of these children with severe communication difficulties, to indicate that they are in pain, such as a change in behaviour. This might result in the non-treatment of pain. Besides communicating the presence, nature and intensity of pain for treatment purposes, children typically also use speech to self-comfort themselves, as well as to indicate causes of pain and strategies for avoiding pain in the future as part of their coping with pain.

One way to assist children with significant communication difficulties to communicate their pain is to equip them with augmentative and alternative communication (AAC) systems and strategies. AAC involves the use of means other than verbal communication, including unaided manual signs and/or aided graphic symbols to assist the children with significant communication difficulties to successfully communicate their needs and wants, and to share information (Beukelman & Mirenda, 2013), for example about their pain. Unaided communication strategies involve that persons use certain parts of their bodies to convey their messages, such as signing, gestures and facial expressions. Children with severe disabilities and significant communication difficulties may find the use of unaided strategies too complex or too unreliable due to the type and/or severity of their disability. For example children with athetoid cerebral palsy may not be able to use manual signs due to the involuntary and uncontrolled movements of their upper limbs. Aided AAC strategies range from low-technology (for example symbol-based communication boards, writing, and partner-assisted scanning) to mid- and high-technology techniques such as speech-generating devices (Beukelman & Mirenda, 2013). Preliterate children would often make use of graphic symbol-based AAC systems as these do not require literacy skills. As most of the commonly used graphic symbol collections do not constitute generative systems, vocabulary needs to be preselected. Low-technology communication boards are useful in intensive care settings because they are light, durable, and of low cost, thereby increasing their applicability in such circumstances (Blackstone, Ruschke, Wilson-Stronks, & Lee, 2011). The use of these AAC systems in other settings (such as at home or in school) is also proposed to assist children with significant communication difficulties to communicate their pain.

The speech-language pathologist (SLP) should provide children with significant communication difficulties with the necessary vocabulary on their AAC system to allow them to communicate their pain, as it is the role of SLPs to provide services to children who require AAC in a wide range of clinical settings, including hospital settings. The SLP also needs to support relevant partners such as healthcare staff or parents by training them to understand and implement the AAC systems in the hospital or home settings to ensure that children who could benefit from AAC have the means to communicate their pain.

In order to enable children with communication difficulties to express their pain by using an AAC system, irrespective of the type of system, SLPs should provide a list of possible pain-related vocabulary and assist healthcare staff or parents to add these words on the children's AAC system (e.g. communication board or speech-generating device). Traditionally, when selecting vocabulary for children, SLPs focussed on selecting core vocabulary that can be used across various environments and activities to communicate, as well as fringe vocabulary that is more specific to the context and the individual (Beukelman & Mirenda, 2013). However, little information is available on determining vocabulary for sensitive topics, such as pain. In the published core vocabulary lists for toddlers and children (Banajee, Dicarlo, & Buras Stricklin, 2003; Marvin, Beukelman, & Bilyeu, 1994; Trembath, Balandin, & Togher, 2007), no pain words were included. It is therefore important to determine pain-related vocabulary that children can use to communicate pain. Although vocabulary selection is time consuming, it is an essential procedure in order to provide children with significant communication disabilities the relevant vocabulary to communicate their pain effectively.

The aim of this research is to develop a list of pain-related vocabulary by using typically developing children, parents and teachers to suggest children's vocabulary and then to socially validate the list by means of a stakeholder review. This list may ultimately be incorporated in an AAC system for children with significant communication difficulties to enable them to express their pain. The availability of a list of pain-related vocabulary will equip these children with suitable words and/or phrases to self-report their pain experiences, thereby ensuring that they receive pain-relieving treatment. It could also lower the frustration and stress levels of the children themselves, the healthcare staff, as well as parents and caregivers who need to support these children.

1.3 Terminology

The following terms are critical to this study and are therefore clarified:

Augmentative and alternative communication (AAC)

Augmentative and alternative communication (AAC) refers to the supplementation or replacement of natural speech and/or writing using either aided symbols and/or unaided signs

(Lloyd, Fuller, & Arvidson, 1997) in order to support the communication attempts of persons whose speech is inadequate to meet all their communication needs. This study will focus on the importance of preselecting vocabulary related to a specific topic, namely pain for an AAC system without generative capabilities (i.e. a graphic symbol-based communication board or speech-generating device) in order to enable children with significant communication difficulties to express their pain.

Children with significant communication difficulties

In this study, the term, "children with significant communication difficulties" is used to describe both children with "complex communication needs" as defined below, as well as children with a temporary inability to speak, due to medical procedures (e.g. due to tracheotomy). The latter are also referred to as "communication vulnerable patients" in the literature (Banerjee, Bennett, & Luke, 2012).

Communication vulnerable patients

Communication vulnerable patients have reduced expressive and/or receptive communication abilities (Banerjee et al., 2012). Vulnerabilities can be due to the reason for hospital admission (e.g., pulmonary disease, craniofacial surgery, Meningococcemia) or as a result of medical interventions, such as a tracheotomy, compounded medications, or physical restraints (Banerjee et al., 2012). Some children and/or their families may not understand or speak the language of the ICU environment, and they are therefore regarded as communication vulnerable (Banerjee et al., 2012). In the present study, communication vulnerable patients form part of the group described as "children with significant communication difficulties".

Complex communication needs (CCN)

Persons whose expected speech and language skills have not developed due to motor, cognitive and/or sensory perceptual impairments that may result from cerebral palsy, autism spectrum disorder, Down syndrome, or other developmental disabilities (Light & Drager, 2007) – and that result in fewer communication opportunities due to limited access to the environment, and restricted interactions with their communication partners – are regarded as persons with complex communication needs (CCN). In this study, children with CCN form part of the children referred to as those having significant communication difficulties.

Core vocabulary

Core vocabulary refers to the vocabulary that can be used across environments and activities to communicate a range of communicative functions (Beukelman & Mirenda, 2013; Boenisch & Soto, 2015). In this study, the core vocabulary that appeared in the socially validated pain-related composite vocabulary list, were highlighted for use on a pain-related AAC communication board.

Fringe vocabulary

Fringe vocabulary refers to context-specific words (e.g. injection, medicine, hurt) that are unique to the individual's specific interests, and that are influenced directly by the immediate environment and activities (Beukelman & Mirenda, 2013). In this study, the fringe vocabulary that appeared in the socially validated pain-related composite vocabulary list, were divided into pain-related fringe vocabulary as suggested to be included in a pain-related AAC communication board and other fringe vocabulary, which may be omitted from the pain-related communication board.

Healthcare staff

In this study, the term "healthcare staff" refers to various professionals in the hospital setting who are involved with the assessment and treatment of children in pain, such as the audiologists, dieticians, doctors, medical social workers (who fulfil the role of child life specialists), occupational therapists, paediatric nurses, physiotherapists, radiographers, radiologists, and SLPs.

Paediatric patients

In this study, the term "paediatric patients" refers to patients between the ages of 4;0 and 12;11 who are treated in the paediatric wards of the hospitals.

Pain

The theoretical definition of the International Association for the Study of Pain is used in this study: "Unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (International Association for the Study of Pain (IASP), 1979). Therefore, the focus of this study is on physical pain, such as tissue damage caused by minor bumps and bruises, illness, injections, etc., and not on emotional pain caused by neglect, bullying, emotional abuse, etc. It is also important to take the subjective nature of pain into account despite its being difficult to describe and the fact that it is experienced differently by different persons (Jerrett & Evans, 1986; Kortesluoma, Punämaki, & Nikkonen, 2008). Expressive pain-related language (vocabulary) is needed to express pain experiences.

1.4 Abbreviations

AAC : Augmentative and alternative communication
ASD : Autism Spectrum Disorder
BFMF : Bimanual Fine Motor Function (Beckung & Hagberg, 2002)
CAS : Coloured Analogue Scale (McGrath, Seifert, Speechley, Booth, Stitt, & Gibson, 1996)
CCN : Complex communication needs
CFS : Children's Fear Scale (McMurtry, Noel, Chambers, & McGrath, 2011)
CHEOPS : Children's Hospital of Eastern Ontario Pain Scale (McGrath, Johnson, Goodman, Schillinger, Dunn, & Chapman, 1985)
CHIPPS : The Children's and Infants Post-operating Scale (Willis, Merkel, Voepel-Lewis, & Malviya, 2003)
COMFORT-R : Revised scale of COMFORT (Ambuel, Hamlett, Marx, & Blumer, 1992)
CPI : Children's Pain Inventory (McGrath et al., 1996)
CPPP : Charleston Pediatric Pain Pictures (Belter, McIntosh, Finch Jr, & Saylor, 1988)
FAS : Facial Affective Scale (McGrath, Seifert, Speechley, Booth, Stitt, & Gibson, 1996)
FPS : FACES® Pain Scale (Bieri, Reeve, Champion, Addicoat, & Ziegler, 1990)
FPS-R : FACES® Pain Scale – Revised (Hicks, Von Baeyer, Spafford, Van Korlaar, & Goodenough, 2001)
FLACC : Face, Legs, Activity, Cry and Consolability (Merkel, Voepel-Lewis, Shayevitz, & Malviya, 1997)
GMFCS : Gross Motor Functional Classification System (Palisano, Rosenbaum, Walter, Russell, Wood, & Galuppi, 1997)
HPCSA : Health Professions Council of South Africa
HPPS : Hypothetical physical pain scenarios
HPPS-C : Hypothetical physical pain scenarios: Children
HPPS-P : Hypothetical physical pain scenarios: Parents
HPPS-S : Hypothetical physical pain scenarios: Stakeholders
HPPS-T : Hypothetical physical pain scenarios: Teachers
IASP : International Association for the Study of Pain
ICU : Intensive care unit
IV : Intravenous line
JCAHO : Joint Commission on the Accreditation of Healthcare Organizations
LAM : Language activity monitor
LoLT : Language of learning and teaching
NRS : Numerical rating scale (Connelly & Neville, 2010)

OPS : Objective Pain Scale (Suraseranivongse et al., 2001)
ObsAAC : Observation Screening Checklist for persons who use AAC
PBRS-R : Procedure Behavioural Rating Scale – Revised (Katz et al., 1980)
PICU : Paediatric intensive care unit
PI-NRS : Pain intensity numerical rating scale (Jensen, Turner, & Romano, 1994)
PPI : Pediatric Pain Inventory (Lollar, Smits, & Patterson, 1982)
PPPM : Parents' Post-operative Pain Measure (Chambers, Finley, McGrath, & Walsh, 2003)
PPVT-IV : Peabody Picture Vocabulary Test, Fourth Edition (Dunn & Dunn, 2007)
r-FLACC : Revised Face, Legs, Activity, Cry and Consolability (Malviya, Voepel-Lewis, Burke, Merkel, & Tait, 2006)
SACE : South African Council for Educators
SACSSP : South African Council for Social Service Professions
SANC : South African Nursing Council
SAS® : Statistical Analysis Software
SLP : Speech-language pathologist
SMS : Short message system
STAI : Short State-Trait Anxiety Inventory (Marteau & Bekker, 1992)
STAIC : State-Trait Anxiety Inventory for Children (Spielberger, 1973)
VAS : Visual Analogue Scale (McGrath et al., 1996)
WBFPRS : Wong and Baker FACES® Pain Rating Scale (Wong & Baker, 1988)

1.5 List of brand names

Table 1.1 provides an overview of brand names and common product names mentioned in this study.

Table 1.1

Brand Names and Common Product Names (Listed in Alphabetical Order)

Brand name	Use of product
Allergex	Antihistamine used for allergies such as hay fever and insect bites (http://home.intekom.com/pharm/adcock/allergex.html)
Arnica oil	A herbal oil used for massaging and as a pain-relieving muscle treatment (http://www.essentialoilssouthafrica.co.za/products-page/carrier-massage-oils/arnica-oil-arnica-montana/)
Band-Aid	Used to cover scars and cuts and refers to adhesive bandages and related products. BAND-AID ® is a brand name of Johnson & Johnson's and American pharmaceutical and medical devices company. In South Africa, "band aid" refers to any type of plaster and is thus not regarded as a specific brand name ("Band-Aid"). (http://www.band-aid.com/products)
BioOil	Used to treat scars, uneven skin tones and dehydrated skin (https://www.bio-oil.com/en/)
Burn shield	Sterile trauma hydrogel burn dressing used for burns and scalds (http://www.burnshield.com/)
Calpol*	Contains paracetamol, and is used as a pain stiller (http://www.calpol.ie/)
Celestamine	Used for general inflammatory conditions of the skin and allergies

Brand name	**Use of product**
	(http://www.patientslikeme.com/treatments/show/26094-celestamine-side-effects-and-efficacy?brand=t)
Dettol	Anti septic liquid (http://www.dettol.co.za/)
Panado	Contains paracetamol and codeine phosphate, and is used as a pain stiller (http://home.intekom.com/pharm/adcock/panadoco.html)
Rescue tablets	Natural product used for stress and anxiety relief, emotional shock and fear (http://www.natura.co.za/B_PStress_Rescue.asp)

*Calpol was mentioned in other studies and not by participants in the current study.

1.6 South Africanisms

Due to the multilingual context in which South African children grow up, they often use words borrowed from one language while speaking another language (code-switching) (Moodley, 2007). Examples of pain-related code-switching words that children used in this study are the following:

- "eina" ("Eina" is originally an Afrikaans word used to express pain. "Eina" is the equivalent of the English word "ouch". It is used by children from various South African languages to express physical pain.)

- "eish" ("Eish" is an isiZulu exclamation indicating disapproval or surprise.)

- "muti" ("Muti" is an isiZulu word for traditional medicine, but is often used to refer to any type of medicine.)

1.7 Overview of the chapters

This thesis is presented in seven chapters. Chapter 1 provides the background and rationale for the study as well as the definition of frequently used terms. It furthermore contains descriptions of the abbreviations used, a list of brand names mentioned in the study, as well as descriptions of the South Africanisms used by participants. Chapter 1 concludes with an overview of the various chapters.

In Chapter 2, the theoretical background and research findings that relate to the development of children's pain-related vocabulary are explored. The study of the literature on children's pain-related vocabulary begins with a discussion of the historical perspective of pain.

Next, the current perspective of pain addresses the socio-communication model of pain as the theoretical lens through which this study is viewed. First, the effect of interpersonal determinants on the expression of pain of the child with significant communication difficulties is discussed, for example the influence of family settings, cultural and social environments on children's pain vocabulary development. Then the effect of the child's biological systems (such as severity of disability and significant communication challenges) and personal history of pain are mentioned. The dilemma of self-report about the pain experience for children with significant communication difficulties is also highlighted. The reactions of healthcare staff to the child's communicative actions conclude the chapter and emphasise the importance of implementing alternative means, such as AAC to enable children with significant communication difficulties to communicate their pain.

The methodology used in the study is discussed in Chapters 3 and 4. Chapter 3 starts by describing the aims and research design and outline the four research phases, but it focuses only on the first two phases of the study. Phase 1 is the Qualitative phase where the phenomenon (i.e. children's pain-related experiences) is investigated and it is presented in terms of its aims, steps taken, participants, material and equipment. The data collection procedures and trustworthiness considerations are discussed next, after which data analysis and implications for the next phase are described. Phase 2 focused on the development of suitable instruments, including the development of a set of hypothetical physical pain scenarios (HPSS) that comprise of the vignettes, and the measuring instrument based on the findings of Phase 1. A pilot study to test these instruments and a discussion of the data collection procedures completed Phase 2.

Chapter 4 continues with the methodology used in the study and discusses the methodology employed in Phase 3 (Quantitative phase), as well as Phase 4 (Social Validation phase). Phase 3 is presented in terms of its aims, steps taken, participants, material and equipment. In addition, the different methods of data collection, analysis and comparison are explained within the sequential exploratory mixed method design employed in the study. Six respondent groups participated in the study, namely children aged 6;0–7;11 (the so-called younger group), and children aged 8;0–9;11 (the so-called older group); parents of children in both the younger and older groups, as well as teachers of Gr 1 children (the younger group), and Gr 3 teachers who typically teach the older group. In Phase 4, the social validation of the list of pain-related words and/or phrases, is presented in terms of its aims, steps taken, participants, material and equipment, data collection procedures and data analysis.

The results of the Qualitative (Phase 3) and Social Validation (Phase 4) phases are described, analysed and interpreted in Chapter 5. This chapter deals with the results of sub-aims (i) to (vi) of Phase 3 and (i) and (ii) of Phase 4. Chapter 5 starts with a discussion of the reliability of the data and organisation of respondent groups in Phase 3. Then the six sub-aims are addressed. In order to address the first sub-aim, the number of occurrences of pain-related words and/or phrases per respondent group per scenario is described. The pain-related words and/or phrases are then described and refined within pain-related categories before statistical inference is addressed. Statistical inferences are made to determine the effect that age, gender, children's previous hospitalisations, the presence of older siblings, parents' age and their qualifications have on pain-related vocabulary suggested by their children. The compilation of the composite list of pain-related words and/or phrases within respondent groups follows next. Phase 4, the Social Validation phase which involves literate adults who use AAC, commences with a discussion of the appropriateness of the list of pain-related vocabulary to answer three hypothetical physical pain scenarios and it is followed by a description of the use of pain-related categories and sub-categories by participants in answering the questions for the three scenarios. The participants' suggestions for improvement of the vocabulary list (words and/or phrases) for children are considered before the presentation of the final socially validated list of pain-related vocabulary. Chapter 5 concludes with a short summary of the results.

In Chapter 6, the results of the study are interpreted and discussed in the light of the current relevant literature. The challenges that children with significant communication difficulties experience to communicate pain are highlighted in order to emphasise the importance of providing these children with preselected vocabulary to express their pain. Various methods for vocabulary selection are addressed, for example focusing on activities such as those of daily living (e.g. eating and dressing) or fun activities (e.g. book reading or play) as well as observations to determine the frequency of vocabulary used by children. The use of drawings and hypothetical scenarios in research to determine vocabulary for sensitive topics is discussed next. The inclusion of participants with different perspectives and from different contexts and experiences is also addressed as they could contribute to a different vocabulary. The involvement of stakeholders in the process of vocabulary selection on the sensitive topic of pain is discussed as it would determine the customisation of the results for a specific group, such as children with

AAC. A proposed model for vocabulary selection when determining vocabulary for sensitive topics concludes Chapter 6.

Finally, the most important conclusions are presented in Chapter 7. The chapter begins with a summary of results of this study. Clinical implications of the results are then presented in conjunction with a critical appraisal of the research focusing on both its strengths and its weaknesses. Chapter 7 concludes with recommendations for further research.

1.8 Conclusion

Chapter 1 provides a justification for the study by highlighting the difficulties experienced by children with significant communication difficulties in expressing their pain. Previous research in this area was briefly presented and the need to extent this research was highlighted. This is followed by an explanation of frequently used terms, abbreviations, brand names and South Africanisms used in the study. The chapter concludes with an overview of the chapters in this thesis.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

The aim of this chapter is to provide an overview of the relevant literature on how the communication challenges of children with significant communication difficulties affect their ability to express pain.

Chapter 2 starts with a discussion of the historical perspective on the construct of pain. Then the socio-communication model is introduced, focusing on how intrapersonal and interpersonal factors that affect pain are experienced and expressed by children with significant communication difficulties. The intrapersonal factors include etiologies, language development, cognitive development and gender. Interpersonal factors, such as family influences (parents, presence of older siblings), previous hospitalisations and socio-cultural influences are then discussed. This is followed by a discussion of the importance of selecting vocabulary, and specifically the words and/or phrases that are required by children with significant communication difficulties to self-report pain-related experiences. Various vocabulary selection strategies are explored, such as observations, language activity monitoring, activity and/or topic-based strategies, core vocabulary and the use of informants to suggest vocabulary and stakeholders to socially validate the suggested vocabulary.

2.2 The history of pain

For many years, healthcare staff incorrectly believed that very young children and children with disabilities, in particular those who have significant communication difficulties, either do not feel pain or that they may have very high pain thresholds (Abu-Saad, 1984; Beacroft & Dodd, 2011; Bottos & Chambers, 2006). These myths were reinforced because of McCaffery's widely accepted definition of pain that stated "pain is what the person says it is and exists whenever he or she says it does" (1968, p.95), thus implying that all individuals who were unable to express their pain verbally may not have pain. As a result, healthcare staff often overlooked other signs, such as changes in patients' behaviours. For example, a young man with significant communication difficulties started to display severe aggressive behaviour when he could not obtain the food or activities that he preferred. Upon further investigation, the healthcare staff realised that this behaviour became worse when he was known to be suffering from severe ear ache caused by otis media (Carr et al., 1994). This type of behaviour is often regarded as challenging behaviour and not as alternative attempts to communicate pain experiences in this population (Bottos & Chambers, 2006). It is only lately (in the past three decades since 1985) that healthcare staff have started acknowledging that individuals’ difficulty or inability to communicate verbally does not cancel out the possibility that they experience pain and are in need of appropriate pain-relieving treatment (Bottos & Chambers, 2006). However, irrespective of patients’ ability to verbally self-report their pain, it is the ethical obligation of all healthcare staff to acknowledge and relieve these patients’ pain (Herr et al., 2006; Herr et al., 2011).

Children with a variety of disabilities including significant communication difficulties experience pain more frequently in comparison with their typically developing peers and they display their pain in unique ways (Breau, 2003; Gilbert-MacLeod, Craig, Rocha, & Mathias, 2000). Furthermore, children experience their illness and pain as a threat and feel out of control of the situation – thus hindering them to develop basic feelings of invulnerability and security to communicate their pain (Gaynard et al., 1990; Kortesluoma, Punämaki, et al., 2008). A greater understanding of this intricate pain communication process is therefore needed to comprehend the challenges that people with disabilities; and especially those with complex communication needs, may experience when trying to express their pain. The socio-communication model of pain (Craig, 2009; Hadjistavropoulos & Craig, 2002) provides a theoretical framework for this study because it views pain as an interactive social-cultural process with both interpersonal factors (e.g. etiology, language, cognition and gender) and intrapersonal factors (e.g. family, parents’ qualification) forming part of the pain communication process (Azize, Humphreys, & Cattani, 2011; Finley, Kristjánsdóttir, & Forgeron, 2009).

2.3 Socio-communication model of pain

The socio-communication model of pain (Craig, 2009; Hadjistavropoulos & Craig, 2002) describes the multifaceted communication process needed to sufficiently express pain and be understood by others. This three-step process involves (a) the internal subjective experience of pain, which is affected by both intrapersonal (biological and psychological) and interpersonal factors; (b) the encoding of the pain experience and expressive behaviour (e.g. self-report or vocalisations) communicated to observers (e.g. healthcare staff or parents), and (c) the process whereby observers decode pain behaviours in order to provide pain-relieving treatment (Hadjistavropoulos, Breau, & Craig, 2011). Figure 2.1 depicts the suggested socio-communication model of pain (based on Craig, 2009) as it relates to children with significant communication difficulties.

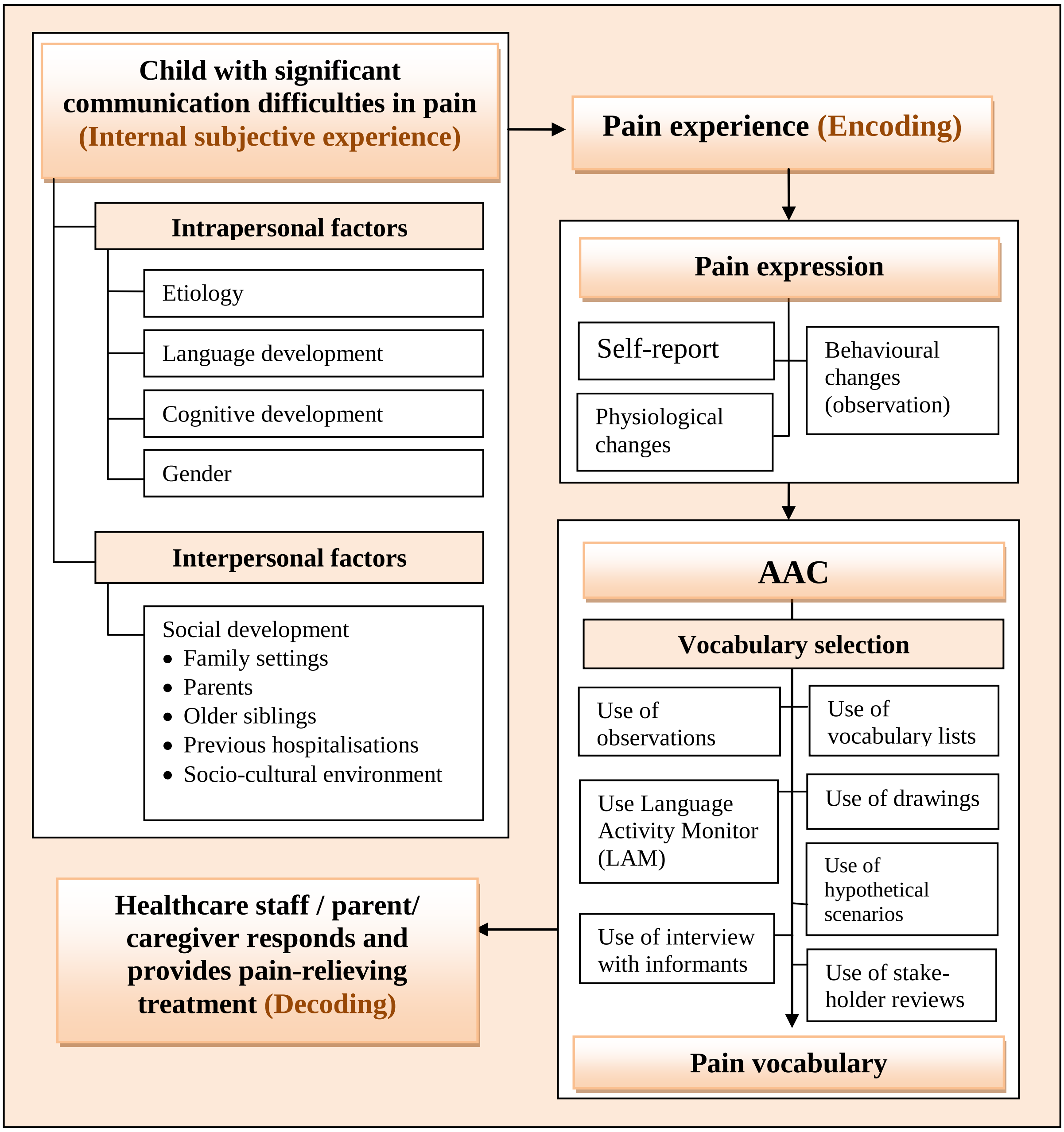


Figure 2.1. Adapted socio-communication model of pain for children with significant communication difficulties (as based on Craig, 2009).

The socio-communication model can be used to understand pain expression in those persons with and without communication difficulties (Craig, 2009). The child's emotional, sensory, cognitive, developmental and cultural composition, as well as the pain context influences a child's self-report of pain (Finley et al., 2009; Kortesluoma, Punämaki, et al., 2008). The socio-communication model of pain emphasises both the role of the person in pain and the ability of the observer of the pain (healthcare staff member) to understand the person's experience of pain. Biomedical models on the other hand focus only on the sensory features of pain with no emphasis on the social factors of pain (Craig, 2006, 2009; Hadjistavropoulos & Craig, 2002). In this discussion, the focus will be on the challenges that a child with significant communication difficulties experience to communicate pain to the observers (e.g. healthcare staff or parents).

2.3.1 The internal subjective pain experience of children with significant communication difficulties

Each individual has a range of potential behavioural reactions based on his/her own experiences with pain (Craig, 2009). Furthermore, their own biological capabilities underlie their complex experience of pain. Children with significant communication difficulties may be affected by diverse types of disabilities that result in unique pain-related experiences related to these disabilities.

2.3.1.1 Intrapersonal factors

Together with biological capabilities, the constructs underpinning pain expression are the influence of language development and cognitive development as well as social interaction and experiences. The development of pain-related vocabulary proceeds along a similar course as natural language development (Franck, Noble, & Liossi, 2010; Stanford, Chambers, & Craig, 2005). The theoretical constructs that underlie pain expression will now be discussed in more detail.

2.3.1.1.1 Etiologies

All children are believed to experience pain on a daily basis. Research has found that typically developing young children may experience minor everyday pain on average once every three hours (Fearon, McGrath, & Achat, 1996; Von Baeyer, Baskerville, & McGrath, 1998). Classic pain experiences include everyday bumps and bruises resulting from small accidents during everyday activities. Typically developing children naturally use crying, verbalisations or words to communicate their pain experiences, but only start to use the word "pain" by the age of six years (Stanford, Chambers, & Craig, 2005).

Children with disabilities, on the other hand, are assumed to experience pain episodes more often than their typically developing peers. These children's pain experiences include acute pain episodes caused by needle injections, blood-drawing procedures, and repeated medical procedures and treatments (such as physiotherapy) to maintain their health (Bottos & Chambers, 2006; Breau, Camfield, McGrath, & Finley, 2003; Nilsson, Finnström, & Kokinsky, 2008). Children with different types of disabilities have unique pain-related experiences associated with their specific disabilities.

The occurrence of pain in young children with cerebral palsy (CP) is high (Parkinson et al., 2013). The abnormal muscle tone that influences movement and posture also increases chronic pain experiences. Spasticity and the inability to change position in order to reduce pressure on certain body parts also lead to musculoskeletal and gastrointestinal pain (Engel & Kartin, 2006). People with CP furthermore have to undergo ongoing surgical and medical procedures and interventions throughout their life span in order to correct or rehabilitate orthopaedic problems associated with their condition – such as hip dislocations (Engel & Kartin, 2006; Ramstad, Jahnsen, Skjeldal, & Diseth, 2011). All these procedures, including needle injections, range-of-motion manipulation and assisted stretching are painful experiences (Ramstad et al., 2011). Communication on and self-report of their pain experiences are of utmost importance for children and adults with CP in order to ensure appropriate pain treatment.

Children with Down syndrome are another group who are likely to experience pain as a result of their disability. The high risk for possible development of oral health issues, hip abnormalities and certain types of cancer, such as leukaemia; are the main reasons for secondary pain-related experiences by these people (Bottos & Chambers, 2006). Children with Down syndrome have higher incidences of dental problems than their typically developing peers because of the frequent occurrence of chronic facial pain disorders and periodontal disease (Bottos & Chambers, 2006). Ear, nose and throat problems, such as middle ear effusions, chronic ear infections and sinusitis, are common in children with Down syndrome (Shott, 2006). In addition, hip abnormalities are a common source of distress and pain for them (Bottos & Chambers, 2006) and if left untreated, it may lead to painful arthritis. Children with Down syndrome possibly have a decreased tendency to react to pain and do not have the ability to localise the painful stimulus – but that does not mean that they are insensitive to pain (Cohen, 2003). The fact that many children with Down syndrome have a small pain-related vocabulary that emerges only at a later developmental stage may influence their ability to communicate pain (Franck et al., 2010).

Children with profound cognitive impairments have higher rates of injury incidences than their typically developing peers (Breau et al., 2003). These children are at risk of experiencing a variety of painful somatic conditions such as gastro-oesophageal refluxes, contractures and epilepsy (Terstegen, Koot, De Boer, & Tibboel, 2003). Many children with profound cognitive impairment experience socio-communicative deficits similar to children with autism spectrum disorder (ASD), which results in failure to use facial expressions or eye-contact to exhibit pain or other emotions (Gilbert-MacLeod et al., 2000; Terstegen et al., 2003). Furthermore, children with profound cognitive impairment also experience and express their pain in relation to their state of cognitive and physical development and not their chronological age (Terstegen et al., 2003).

Similar to children with CP, Down syndrome and profound cognitive impairments who experience a larger number of pain incidents, children with ASD are occasionally two to three times more at risk of sustaining an injury than are their typically developing peers (Yung, Haagsma, & Polinder, 2014). In addition, these children also have difficulty regarding how they express their pain. The fact that children with ASD display their pain-related experiences differently from typically developing peers, does not mean that they do not experience pain (Nadar, Oberlander, Chambers, & Craig, 2004). Children with ASD typically have delayed language development (Craig, Lilley, & Gilbert, 1996). If they do use speech, their intonation and inflection are flat and therefore they struggle to convey their emotions and the intensity of pain experiences. In addition, they do not necessarily use the same facial expressions and gestures that their typically developing peers would do to express their feelings. The expressions of pain by children with ASD are uniquely individual and will also differ from the larger population, given the fact that children with ASD suffer socio-communicative impairments and therefore do not experience social closeness as typically developing peers would do (Bottos & Chambers, 2006). However, a study demonstrated that self-reported pain intensity in high-functioning children with ASD did not differ from their typically developing peers (Bandstra, Johnson, Filliter, & Chambers, 2012). Another example is girls with Rett syndrome, a neurodevelopmental disorder that primarily affects girls, who often experience abdominal pain but show delayed responses and expression to pain (Percy & Lane, 2005).

In a systematic review that compared the risk of injuries for people with CCN and their typically developing peers, it was found that people with CCN were 1.3 to 2.2 times more likely to sustain injury than those without disability. Children with CCN also run significant high risks of burn-related injuries or crashes involving motor vehicles or bicycles (Yung et al., 2014).

Unlike the previous conditions that render children with permanent communication difficulties, some children experience temporary communication vulnerability This includes critically ill children admitted to paediatric intensive care units (PICUs). These children experience a temporary loss of their expressive or receptive communication ability due to medical procedures or life-threatening conditions, such as unstable cardiovascular conditions, cancer, or life-threatening airway- and endocrine diseases (Banerjee et al., 2012). They demonstrate stress and anxiety, and are regarded as communication vulnerable. Hence they are at a greater risk of being treated incorrectly by healthcare staff who may misunderstand the pain message and who also tend to sedate these children more often (Banerjee et al., 2012; Costello, 2000; Coyne, 2005).

However, it is not only the patient who is affected by this temporary loss of communication. Their family members typically also have fears of their children not being able to communicate their basic needs and wants because of their critical condition. They are anxious since their child has no means to ask them for comfort and fear that the child may feel abandoned. Parents are also of the opinion that the inability to communicate may cause their child to temporarily lose his/her personality. According to Costello (2000), both family members and the paediatric patient experience feelings of frustration and helplessness and feel that they are out of control of their situation. The importance of effective alternative means of communication to ensure safe treatment of paediatric patients is therefore emphasised (Banerjee et al., 2012; Costello, 2000). Even nurses indicate their feelings of frustration when they do not understand what their paediatric patients are trying to communicate (Costello, 2000).

From the discussion above, it is clear that all children, including children with disabilities and communication vulnerable paediatric patients, experience pain, although they are not always able to express it. Due to the severity of their communication challenges, it takes too much effort or time for them to ask for assistance or to show their discomfort – which often results in them being ignored or not treated for pain (Briggs, 2010; Dubois, Capdevila, Bringuier, & Pry, 2010; Gilbert-MacLeod et al., 2000). Children base their responses to pain on previous life experiences, and many children with disability have learned that expressing pain receives either no response or a negative response (Beacroft & Dodd, 2011). Some children therefore give up trying to get the attention of healthcare staff or parents, or they simply do not seek attention when hurt to the same degree as their typically developing peers. The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) nevertheless emphasise the rights of individual patients to receive proper pain assessment and management rather than being ignored or mistreated (The Joint Commission, 2010). It is therefore important to investigate alternative ways of helping children with significant communication difficulties to express their pain in a way that ensures sufficient treatment, rather than to allow healthcare staff to make unfounded assumptions about these children's pain experiences.

2.3.1.1.2 Language development

Language is regarded as the most important means of communicating pain (Azize et al., 2011). Language learning is set in a physical context and it is defined by real people, objects, activities and events in the child's environment (Light, 1997). Through these interactions with the physical environment, the child learns about new concepts in the world that constitute the foundation for lexical development (Light, 1997). Language is therefore a social thought developed through social interactions or communication (Crawford, 1996; Vygotsky, 1978).

Vygotsky's social constructivist theory highlights the effect of adult intervention on a child's language development – through social interactions, more experienced members of society (i.e. adults) teach younger, less experienced members (i.e. children) and equip them with the knowledge, skills, and values to be active members of that society (Vygotsky, 1978). Language acquisition entails a child's exposure to words in order to stimulate his/her development of thought. The Vygotskian theory describes the "zone of proximal development" that is present in interactions between adults and children. This zone is described by Vygotsky (1978, p.86) as the "distance between the child's actual developmental level determined by independent problem solving and the level of potential development as determined through problem solving under adult guidance". This adult guidance is referred to as scaffolding. For scaffolding to be effective, it must be at the child's level of development and make the child feel comfortable to use the adult's guidance, as it may present a challenge to reach the next level in a particular area (Vygotsky, 1978).

It is difficult to describe pain, because it requires translating feelings into words (Kortesluoma, Punämaki, et al., 2008). Parents' communication with their children during painful experiences and the words that parents use ensure that children learn new pain-related vocabulary (Franck et al., 2010). Vygotsky regarded words as signals. Rather than connecting with their children in a primary signal system, where objects are referred to merely as themselves, adults introduce children to a secondary signal system, where words are used to represent objects and ideas (Vygotsky, 1978). By interacting with his environment, the child is empowered to develop private, inner speech where thoughts are formed. This is the link between the secondary signal system of the environment and the individual's own thoughts. Through their development of inner speech, children overcome the gap between language and thought, which enables them to express their thoughts logically to others (Vygotsky, 1978).

Vocabulary learning is an important part of the language learning process (Penno, Wilkinson, & Moore, 2002). Children learn vocabulary through direct instruction (scaffolding) when parents teach them the words and specific meaning to link the secondary signal system of the environment with the child's inner thoughts (Vygotsky, 1978). Children also learn incidentally, where the circumstances in which words are encountered add to their understanding or partial understanding of the meanings of such words. They can also learn through a combination of direct instruction and incidental learning (Penno et al., 2002). Although children can learn vocabulary incidentally, they have better vocabulary growth if the words are explained to them compared to those for whom the words are not explained (Penno et al., 2002). Within the pain literature, parents' verbal responses to their children's pain are highlighted as influential to their children's development of pain-related vocabulary (Franck et al., 2010; Koopman, Baars, Chaplin, & Zwinderman, 2004). In other words, when parents talk to their children about pain on an age-appropriate level, children enlarge their pain-related vocabulary. For example, when a child cries when injured, the parent could responded with words or exclamations such as "Oh dear!" or "Ouch! You got hurt!" thus allowing the child to attach meaning to his/her painful experience. As a result, the child is likely to use those same words in future when he/she experiences pain. Although parents tend to use more complex words than their children to express pain, parents teach their children exclamations, single words, simple word juxtapositions and later also sentences, thus enlarging their children's pain-related vocabulary repertoire (Craig, Stanford, Fairbairn, & Chambers, 2006). Because language development happens within a social environment, a more detailed explanation of the influence of parents and families on children's pain-related vocabulary is given later in this chapter.

However, for children with severe disabilities and significant communication difficulties who require AAC, the language learning process is challenging. This may inter alia be due to the fact that they do not have the same access to their social environment as their typically developing peers and have an impoverished experiential base for conceptual and lexical development (Light, 1997). Typically, children build on their conceptual base as they experience and gain new knowledge about the world they live in, whereas children with disabilities have limited access to their environment, which makes it more difficult for them to acquire new concepts without relevant previous knowledge to build on (Light, 1997). It is therefore the responsibility of adults to ensure that children with severe disabilities and significant communication difficulties are exposed to a social environment that comprises people, objects and experiences (i.e. adaptive play activities with peers or structured reading activities) to facilitate their language development (Light, 1997). Exposing children to experiences that will allow for the development of vocabulary related to pain is, however, complex and requires careful planning, e.g. arranging a "Doctor-Doctor play activity".

Children only begin to use the word "pain" at around 3;8 to 6;0 years old (with full use of the word at 6;11 years old). Further discussions on the influence of age, cognition, as well as social contexts on the use and development of pain-related words (Azize, Endacott, Cattani, & Humphreys, 2013; Ely, 1992; Jerrett & Evans, 1986) will follow in this chapter.

It is important to note that Vygotsky's social constructivist theory of language development exists in opposition to Jean Piaget's theory of language acquisition. Vygotsky viewed language as a developing thought, whereas Piaget believed that cognitive development brings about language growth. Vygotsky stressed the social aspect of language learning and focused on the environment in which a child is raised. In contrast, Piaget believes that children build their knowledge about language through complex processes of integration, highlighting the natural ability of a child's brain to adapt to stimulation. The influence of cognitive development on children's pain-related vocabulary will therefore be addressed next.

2.3.1.1.3 Cognitive development

The Piagetian framework has been found appropriate and useful in a number of studies on the development of constructs of illness and pain (Gaffney & Dunne, 1986; Hay, Oates, Giannini, Berkowitz, & Rotenberg, 2009) and was therefore selected as the basis for explaining the development of children's pain-related vocabulary.

The skill to use words to describe pain is a significant developmental milestone for children, which enables them to communicate (self-report) their painful experiences in such a way that doctors, nurses or parents understand their discomfort better and react accordingly (Craig et al., 2006; Franck et al., 2010). Children's language development and, subsequently, their pain vocabulary are influenced by Piaget's general stages of cognitive development (Dubois et al., 2010; Franck et al., 2010; Johnson, Boshoff, & Bornman, 2015). Language development corresponds with cognitive maturation (Craig & Korol, 2008) and as children cognitively mature, they can describe their pain more successfully (Azize et al., 2011). Language is important because it both organises insight and permits detailed explanations of subjective experiences (Craig & Korol, 2008). As children grow older, their natural ability to express abstract, complex and multidimensional descriptions of pain increases (Stanford, Chambers, Craig, McGrath, & Cassidy, 2005).

Piaget (2003) suggested four general stages of cognitive development. In Stage I, the sensori-motor stage (age 0–1;11), babies function on a concrete level and focus only on what they can see. With more experience, for example in activities such as mouthing, throwing, or shaking things, they develop object permanence. Towards the end of the sensori-motor stage, early language skills start to develop. In Stage II, the pre-operational stage (age 2;0–6;11), children begin to reflect about things on a symbolic level. Their use of language matures and they develop imagination and memory whilst being involved in make-believe activities. During Stage III, the concrete operations stage (age 7;0–11;11), children show more concrete, logical reasoning skills when doing mental operations. In Stage IV, the early formal operations stage (age 12;0–14;11), it is possible for children to focus further than the here and now, enabling them to use formal operational thought to think about the future, the abstract and the hypothetical (Piaget, 2003).

In a systematic review aimed at identifying the vocabulary that children use to describe their pain experiences. Boolean searches were conducted in four individual journal databases – Medline Proquest, Scopus Search, Web of Science and PubMed – using the keywords "*all(pain) AND all(children OR young children) AND all(vocabulary) OR words*" (Johnson et al., 2015). Only studies published in English that represented examples of children's own voices of pain-related vocabulary were included in the systematic review. The review revealed that children's pain vocabulary develops according to Piaget's stages of cognitive development. Two main themes were identified on how children express their pain experiences, namely describing their pain and coping with their pain. The “coping with pain” theme shows how children express their cognitive strategies to cope with their pain, as this involves the translation of feelings into words.

From the systematic review, it was found that young children in Stage I (the sensori-motor stage) start to develop pain-related vocabulary between the ages 1;0 and 2;5 years old with words for pain as a result of injury emerging first (Franck et al., 2010). The use of interjections and graphic word descriptors falls under the theme “describing pain”. Babies have no words for pain and their cries are gradually substituted by more specific verbal expressions or interjections (“*ouch*, *owie”*), followed by specific pain words as they grow older; until children eventually start to use sentences to describe their pain (Azize et al., 2013; Stanford, Chambers, & Craig, 2005). Young children in Stage I, the sensori-motor stage (0–1;11), do not have the linguistic and cognitive skills to explain the bodily sensations experienced during pain, and therefore mostly use interjections, for example “ow” , “ouch” and “hurt” (age 1;0–2;0) to describe their pain (Dubois, Bringuier, Capdevila, & Pry, 2008). Research by Craig and colleagues (2006) found that the earliest age at which children used a pain-related word (‘ouch”) was at 17 months of age.

Children of 2;0–6;11 years old in Piaget’s pre-operational stage of cognitive development (Stage II) have a concrete concept of pain but do not yet have the linguistic and cognitive skills to describe the physical sensations that they experience during pain (Craig & Korol, 2008; Dubois et al., 2010; Jerrett & Evans, 1986; Piaget, 2003). Children describe pain experiences in terms of people, objects and events in their direct environment (Esteve & Marquina-Aponte, 2011; Koopman et al., 2004), for example they said they “lose their smile and feel bad” (Jerrett & Evans, 1986) when they are in pain. These children continue to use interjections such as “ow” (Ely, 1992) and started to use the word “pain” for the first time at around 3;8 to 6;11 years (Craig et al., 2006; Stanford, Chambers, & Craig, 2005). Pain is defined by this age group as a physical symptom related to location and associated with illness (Dubois et al., 2008). Pain is explained as “unpleasant body sensations” (Esteve & Marquina-Aponte, 2011). As cognition develops, children’s concept of pain becomes more abstract, and psychological aspects are included (Hay et al., 2009)

Children in the pre-operational stage (2;0–6;11) start to use vocabulary to express the way they are coping with pain, which was not observed with children in the sensori-motor phase (0–1;11). Some of these pain expressions indicate how they are coping with pain such as asking for the emotional support from their parents (“I want to sit on mummy’s knee” or distraction from the pain (“I want to play”) (Wennström & Bergh, 2008). Other ways of coping with pain would include statements such as “Put on plaster”, indicating the use of concrete treatment in an effort to reduce the pain. Otherwise they would use self-comforting words such as “I wasn’t afraid...” to demonstrate their ability to cope with the pain (Wennström & Bergh, 2008). Older children (from 6;0 years old) in Stage II started to use the word stem “pain”. The term was however regarded as somewhat difficult by the younger children, who did not use it spontaneously to express pain (Craig et al., 2006).

Although they are able to describe their pain experiences by using a variety of descriptors (Abu-Saad, 1984), typically developing children in Stage III (concrete operations stage, age 7;0–11;11) and Stage IV (early formal operations stage, age 12;0–14;11) become more selective and economic in their choice of pain words as they mature, in contrast with younger children who have a smaller vocabulary (Harman, Lindsay, Adewami, & Smith, 2005). While children with a smaller vocabulary may choose more words, regardless of their meaning, to describe more severe pain, older children choose the fewest words to describe their pain, possibly because they believe they are not supposed to act weak (Harman et al., 2005). Adolescents may also prefer not to verbalise their pain because they think that the healthcare staff should know that they are in pain. Adolescents are also under the impression that they need to uphold their self-esteem and control and are therefore cautious to mention that they are in pain, since they are worried that they would be seen as “babies” (Azize et al., 2013).

Children in Piaget’s concrete operations stage (age 7;0–11;11) and early formal operations stage (age 12;0–14;11) still use exclamations such as “ow”, but are also inclined to use intensifiers with sensory descriptor words (Esteve & Marquina-Aponte, 2011) such as “pounding, stabbing, throbbing”; “really bad”; “pain was radiating...” (Kortesluoma & Nikkonen, 2006); “pin-like; horrible; sharp; shooting” (Wilkie et al., 1990) or “itching, stinging, aching” (Abu-Saad, 1984).

With the development of cognition, children’s concept of pain become more abstract and psychological aspects are incorporated (Hay et al., 2009). Indications of more abstract thinking are seen in the complex expressions they start to use for example: “Sometimes it is worse and sometimes more like stabbing, but I can stand it because it is always over soon” (Kortesluoma & Nikkonen, 2006). They also tend to begin to reason psychologically, mentioning that their pain was caused by their own actions for example: “I know I will feel sick when I eat sweets” (Esteve & Marquina-Aponte, 2011). Thus, to determine children’s pain-related words, words from different developmental language inventories should be taken into account (Banajee et al., 2000), since children in the different developmental phases apparently make use of different vocabularies to express their painful experiences. An understanding of children's language use in expressing their personal pain experience may lead to improved pain assessment and intervention (Adesman & Walco, 1992; Craig et al., 2006).

Apart from the child's type of disability, language development and cognitive development, gender is another intrapersonal factor that affects the development of pain vocabulary (Azize, 2012; Franck et al., 2010; Jerrett & Evans, 1986; Stanford, Chambers, & Craig, 2005).

2.3.1.1.4 Gender

Various researchers have reported gender differences in pain-related vocabulary despite similar pain experiences (Briggs, 2010; Fearon et al., 1996; Franck et al., 2010; Huguet, Miró, & Nieto, 2008). Although girls typically develop expressive vocabulary faster than boys (Karmiloff & Karmiloff-Smith 2001), Frank et al. (2010) only found a slight advantage in pain-related vocabulary by girls, which may imply that pain-related language acquisition could be related to other factors.

Girls tend to complain more about their pain-experiences than boys (Huguet et al., 2008) and are more likely to report their pain than boys (Azize et al., 2011). Girls also respond more frequently than boys at the higher end of the distress scale which may be due to girls' greater physiological sensitivity to pain (Fearon et al., 1996). Furthermore a difference is reported in the response style between boys and girls, with girls being more verbal about pain than boys (Fearon et al., 1996). When girls talk about pain, they would say "I feel like crying" more often than boys (and they actually do cry); "I feel sick to my stomach"; "feel embarrassed" or "feel nervous" to express their pain (Savedra, Gibbons, Tesler, Ward, & Wegner, 1982).

Moreover, research found that adults' responses to children's pain experiences were influenced by gender-stereotyped attitudes, and that boys were treated differently than girls (Briggs, 2010; Fearon et al., 1996). Girls received more physical comfort from their adult caregivers than boys, because girls' intense vocal response styles were effective to alert their caregivers about their distress (Fearon et al., 1996). This reason understandably reinforced girls' vocal responses to pain, while boys learnt not to respond vocally to pain experiences as "boys don't cry" (Briggs, 2010; Fearon et al., 1996; Nortjé & Albertyn, 2015). For the same reason, girls typically develop expressive vocabulary related to pain at a faster rate than boys (Briggs, 2010) and have a larger pain-related vocabulary (Franck et al., 2010). Girls, for example, would use more words like “sad”, “miserable” and “like a hurt” to describe pain, whereas boys would use pain-related words, like “cutting” (Savedra et al., 1982). In contrast to girls, boys tend to have more anger-related vocabulary in reaction to an injury (Franck et al., 2010). In the case of children with significant communication difficulties the differences between the reactions to pain by boys and girls are not clear.

2.3.1.2 Interpersonal factors: Social development

Within the socio-communication model of pain, interpersonal factors also influence children’s experience and expression of pain (Craig, 2009). These factors include family settings (such as parents’ responses to children’s pain experiences, the presence of older siblings), children’s previous hospitalisations, and their social and cultural environment (Carandang, Folkins, Hines, & Steward, 1979; Koopman et al., 2004).

2.3.1.2.1 Family setting

The whole family is influenced by paediatric chronic pain. Family factors have an effect on the child in pain (Jordan, 2005) and reciprocally family settings influence the way children talk about their pain (Briggs, 2010; Craig et al., 2006; Koopman et al., 2004; Kortesluoma & Nikkonen, 2004; Von Baeyer, Marche, Rocha, & Salmon, 2004). Families have a tendency to act as a unit when illness and subsequent pain are experienced – all family members are affected to a greater or lesser degree by the illness of another family member (Palermo, Valrie, & Karlson, 2014; Shapiro, 1983). Therefore, from the perspective of the family systems theory, the illness of one family member influences the rest of the family (Carandang et al., 1979) as family members learn by observing on another (Bandura, 1977; Jaaniste, Phipps, Lang, & Champion, 2013). Although some features of pain-related language appear to be universal, significant contributions of family and ethnic contexts are also echoed in the specificity of pain-related language with regard to the social setting in which children grow up (Craig et al., 2006).

2.3.1.2.2 Parents

Parents are role models and scaffolders for their children to learn words to express pain (Craig et al., 2006). The result is that children learn to talk about illness and pain through their parents’ viewpoints. In other words, as children’s cognitive and social skills develop, they start to think and talk in ways similar to their parents about illness and pain (Koopman et al., 2004).

Parents who have higher education levels stimulate their child's understanding of pain and may help their child to develop a larger pain-related vocabulary than children from less educated and less advantaged parents (Lau, Bernard, & Hartman, 1989). This is because more educated parents and parents from advantaged backgrounds have greater language skills to draw on when they interact with their children. Not only do they talk more often to their children, but they also use a greater variety of words and longer utterances (Hoff, 2003; Rowe, 2008). The result is that children of more educated parents are less dependent and less passive in how they interpret the causes of pain, because it has been communicated to them by their parents (Shapiro, 1983). Furthermore, parents with higher education levels have more knowledge of child development making them more focused on their child's language abilities and more aware of using child-directed speech at the specific level of their child's development (Rowe, 2008). Mothers in Rowe's study (2008) acknowledged their young children's burps, smiles and small injuries, and responded to these verbally, thus expanding their children's language ability and pain-related vocabulary.

The parent's age may influence the way in which he/she responds to the child in pain. Younger parents may use different pain-words compared to older parents (Turck, Flor, & Rudy, 1987).

Different stress factors are involved in families with both or single parents and may influence parents' reactions to their child's pain experiences (Turck et al., 1987). The way parents think and talk about pain and illness differs in "poorly functioning families" (such as families where parents are divorced; one parent passed away or have a psychiatric illness) than in "typical healthier" families (Jordan, 2005; Palermo et al., 2014; Shapiro, 1983). In the healthier family units, parents talk more positively about pain experiences and are more willing to adapt the environment to assist the child who is ill than in dysfunctional families (Shapiro, 1983).

Although parents stimulate their children's pain-related vocabulary (Franck et al., 2010), children learn more pain vocabulary from observing their parents and how the parents react to pain than from the verbalisations of their parents (Koopman et al., 2004). Parents' behaviours, such as social reinforcement of pain behaviours (e.g. allowing their child to avoid his/her normal activities) have been identified as being significant in children's responses to pain (Palermo et al., 2014). These reactions from parents may encourage the child to use pain for secondary gain, for example by asking for "rewards" such as toys after an operation, or not going to school for minor illnesses (Harbeck & Peterson, 1992). Then again, a child whose parents told him to “calm down” or “stop crying” may learn to refrain from expressing pain during subsequent pain experiences (Briggs, 2010).

2.3.1.2.3 Presence of older siblings

Earlier research showed that children with one or more older siblings had more pain words than those without older siblings (Franck et al., 2010). In addition, children with siblings with previous hospitalisations had a larger vocabulary than those with siblings who had never been hospitalised before. This suggests that experience plays a role in pain language acquisition because these children had to cope with the illness or hospitalisation of their sibling(s) (Franck et al., 2010). The way their parents talked about and dealt with the illness of the sibling(s) provided them with more pain-related vocabulary than those children without older siblings (Carandang et al., 1979). The younger siblings learn through observing their older siblings, which stimulates their own pain-related vocabulary (Franck et al., 2010; Koopman et al., 2004).

2.3.1.2.4 Previous pain experiences and hospitalisations

Children’s first experience of tissue injury is painful, and their understanding and significance of these sensations will increase with experience through contextual and either positive or negative associations (Anand & Craig, 1996). Therefore, Anand and Craig (1996) are of the opinion that the memory and learning of the concept and experience of pain cannot be separated from the behaviour of the person. Children who experience injuries more often, also respond more strongly to their painful experiences than those with fewer injuries (Fearon et al., 1996). As the body matures, so does its behavioural repertoire and its understanding of subjective experiences (Breau et al., 2003). As a result, children with previous hospitalisations who were exposed to more pain events and who have learnt and processed the concept of pain will have a larger pain-related vocabulary than those who have never been in hospital before (Franck et al., 2010).

Children learn the application of the word “pain” through their experiences related to injury (Jerrett & Evans, 1986; Merskey & Bogduk, 1994). For example, hospitalisations help children to develop pain words due to their personal experiences with pain. In a study comparing children who had been hospitalised before to those who had never been (Savedra et al., 1982), the children with previous hospitalisations used words like “sickening”;

"uncomfortable"; "like a pinch"; "horrible" and "tiring" more often to describe their pain. Children who had never been hospitalised used the word "biting" to describe their pain. Children with previous experiences of hospitalisations would talk about medical procedures (e.g. "shots" [injections]; "tubes in my chest" or "my brain surgery"); and also their feelings related to the hospital environment and feelings surrounding pain ("I feel like crying/screaming"; "I feel nervous") (Savedra et al., 1982). In contrast, children with no previous hospitalisations opted to talk about their physical pain ("my head is sore") or they would say that they "feel like hitting someone or something" because of their pain (Savedra et al., 1982). Hospitalised children would more frequently use words to describe pain related to tension, fear and overall pain intensity than non-hospitalised children (Savedra et al., 1982). This may be because these children experience the hospital as extremely stressful because they are separated from their family (Shapiro, 1983) and feel out of control of the situation (Gaynard et al., 1990).

2.3.1.2.5 Socio-cultural influence

Apart from family practices, children acquire knowledge of language related to pain within their sociolinguistic environment (Schieffelin & Ochs, 1986). Children's language is influenced by their social groups, communities and cultural beliefs (Schieffelin & Ochs, 1986). Information about the organisation of society and cultural knowledge is expressed through the content of language, as well as through its grammatical and dialogical form (Franck et al., 2010; Schieffelin & Ochs, 1986). In some cultures, for example, parents will repeatedly engage with their young children in certain verbal routines, thus modelling something to be said and directing the child to repeat it. These routines are often characterised by the crucial "say" and/or a typical intonation (Schieffelin & Ochs, 1986).

There are differences between the beliefs of different cultures regarding parents' roles in their children's language development. In some cultures, parents do not respond to their child's utterances because they believe that adults cannot teach babies to talk and that children will eventually learn to talk on their own (Rowe, 2008). In contrast, parents from other cultures label objects for their children, which emphasises their belief in their role as parents in their child's language development (Rowe, 2008). Furthermore, different family and cultural beliefs can lead to differences in how children learn about pain and how they behave when in pain (Kortesluoma, Punämaki, et al., 2008). For example, it is taboo for boys (and men) in the Sotho and Nguni cultures in South Africa to cry – it is regarded as a weakness or lack of courage and honour should they express their pain (Nortjé & Albertyn, 2015). It is thus important that healthcare staff should be aware of cultural differences and understand the patient's culture. They should ask questions to help the child describe his/her pain condition in detail to prevent any misunderstanding (Azize et al., 2011). In some cultures it is, for example, disgraceful to ask for pain relief and some people believe that a godly intervention will relieve pain when it is appropriate (Briggs, 2010; Nortjé & Albertyn, 2015). The result is that children will not express their pain or ask for pain relief medication.

2.3.2 Pain experience and expression

Children with disabilities and significant communication difficulties experience pain more frequently than those without, and they display their pain uniquely (Breau et al., 2003). The importance of pain assessment is therefore highlighted. The aim of pain assessment is to (a) identify the cause of the pain; (b) determine the effect of pain on the individual; (c) decide on appropriate pain-relieving strategies, and (d) assess the effectiveness of such strategies (Briggs, 2010). During the assessment of pain in children, the child's age, developmental level, cognitive level, communication skills and medical diagnosis should be taken into consideration (Azize, 2012; Haley, 1985; Hamers, Abu-Saad, Halfens, & Schumacher, 1994).

2.3.2.1 Self-report

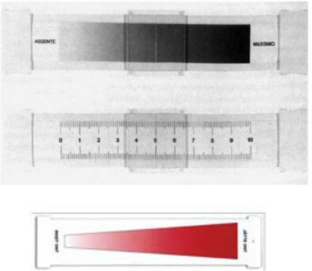
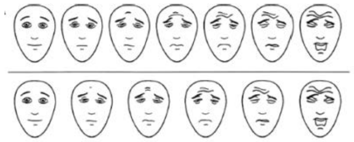
Self-report methods should be the first step (also referred to as the "golden standard") in the pain assessment process for children and proxy reports from parents or caregivers should only be used when the child's self-report is in doubt (McCaffery & Ferrell, 1997). Proxy reports by parents or caregivers should be regarded merely as an estimation of the child's pain (Schiavenato & Craig, 2010; Zhou et al., 2008) and not as valid as the child's self-report. The involvement of children in informed decision-making processes is in agreement with the United Nations' Conventions on the Rights of Children (CRC, 1989), as well as the European Convention on the Exercise of Children's rights (Council of Europe, 1996).

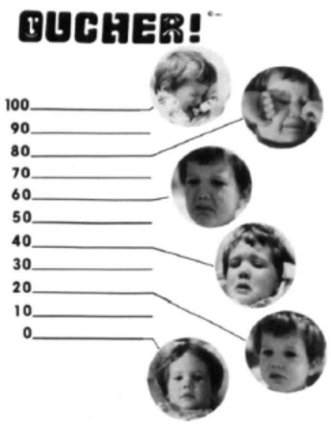
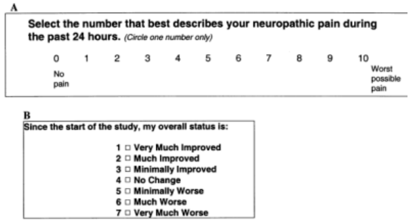
The use of self-report methods was often promoted as the main method for measuring intensity and other features of pain (Adesman & Walco, 1992; Belter, McIntosh, Finch, & Saylor, 1988; Hay et al., 2009; Nilsson, 2010; Von Baeyer, Forsyth, Stanford, Watson, & Chambers, 2009; Von Baeyer, Marche, Rocha, & Salmon, 2004). Two types of self-assessment instruments are typically used. The first type is the facial scale, based on how the child communicates his/her feeling(s) in a facial expression, for example the Faces Pain Scale (FPS). The other types are visual analogue scales, (i.e. Coloured Analogue Scale [CAS] and Visual Analogue Scale [VAS]) or numeric scales (i.e. Numerical Rating Scale [NRS]), which are based on increments to indicate the severity of pain, where children will indicate that a slightly larger or smaller pain is experienced.

Table 2.1 shows 12 self-report instruments that can be used to ensure that children are involved in the decision-making process to address their pain-treatment. These are grouped according to pain intensity, distress, anxiety and coping with pain.

Table 2.1

Self-Report Instruments Used in Pain-Assessment

Name of scale and author	Intended age group	Description	Visual example	Administered by	Purpose	Evaluation
Instruments to assess pain intensity						
Coloured Analogue Scale(CAS) (Mc Grath et al., 1996)	4;0–17;11	A modified visual analogue scale (VAS) with bright gradations in colour and length, allowing children to clearly see how the different scale positions would indicate different values in their pain intensity. A mechanical slider is used to indicate the severity of pain experienced (Miró & Huguet, 2004; Von Baeyer, 2006).		Healthcare professionals; parents	To assess pain intensity.	Easy to use with minimum instruction needed (Tomlinson, Von Baeyer, Stinson, & Sung, 2010).
FACES® Pain Scale (FPS) (Bieri et al., 1990)	3;0–12;11	Facial scale comprising of seven faces in a row, the face on the far left is representing “no pain” and the face on the far right indicating a lot of pain. Children point to the face that shows their pain.	 Top: Faces Pain Scale, scored 0 to 6. Bottom: Faces Pain Scale-Revised, scored 0 to10 (or 0 to 5). Instructions: “These faces show how much something can hurt. This face [point to left-most face] shows no pain. The faces show more and more pain [point to each from left to right] up to this one [point to right-most face] – it shows very much pain. Point to the face that shows how much you hurt [right now]”	Healthcare professionals; parents	To assess pain intensity.	Easy to use with minimum instruction needed (Tomlinson et al., 2010).
FACES® Pain Scale – Revised (FPS-R) (Miró & Huguet, 2004)	3;0–12;11	The revised version of the scale contains only six faces that depict the increasing intensity of pain from the left to the right (Connelly & Neville, 2010)		Healthcare professionals; parents	To assess pain intensity.	Children prefer faces scale to assess pain. Self-administered scale (Connelly & Neville, 2010). Quick and easy to use with minimum instruction needed (Tomlinson et al., 2010).

Name of scale and author	Intended age group	Description	Visual example	Administered by	Purpose	Evaluation
The Oucher (Beyer, McGrath, & Berde, 1990; Tomlinson et al., 2010)	3;0– 12;11	Photographic faces scale of 6 vertical faces of one child's face scored from 0 ("no hurt") to 10 ("biggest hurt you can ever have"). This scale has an adjacent numerical scale scored from 0 to 100 for older children.		Healthcare professionals; parents;	To assess pain intensity	To address cultural differences, different versions of the scale are available for Caucasian, African, Hispanic, and Chinese patients (Tomlinson et al., 2010).
Visual analogue scale (VAS) (McGrath et al., 1996)	≥5;0	A 10-centimetre horizontal line with the ends labelled as the extremes ('no pain" and "pain as bad as it could be"); the rest of the line has no labels. Children have to mark anywhere on the line how much pain they experience (Connelly & Neville, 2010).	No pain Pain as bad as it could be	Healthcare professionals; parents; (O'Rourke, 2004)	To assess pain intensity	The traditional black lines of the VAS were found too difficult for children and the Coloured Analogue Scale (CAS) was consequently developed (P. A. McGrath et al., 1996).
Wong and Baker FACES Pain Rating Scale (WBFPRS) (Tomlinson et al., 2010; Wong & Baker, 1988)	3;0–17;11	Horizontal scale of 6 hand-drawn faces, scored from 0 to 5, with a smiling "no hurt" face on the far left and a crying "hurts worst" face on the far right.		Healthcare professionals; parents	To assess pain intensity	Children and adolescents prefer scales that show faces to assess pain.
The numerical rating scale (NRS) (Connelly & Neville, 2010; Von Baeyer et al., 2009) Pain intensity numerical rating scale PI-NRS	≥ 8;0	The NRS is an 11-point scale from 0 ("no pain") to 10 ("worst possible pain"). The scale can be verbally administered by asking children how much pain they have by using whole numbers from 0 ("no pain") to 10 ("worst possible pain").	A **Select the number that best describes your neuropathic pain during the past 24 hours.** *(Circle one number only)* 0 1 2 3 4 5 6 7 8 9 10 No pain … Worst possible pain B **Since the start of the study, my overall status is:** 1 ☐ Very Much Improved 2 ☐ Much Improved 3 ☐ Minimally Improved 4 ☐ No Change 5 ☐ Minimally Worse 6 ☐ Much Worse 7 ☐ Very Much Worse	Healthcare professionals	To assess pain intensity	More likely to produce higher estimates of pain than FPS-R or VAS. Children need to have skill to think and express themselves in quantitative terms, and to communicate verbally.

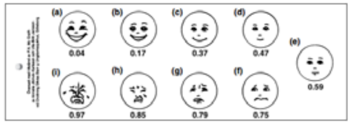
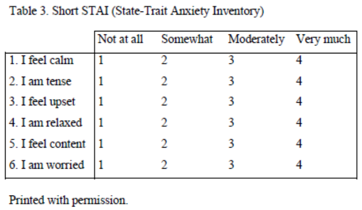
Name of scale and author	Intended age group	Description	Visual example	Administered by	Purpose	Evaluation
Instruments to assess distress						
Children's Fear Scale (CFS) (McMurtry et al., 2011)	5;0–10;11	Consists of five faces that show various degrees of fear in an ordered sequence with no fear on the far left and a lot of fear on the far right.		Healthcare professionals	To assess fear related to the pain experience.	Recommended for use with children.
Facial Affective Scale (FAS) (Connelly & Neville, 2010; P. A. McGrath et al., 1996)	5;0–17;11	A set of 9 faces that vary in the level of overt distress expressed. The scale is usually presented in random order, with three faces displayed in each of three rows on a piece of paper of approximately 20 x 28 cm. They have to choose a face to indicate how they feel at that moment.		Healthcare professionals	To determine children's distress.	Recommended for use with children before a medical procedure.
Instruments to assess anxiety						
State-Trait Anxiety Inventory for Children (STAIC) (Spielberger, 1973)	9;0–12,11	A 40-item questionnaire in which children are asked to select adjectives that vary in intensity to best describe the way they feel at the time (Connelly & Neville, 2010).		Healthcare professionals	To measure anxiety	Recommended for children and adolescents.
Short State-Trait Anxiety Inventory (STAI) (Marteau & Bekker, 1992)	5;0– 16;11	Contains six items. A score of six points signifies no anxiety, and a score of 24 points signifies the highest level of anxiety (Marteau & Bekker, 1992)	Not available.	Healthcare professionals	To diagnose clinical anxiety in surgical patients.	Recommended for use in settings where time restrictions prevent the use of the full-form.

Table 3. Short STAI (State-Trait Anxiety Inventory)

	Not at all	Somewhat	Moderately	Very much
1. I feel calm	1	2	3	4
2. I am tense	1	2	3	4
3. I feel upset	1	2	3	4
4. I am relaxed	1	2	3	4
5. I feel content	1	2	3	4
6. I am worried	1	2	3	4

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Name of scale and author	Intended age group	Description	Visual example	Administered by	Purpose	Evaluation
Modified form of the short STAI using a modified Talking Mats method (Nilsson, Buccholz, & Thunberg, 2012)	7;0–9;11	Uses four facial expressions – two of which display negative feelings, while the other two show positive feelings. Children are given the facial expression cards one at a time and are instructed to place them according to their preference. The instrument gives a score for the child's level of anxiety ranging from four to 12 points.		Healthcare professionals	To measure anxiety	Children effectively used the modified short State-Trait Anxiety Inventory (STAI) in the Talking Mats framework.
Instruments to assess coping with pain						
Pain coping questionnaire (Reid, Gilbert, & McGrath, 1998)	9;0–17;11	Consists of 8 subscales listing 39 strategies that children may use when in pain for a few hours or days. The children have to rate on a five-point Likert scale (1 never; 2 hardly ever; 3 sometimes; 4 often; 5 very often) how often they use each strategy, in response to the prompt, 'When I am hurt or in pain for a few hours or days, I…'.	The subscales are: Information Seeking, Problem Solving, Seeking Social Support, Positive Self-Statements, Behavioral Distraction, Cognitive Distraction, Externalising, and Internalising/Catastrophising.	Children complete questionnaire	To measure coping with pain	This instrument has been used effectively with children and adolescents to assess their coping with pain strategies.

From Table 2.1 it is clear that there are various self-report instruments that can be implemented by healthcare staff during pain assessment. The most commonly used instrument in this category is probably the VAS although children generally prefer scales with faces to visual analogue scales when given a choice (Von Baeyer, 2006). The VAS has been widely regarded as probably the most reliable way of indicating pain intensity (Sánchez-Rodríguez, Miró, & Castarlenas, 2012). Sliding a cursor that represents pain intensity requires that children should have enough abstract ability to understand and transform their experience of pain intensity to the line on the VAS (Breau, 2003). This means that young children and children with cognitive disabilities often have difficulty understanding how the VAS works (Breau et al., 2003). Furthermore, children with physical disabilities and poor motor movement may find the use of this scale challenging.

When implementing self-report scales, developmental factors connected to children’s skill, e.g. cognitive development and age should be considered (Connelly & Neville, 2010). Children in Piaget’s pre-operational cognitive developmental stage (2;0–6;11), for example, may not yet have the cognitive ability to quantify and choose the extremes from a specific scale such as the visual analogue scales (Von Baeyer, 2006). When for instance, children use the numerical rating scale (NRS), they should be able to classify their rating in numerical terms, which is why the NRS has previously shown good evidence for children aged eight years and older (Von Baeyer et al., 2009). Recently is has recommended even from the age of six years old (Castarlenas, Miró, & Sánchez-Rodríguez, 2013; Von Baeyer et al., 2009).

Although some self-report assessment strategies such as the VAS do not require expressive language (Hadjistavropoulos & Craig, 2002), receptive language skills are needed, as children are expected to understand or know the meaning of words such as “pain” or “hurt” when using these scales (Hadjistavropoulos & Craig, 2002; Stanford, Chambers, & Craig, 2005).

Researchers acknowledge the difficulty in evaluating and diagnosing pain in children with disabilities (Stähle-Öberg & Fjellman-Wiklund, 2009) because healthcare staff and parents often underestimate children’s levels of pain (Chambers, Reid, Craig, McGrath, & Finley, 1998; Stallard, Williams, Lenton, & Velleman, 2001). Schiavento and Craig (2010) are of the opinion that communication vulnerable populations such as critically ill paediatric patients, infants and children with cognitive disabilities, may struggle to provide self-report due to their limited linguistic and social skills. Therefore, healthcare staff involved in pain assessment should be open to all non-verbal communication attempts including unaided and aided strategies (Banerjee et al., 2012).

2.3.2.2 Behavioural observations

Observational strategies are used when the ability to self-report is not available or when the accuracy of the self-report is in doubt (Hadjistavropoulos & Craig, 2002). When children cannot speak, healthcare staff, parents and caregivers can only estimate the pain by interpreting the children's bodily signs with the use of observational scales (Kortesluoma & Nikkonen, 2004; Stähle-Öberg & Fjellman-Wiklund, 2009).

There are several validated observational instruments that can be used to assess pain in children when self-report is not possible. As behavioural observations are not the main focus of this thesis, the 12 most frequently used measures are summarised in Appendix A. Observational tools are classified according to their purpose, e.g. (a) procedural pain – brief painful events; (b) post-operative pain in hospital; (c) post-operative pain at home (parent assessment); (d) on ventilator or critical care and distress, (e) pain-related fear and anxiety (Von Baeyer & Spagrud, 2007). From the examples of observational scales as presented in Appendix A, the use of the FLACC (Face, Legs, Activity, Cry, Consolability) scale is recommended for procedural as well as post-operative pain assessment. This is due to its reliability, validity and the responsiveness of the tests, as well as the fact that it has been validated more extensively than the Children's Hospital of Eastern Ontario Pain Scale (CHEOPS) in post-operative settings (Von Baeyer & Spagrud, 2007). Although observational scales have the advantage of not being dependent on the child's verbal ability or co-operation, a study by Beyer et al. (1990) highlights discrepancies between the scores of the observational scales and self-report of children, thereby emphasising the importance of obtaining the child's voice to self-report.

Behavioural observations do not deal fairly with individuals with disabilities (Schiavenato & Craig, 2010). Their idiosyncratic behaviours may give the wrong impression about their pain, resulting in underestimation of pain intensity and less treatment (Beyer et al., 1990). For example, children with cognitive impairments use moaning and facial changes even when they are not in pain and may then receive unnecessary pain treatment, as these behaviours are regarded as classic indicators of pain (Terstegen et al., 2003). Because children with disabilities may not present similar bodily behaviours as their typically developing peers, wrong pain treatments or no pain treatments, may be provided (Gilbert-MacLeod et al., 2000). Another study found that children with severe neurological impairment did not show typical facial reactions or physiological responses (such as accelerated heart rate) when receiving a flu injection (Oberlander, Gilbert, Chambers, O'Donnell, & Craig, 1999). This is one of the reasons why the FLACC, despite its reliability for typically developing children, may not be the most appropriate observational tool to use for this group of children (Bottos & Chambers, 2006; Engel & Kartin, 2006). The Parents' Post-operative Pain Measure (PPPM) is recommended and was specifically designed for use by parents to do post-operative pain assessment at home when their child is discharged from hospital (Von Baeyer & Spagrud, 2007). The Procedure Behavioural Rating Scale – Revised (PBRS-R) is suggested as the best observational tool to observe if children have distress or pain-related anxiety; however the implementation of this scale with children with disabilities may not be possible due to reasons mentioned before (Von Baeyer & Spagrud, 2007).

As discussed earlier, children with disabilities may sometimes not respond to pain or may not have the ability to display those behavioural changes that healthcare staff typically use as indicative of children's pain experience. Staff often guess at the amount of pain the child may experience (Bottos & Chambers, 2006; Gilbert-MacLeod et al., 2000). Parents develop skills to know their child's individual pain expressions (Clarke, Thompson, Buchan, & Combes, 2008). Over time, parents start to recognise certain behaviours that their child displays, which may point to the occurrence of pain. Although parents are open to specific behaviours indicating pain, they also admit that they sometimes have difficulty to identify pain in their child (Clarke et al., 2008; Craig et al., 2006). Historically parents' proxy reports on their child's pain have been used to report such pain, because healthcare staff were of the opinion that parents know their child the best and may be the best reporters of the his/her pain (Chambers et al., 1998; Coyne, 2005). Nevertheless, researchers (Bandstra et al., 2012; Chambers et al., 1998; Hay et al., 2009) found considerable discrepancies between the proxy reports of parents and self-report of children on the children's perceived pain – parents usually underestimated their children's pain. With the above in mind, the importance is emphasised of obtaining a direct report from children, especially those with disabilities (Coyne, 2005).

2.3.2.3 Physiological assessments

Physiological indicators (such as blood pressure, changes in heart rate and respiratory rate) are not sensitive enough to discriminate pain intensity. Therefore, healthcare staff should first opt for self-report and then behavioural observations to determine the presence of pain. Herr et al. (2011), further state that the absence of changes in vital signs does not necessarily indicate that no pain is experienced.

In summary, three types of assessment are typically used to determine pain in children, namely self-report, behavioural observations and physiological assessment. It appears that children's self-report of pain intensity is a valuable and credible source of information provided that a combination of different self-report scales is used (Adesman & Walco, 1992; Belter et al., 1988; Huguet, Stinson, & McGrath, 2010; Von Baeyer et al., 2009). However, it is important that the interpretation and analysis should be done in tandem with other types of assessment, i.e. observation, self-report, parent proxy report and the physiological information of the child (Von Baeyer, 2006).

Children need pain vocabulary to do self-report. The socio-communication model of pain clarifies the complicated communication process that children with significant communication difficulties may experience in communicating their pain to others. The model can be used, for example, to examine bodily expression of pain, to beat social difficulties to provide the best possible care of infants and children, and to differentiate between the usefulness and implications of observational measures and self-report of pain (Hadjistavropoulos & Craig, 2004). This socio-communication model of pain supports the inclusive understanding in challenges by parents and healthcare staff to control pain in children with significant communication difficulties (Craig, 2006; Hadjistavropoulos & Craig, 2002). Children use language to express (encode) their pain, whereas healthcare staff need to understand the children's language in order to assess (decode) pain (Azize et al., 2011; Finley et al., 2009). Children with significant communication difficulties may however not have the means to communicate their pain. This results in them being misdiagnosed and incorrectly treated, because healthcare staff decode their pain incorrectly due to these children's uniquely individual responses to pain and their inability to communicate pain verbally (Azize et al., 2011; Coyne, 2005; Gilbert-MacLeod et al., 2000). In a study by Stallard and colleagues (2001), it was found that 67% of the participants with significant communication difficulties, and who had moderate to severe pain did not receive active pain treatment. The result was that misinterpretation and under treatment of pain limited children's participation and affected their quality of life negatively (Stallard et al., 2001). However, research that focuses on the communication features of pain has emphasised that pain is often public and of critical importance to others (Craig, 2004) – an aspect of pain that people with disabilities may experience a challenge to address, due to their communication difficulties.

Furthermore, some children with developmental delays develop different pain responses because they may have a socio-communicative deficit and may thus display inappropriate behaviour during social interactions when compared to their typically developing peers (Gilbert-MacLeod et al., 2000).

The socio-communication model of pain emphasises that the focus should be on more than only the painful experience and the physical damage to the tissue, as has traditionally been implied by the definition of the International Association for the Study of Pain (International Association for the Study of Pain, 1979). Due to the subjective nature of pain experiences, the reaction to tissue injury is not determined by biological processes responsible for these pain experiences only – it corresponds to the sum of sensory, emotional, and cognitive responses to pain (Schiavenato & Craig, 2010).

These reactions are often influenced by a person's personal history, genetic inheritance and social factors, such as the settings in which pain was experienced and the observers present (Craig, 2006). The definition provided by the International Association for the Study of Pain (IASP) further agrees that sensory and emotional experiences that are related to injury in early life may help individuals to learn the application or meaning of the word "pain" (International Association for the Study of Pain, 2011). Other areas that are therefore also addressed in this model are intrapersonal- and interpersonal influences that contribute to the communication of the pain experience.

The active interaction between the encoding of pain by the child with disability (which includes expressive behaviours such as cry, self-report and reflexes), and the decoding of pain by healthcare staff (who make assumptions about the child's experience) requires an understanding of how pain is perceived and expressed to be communicated effectively (Craig, 2004; Hadjistavropoulos & Craig, 2004). Children with disabilities have less effective social or communication skills, since they are often neglected, uncared for and inadequately treated. They stopped trying to engage with others in an effort to receive proper care, because their attempts had previously been ignored (Versloot & Craig, 2009). They also have an increased vulnerability because of their dependence on others for assistance in pain management, which results in them often being neglected due to their inadequate ability to communicate their pain effectively (Hadjistavropoulos & Craig, 2002). The provision of AAC, to empower communication vulnerable paediatric patients to communicate their pain effectively, has therefore been investigated and implemented successfully in various hospital settings (Banerjee et al., 2012; Costello, 2000; Garrett, Costello, & Fried-Oken, 2007). In the absence of AAC, a communication breakdown occurs when healthcare staff members do not understand the efforts made by communication vulnerable paediatric patients to communicate their pain.

In the socio-communication model of pain, social and contextual factors determine the subjective experience of the person in pain, as well as the decisions and temperament of the observer. Healthcare staff may make decisions regarding treatment based on the patient's non-verbal behaviour, self-report and physiological responses, but the healthcare staff or caregiver will also assess the context in which the pain is being assessed (Hadjistavropoulos & Craig, 2004). Personal factors of the healthcare staff, such as their training, background and own personal experiences of pain may also influence their decisions in responding to and treating their patient in pain. It is clear that caring for a child in pain is a complex process – and for children with significant communication difficulties this is even more so. One of the strategies to support children with significant communication difficulties in this complex process of communicating their pain is to use AAC.

2.3.3 Augmentative and alternative communication (AAC)

AAC provides children with significant communication difficulties with the ability to understand and express a variety of messages, including messages related to pain (Banerjee et al., 2012; Beukelman & Mirenda, 2013). The aim of all AAC interventions is to support a child's current and future communication needs. AAC intervention is specific to the individual and will differ according to whether it is a very young illiterate child who just started developing language skills or an older literate child with previous world knowledge and pain experiences (Fager & Spellman, 2010). The severity of the disability and the abilities of each individual child are acknowledged during AAC intervention (Beukelman & Mirenda, 2013). Communication with family members and healthcare staff will also be a priority in a hospital setting.

Traditionally, AAC was categorised based on unaided and aided modes (Wilkinson & Hennig, 2007). Unaided AAC refers to those modes where no external devices are needed (such as manual signs, gestures, and vocalisations). Aided AAC refers to technology – either low-technology, such as paper-based communication boards or high-technology, such as speech-generating devices. Preliterate children are often provided with graphic-symbol-based high- or low-technology systems – where graphic symbols representing specific words or phrases are stored and displayed (Wilkinson & Hennig, 2007). Vocabulary selection is needed to determine which words should be stored and/or displayed on the aided systems.

2.3.3.1 Vocabulary selection

Typically developing children use words from the moment that the need arises to attain various communication goals, such as providing information or indicating needs and wants. Children with significant communication difficulties who make use of graphic symbol-based AAC systems need to have pre-selected messages stored on their AAC systems to communicate and achieve their communication goals. It is the role of SLPs (in collaboration with other role players) to select appropriate vocabulary to assist children with significant communication difficulties to achieve specific communication goals, in this case to communicate pain.

Vocabulary selection describes the process of choosing a set of words from hundreds of possibilities (Yorkston, Dowden, Honsinger, Marriner, & Smith, 1988) so as to achieve two main functions in children using AAC, namely (a) to enable them to convey important messages and (b) to foster the development of language skills (Beukelman & Mirenda, 2013). The selection of vocabulary such as a set of pain-related words and/or phrases is a time-consuming but essential procedure to ensure that children with significant communication difficulties, who could benefit from the use of AAC have access to relevant vocabulary (Balandin & Iacono, 1998a) that allows them to communicate pain effectively.

During the vocabulary selection process in AAC, information is required to inform those involved on how to decide which words to select, especially if the AAC system can store only a limited number of messages (Yorkston et al., 1988). Traditionally, various methods have been implemented to select vocabulary for people who use AAC, such as (a) observing typically developing peers who communicate in natural contexts (Beukelman, McGinnis, & Morrow, 1991); (b) using language activity monitor (LAM) programs within AAC systems to record persons who use AAC's use of specific vocabulary (Hill, 2004); (c) using an activity-based approach (Goossens, Crain, & Elder, 1994); (d) using high-frequency core word lists (Balandin & Iacono, 1998), or (e) obtaining input from informants such as familiar communication partners (Beukelman & Mirenda, 2013). Stakeholder reviews were furthermore used to socially validate the results of the selected vocabulary (Schlosser, 1999). Literature searches on the use of vocabulary in specific topics, such as pain could also inform SLPs and other professionals on suitable vocabulary for a specific population, for instance children.

2.3.3.1.1 Observations

The high-frequency word lists were usually generated through data that was retrieved by using traditional methods such as observing or audio and video recording typically developing peers when they communicate in natural or specific context interactions (Beukelman, Jones, & Rowan, 1989; Beukelman et al., 1991; Marvin et al., 1994). Beukelman and colleagues (1989) studied the vocabulary use patterns of six typically developing pre-schoolers (three boys and three girls) in their classroom setting. Language samples from two to seven hours in length were recorded with microphones and audio recorders attached to the children. Thereafter, these samples were transcribed verbatim and analysed to establish the frequency of words, the total number of words, the number of different words as well as the consistency with which individual words were used by the six children (Beukelman et al., 1989). The same methodology was followed by Marvin et al. (1994) during two specific activities – one adult-directed and one free-play activity. This method to gather data and compile high-frequency word lists to guide vocabulary selection may pose challenges when determining specific pain-related vocabulary, because there is no guarantee that the children may have pain experiences while being recorded. This is despite the fact that literature suggests that, typically, children can on average experience minor bumps and bruises every three hours (Von Baeyer et al., 1998). Pain is often associated with emergency situations, during which the recording of pain-related words may not necessarily be the focus of the situation.

Specific context interactions where participants used audio recorders were also used by researchers to collect language samples for compiling topic vocabulary lists (Balandin & Iacono, 1998b; Stuart, Beukelman, & King, 1997; Tönsing & Alant, 2004). The advantage of using such observational methods to compile these topic lists was that the information was based on actual data rather than on reflections or predictions (Beringer, Tönsing, & Bornman, 2013). In studies on children’s expression of their pain-related experiences, observational methodology has also been applied. Children were video-recorded during their hospital stay before and after operations, although the study did not focus on recording pain-related vocabulary per se, but also bodily pain expressions (Dubois et al., 2008; Dubois et al., 2010; Gilbert-MacLeod et al., 2000; Wennström & Bergh, 2008). An ethical concern of employing an observational type of methodology in sensitive settings (such as post-operative hospitalisations) to determine the child’s pain-related vocabulary may be that observation during a vulnerable stage of the child’s hospitalisation may invade his/her right to privacy, but it also imply that the researcher expected the children to have painful experiences. Furthermore, observational procedures may add additional stress to an already stressful situation, and as a result, the researcher may be causing harm.

2.3.3.1.2 Language activity monitor

In another study on vocabulary selection, data was gathered by recording people who use AAC on their AAC systems by means of the language activity monitor (LAM) (Hill, 2004). Hence the activity was recorded while a person who uses AAC used his/her AAC system for functional communication (Hill, 2004). The LAM is a feature on the AAC system that automatically counts and saves the words used in communication by the person who uses AAC once it has been turned on. The LAM is a time-efficient, cost-effective and convenient way to record and collect a language sample of the communication activity of a person who uses AAC on an AAC system (Hill, 2004). There are, however, ethical concerns with this type of research as all the communication messages are collected – the person who uses AAC may rather have wanted to have some excluded, thereby comprising on the ethical principle of privacy. The use of the LAM will enable clinicians to generate word frequency lists to compare their client’s core vocabulary with those from other studies, such as studies specific to pre-schoolers (Banajee et al., 2003; Beukelman et al., 1989; Marvin et al., 1994). However, graphic symbol-based AAC systems may not contain appropriate pain words, and/or may not be used or be available to communicate when relating painful experiences. The use of the LAM may thus not be suited to determine average pain-related vocabulary frequencies. Furthermore, LAM cannot record non-verbal communication that is pain-related, such as crying and facial expressions.

2.3.3.1.3 Activity-based approach

Goossens, Craig and Elder (Goossens et al., 1994) suggest that vocabulary included in communication boards should be selected according to specific activities. Typical activities of daily living (e.g. eating, dressing) have been used due to their frequent occurrence, or fun activities (e.g. book reading or play) due to their motivational value (Banajee et al., 2003; Da Fonte, Pufpaff, & Taber-Doughty, 2010; Trembath et al., 2007), and in the process more sensitive and “unpopular” topics, such as pain were neglected. To some extent, aspects related to pain might be treated according to the “ostrich principle”. If something is not discussed and described, it does not exist (Shoham, 1986). By implication, if children don’t say that they are in pain, it must mean that they are not – regardless of the fact that they might not have the relevant vocabulary to communicate their pain (Bottos & Chambers, 2006).

Pain-related events (e.g. previous hospitalisations) – even though possibly infrequent and also unpleasant – may have a huge impact on a child’s life, and children with significant communication difficulties will need to be able to communicate such events.

When using an activity-based approach, words and/or phrases appropriate for specific pain-related environments (e.g. hospital) or activities (e.g. visiting the dentist, nursing a sick doll, playing Doctor-Doctor) may be included (Dodd & Gorey, 2013). When this environmental approach or activity-based approach is used, the vocabulary is selected to enable the child who uses AAC to communicate within the specific environments using predominantly fringe vocabulary (Dodd & Gorey, 2013). Fringe vocabulary refers to context-specific words (e.g. injection, medicine, hurt) that are unique to the individual’s specific interests, and that are influenced directly by the immediate environment and activities (Beukelman & Mirenda, 2013). Fringe vocabulary could provide personalised pain-related vocabulary to be included in an AAC system and allow expression of messages and incidents that do not appear in the individuals’ core vocabulary list (Beukelman & Mirenda, 2013). However, Dodd and Gorey (2013) warn that communication aids that focus primarily on fringe vocabulary may result in children using their aids mainly to request things, rather than to use it for other communicative purposes such as commenting and sharing.

2.3.3.1.4 Published vocabulary lists

A developmental approach to vocabulary selection focuses on core vocabulary (Banajee et al., 2003). Core vocabulary refers to words that can be used across environments and activities to communicate a range of communicative functions (Beukelman & Mirenda, 2013). It is suggested that the initial vocabulary set should consist mostly of core vocabulary to enable the child to communicate various communicative functions (e.g. sharing, requesting). Vocabulary items in this core vocabulary set can be combined to meet the various communicative functions, whereas fringe vocabulary may result in unforeseen limitations (Dodd & Gorey, 2013).

The use of mainly core vocabulary has been supported by Baker, Hill and Devylder (2000) who illustrated that sentences in everyday speech consist mainly of core vocabulary and grammatical structure, but that core vocabulary was not the focus of vocabulary development in AAC. The focus was mainly on fringe words, which, according to Baker and colleagues (2000), allowed communication partners to complete the blank spaces in the sentences – something typically developing peers would never tolerate. The researchers further stated that the same core vocabulary words were consistently used in different environments, although topics may have changed (Baker et al., 2000). These findings supported the results of studies with pre-schoolers by Beukelman, Jones and Rowan (1989), as well as Marvin, Beukelman and Bilyeu (1994), who found that 85% of the words used were the 250 most frequently occurring words – which supported the possible use of core vocabulary across a variety of contexts.

Should core vocabulary be used on the AAC systems of children with significant communication difficulties, it is important to note that no pain-related words (defined as single words that describe or report pain, such as hurt, sore and pain) are currently represented in any of the available and published children's core vocabulary lists developed by Banajee et al. (2003), Marvin et al. (1994) and Trembath et al. (2007), despite the fact that these lists include at least 75% to 80% of the total vocabulary that children use (Boenisch & Soto, 2015). The reason for the absence of pain-related words in these core lists may be that the vocabulary was selected by collecting data from audio-recorded interactions of children in specific daily activities (such as play or storybook reading) (Banajee et al., 2003; Marvin et al., 1994; Trembath et al., 2007). The core vocabulary lists were then compiled by determining the frequency of words in transcriptions made of these interactions. It could have been that a limited number of the child participants experienced minor bumps or bruises during data collection, but because of their low frequency, these words were excluded when the final core vocabulary lists were compiled. Furthermore, data collection took place for only a few hours in the day during specific activities (Banajee et al., 2003), which could have led to over-representation of specific experiences and the underrepresentation of others, such as pain experiences. This then resulted in pain-related words not being included in these lists. Although there was no doubt that core vocabulary would play a role when children communicate about their pain, specific fringe words carrying information about pain would be needed as well.

Therefore, workable processes need to be determined by which such appropriate fringe vocabulary could be predicted, selected and added to existing core vocabulary. The combined use of both core and fringe vocabulary would be necessary, because core vocabulary could be used across various contexts, while fringe vocabulary would carry information on the topic of pain (Beukelman et al., 1991; Blackstone, 1988; Yorkston et al., 1988). Hence, with the inclusion of fringe vocabulary, the individual's need to communicate his/her pain experiences would be catered for. The pain-related fringe vocabulary should be available and culturally sensitive – thus including words related specifically to the individual's culture (Beukelman & Mirenda, 2013).

2.3.3.1.5 Informants

Vocabulary selection requires a team who is sensitive and competent to consider the many characteristics and criteria of identifying vocabulary for a specific context (Lloyd et al., 1997). Researchers have recommended the importance of including the child, the family and, where applicable, other persons who use AAC in the vocabulary selection process (Beukelman & Ray, 2010).

Professionals (e.g. SLPs, teachers) often predict the topics and vocabulary needed by persons who use AAC, or obtain the input of significant others to do so. However, research shows that such predictions are not always accurate. Beringer et al. (2013) found that significant others were only 65% accurate in predicting which topics adults with aphasia wanted to talk about. In another study, Balandin and Iacono (1998b) asked SLPs, who were highly experienced in selecting vocabulary and working with adults using AAC in work place setting to predict topics and vocabulary for meal break conversations at work. Of the vocabulary predicted, only 66% occurred in actual meal break conversations. When predicting pain-related vocabulary for use by children with significant communication difficulties, parent and professional input may therefore not be enough to arrive at a comprehensive and appropriate vocabulary list.

2.3.3.1.6 Stakeholders

Social validation is the process whereby consumers assess and evaluate the acceptability and social significance of vocabulary in specific contexts (Balandin & Iacono, 1998a; Dark & Balandin, 2007; Schlosser, 1999). Researchers have acknowledged the need to socially validate vocabulary selected for use by people who use AAC in different contexts (Beukelman et al., 1991; Yorkston et al., 1988). The social validation of AAC vocabulary lists entails the gathering of information from consumers such as persons who use AAC as well as typically developing speakers to enable researchers to assess the appropriateness and functionality of the selected vocabulary (Balandin & Iacono, 1998a; Beukelman et al., 1991).

Balandin and Iacono (1998a, 1998b) insisted that social validation was such an important process that vocabulary could not be accepted before it had been socially validated.

Direct stakeholders (persons who use AAC) and indirect stakeholders (family members of the person who uses AAC) could be involved in the social validation process (Schlosser, 1999). Social validation by means of stakeholders who are competent users of AAC provides useful guidelines that may improve the quality of the list because stakeholders democratically provide lived perspectives that strengthen the social validation process (Kildea, Wright, & Davies, 2011; Schlosser, 1999). Furthermore, stakeholder reviews allow the voices of this potentially vulnerable group to be heard, which may result in improved identification and management of their pain (Kildea et al., 2011). There is a consensus that children with significant communication difficulties experience challenges in verbalising their painful experiences (Cano, Leong, Heller, & Lutz, 2009) and need to be able to report their pain. The social validation via stakeholder reviews by persons who use AAC could confirm and enrich selected vocabulary lists that may be appropriate for use by others who use AAC.

2.4 Conclusion

The socio-communication model of pain underlies the main theoretical constructs of this study. Intrapersonal factors such as type of disability, language development, cognitive development and gender, influence the way in which children with significant communication difficulties experience and express their pain. Furthermore, interpersonal factors (i.e. family influences, previous hospitalisations and socio-cultural influences) also affect the experience and expression of pain by children with significant communication difficulties. Due to these influences, the children need AAC with specific pain-related vocabulary to express pain. This chapter ends with a discussion of specific strategies and/or techniques employed in the AAC field to assist with vocabulary selection.

CHAPTER 3

RESEARCH METHODOLOGY: QUALITATIVE PHASE

3.1 Introduction

This chapter commences with a discussion of the methodology used in this study. First, the main aim and sub-aims as they pertain to the different phases of the research are provided. Next, an overview is given of the four-phase sequential exploratory mixed methods research design that employs a Qualitative phase (Phase 1), a Measuring Instrument Development phase (Phase 2), a Quantitative phase (Phase 3) and a Social Validation phase (Phase 4). The focus of this chapter is on the first two phases, while Chapter 4 is concerned with the Quantitative and Social validation phases. Phase 1 is presented in terms of the aims and steps of the phase, participants, materials and equipment, data collection procedures, trustworthiness considerations, data analysis, and the implications for the next phase. Next, Phase 2, which focuses on the development of the measuring instrument, is presented in terms of the aims and steps of the phase, authentication of the set of hypothetical physical pain scenarios, and material and equipment. Furthermore, the pilot study is discussed in terms of the aims of the pilot study; participants, results and recommendations. Phase 2 concludes with a reflection on the implications for the Quantitative phase.

3.2 Aim of the Study

The main aim of this study was to identify the pain-related vocabulary (words and/or phrases) as elicited by specific hypothetical physical pain scenarios in six respondent groups in order to compile and socially validate a list of pain-related vocabulary to be included in an AAC system to assist children who might benefit from AAC to communicate physical pain. The six respondent groups consisted of children aged 6;0 to 7;11; children aged 8;0 to 9;11; parents of children aged 6;0 to 7;11; parents of children aged 8;0 to 9;11; teachers who teach children aged 6;0 to 7;11 and teachers who teach children aged 8;0 to 9;11. The first age group (6;0–7;11) is consistently referred to as the younger group while the second age group (8;0–9;11) is referred to as the older group.

To address the main aim of the study, the following specific aims were formulated for each of the four phases:

(i) Phase 1: To determine and describe those common activities of South African English-speaking children (aged 4;0 to 12;11) that could result in physical pain experiences so as to develop a measuring instrument based on a set of hypothetical physical pain scenarios.

(ii) Phase 2: To develop and pilot test the measuring instrument (HPPS) to elicit pain-related vocabulary, and then to refine the instrument.

(iii) Phase 3: To identify and describe the vocabulary items suggested by the six respondent groups (younger children aged 6;0 to 7;11; older children aged 8;0 to 9;11; parents of younger children aged 6;0 to 7;11; parents of older children aged 8;0 to 9;11; and teachers who teach younger children aged 6;0 to 7;11 and older children aged 8;0 to 9;11) as those words and/phrases that typically developing children aged 6;0 to 9;11 would use to describe physical pain and/or pain-related experiences.

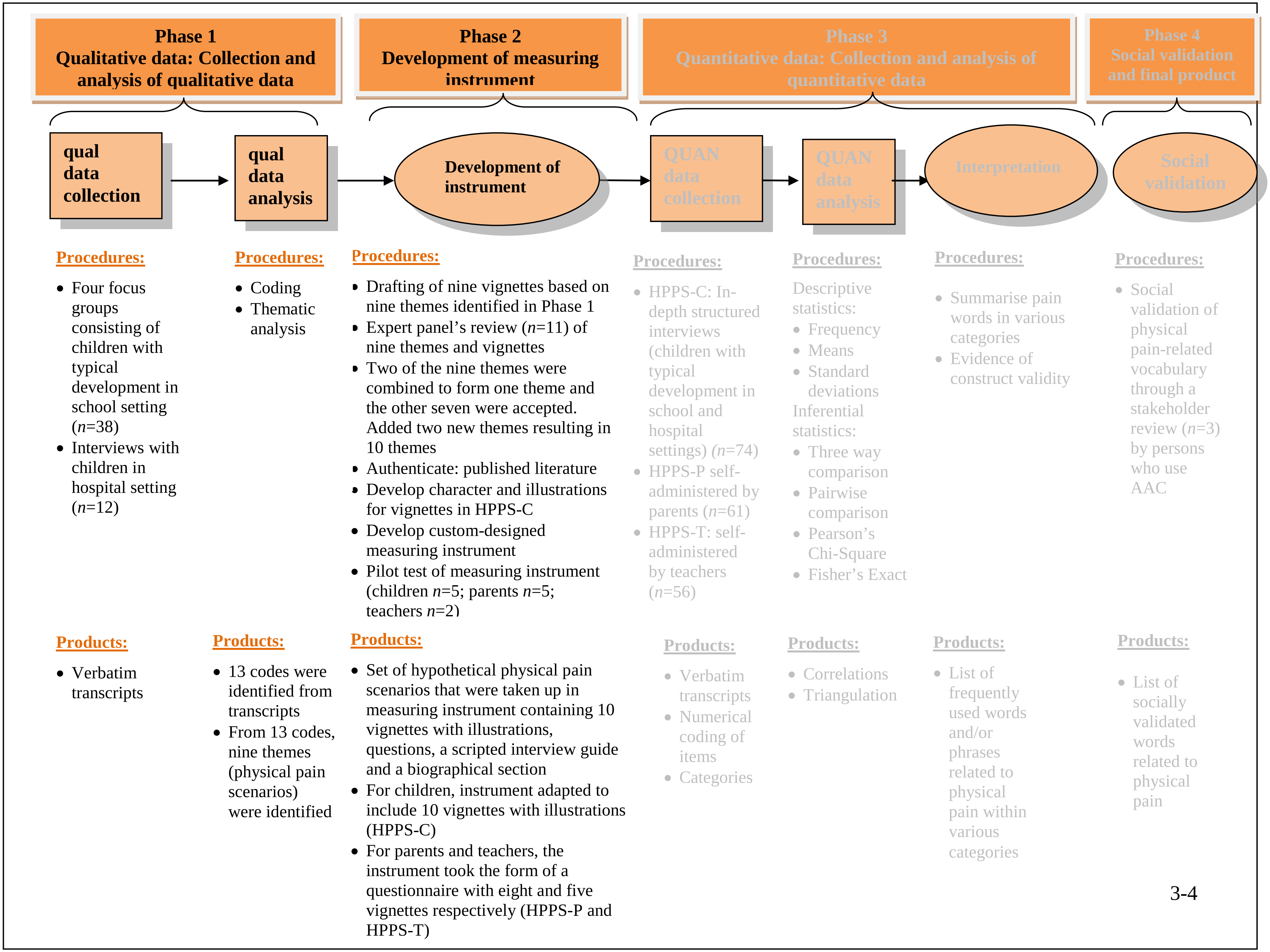
(iv) Phase 4: To determine by means of a stakeholder review of literate adults who use AAC, if the compiled list of pain-related vocabulary (words and/or phrases) would be appropriate for use in scenarios that result in physical pain in order to socially validate the composite list of pain-related vocabulary (words and/or phrases).

3.3 Research design

A sequential exploratory mixed method design (Creswell, 2014) was used to address the main aim of the research. The focus of this design is to investigate the phenomenon (children's pain experiences) qualitatively in an attempt to develop a measuring instrument (a set of hypothetical physical pain scenarios) that can be utilised to gather quantitative data on the given phenomenon (Creswell, 2014). This design was useful in the current study to generalise, evaluate and test the exploratory qualitative results and confirm if they could be generalised to a sample and population (Creswell & Plano Clark, 2011).

The strengths of this design were that during each phase, only one type of data was collected, making it easy to explain, implement, report and produce components of the new measuring instrument as a product of the research process (Creswell & Zhang, 2009). A challenge in the implementation of the exploratory design was that it was time consuming to develop the measuring instrument that involved a set of hypothetical physical pain scenarios (Creswell & Plano Clark, 2011). Previously, two studies used hypothetical pain scenarios with illustrations to evaluate children's ability to self-report on pain scales, namely the Pediatric Pain Inventory (PPI) (Lollar et al., 1982) and the Charleston Pediatric Pain Pictures (CPPP) (Belter et al., 1988). Due to the fact that both these sets were developed in the United States approximately thirty years ago, and since the method through which the scenarios were developed did not adhere to a rigorous scientific process, it was important to develop an instrument relevant for the contemporary South African context. Therefore, children were involved in sharing their physical pain experiences throughout this study to ensure that a child perspective was obtained (Nilsson et al., 2013). The researcher could afterwards extrapolate qualitative themes and codes from the qualitative phase, which were used as the basis for the development of the quantitative measuring instrument (Creswell & Plano Clark, 2011).

Figure 3.1 illustrates the flow of the sequential exploratory design used in this study. During Phase 1, qualitative data was collected and analysed. Based on this data, the measuring instrument was developed in Phase 2. During Phase 3, quantitative data was collected using the newly developed measuring instrument (Creswell & Plano Clark, 2011) and Phase 4 involved the social validation process. Although this chapter focuses on the qualitative phases (Phases 1 and 2), Figure 3.1 also shows Phase 3 (Quantitative phase) and Phase 4 (Social validation) in order to provide a comprehensive overview.



Phase 1
Qualitative data: Collection and analysis of qualitative data

qual data collection

Procedures:

- Four focus groups consisting of children with typical development in school setting (*n*=38)
- Interviews with children in hospital setting (*n*=12)

Products:

- Verbatim transcripts

qual data analysis

Procedures:

- Coding
- Thematic analysis

Products:

- 13 codes were identified from transcripts
- From 13 codes, nine themes (physical pain scenarios) were identified

Phase 2
Development of measuring instrument

Development of instrument

Procedures:

- Drafting of nine vignettes based on nine themes identified in Phase 1
- Expert panel's review (*n*=11) of nine themes and vignettes
- Two of the nine themes were combined to form one theme and the other seven were accepted. Added two new themes resulting in 10 themes
- Authenticate: published literature
- Develop character and illustrations for vignettes in HPPS-C
- Develop custom-designed measuring instrument
- Pilot test of measuring instrument (children *n*=5; parents *n*=5; teachers *n*=2)

Products:

- Set of hypothetical physical pain scenarios that were taken up in measuring instrument containing 10 vignettes with illustrations, questions, a scripted interview guide and a biographical section
- For children, instrument adapted to include 10 vignettes with illustrations (HPPS-C)
- For parents and teachers, the instrument took the form of a questionnaire with eight and five vignettes respectively (HPPS-P and HPPS-T)

Phase 3
Quantitative data: Collection and analysis of quantitative data

QUAN data collection

Procedures:

- HPPS-C: In-depth structured interviews (children with typical development in school and hospital settings) (*n*=74)
- HPPS-P self-administered by parents (*n*=61)
- HPPS-T: self-administered by teachers (*n*=56)

Products:

- Verbatim transcripts
- Numerical coding of items
- Categories

QUAN data analysis

Procedures:

Descriptive statistics:

- Frequency
- Means
- Standard deviations

Inferential statistics:

- Three way comparison
- Pairwise comparison
- Pearson's Chi-Square
- Fisher's Exact

Products:

- Correlations
- Triangulation

Interpretation

Procedures:

- Summarise pain words in various categories
- Evidence of construct validity

Products:

- List of frequently used words and/or phrases related to physical pain within various categories

Phase 4
Social validation and final product

Social validation

Procedures:

- Social validation of physical pain-related vocabulary through a stakeholder review (*n*=3) by persons who use AAC

Products:

- List of socially validated words related to physical pain

Figure 3.1. The flow and phases of the sequential exploratory design used in this study.

3.4 Research Phases

From Figure 3.1 it is clear that the sequential exploratory design as articulated in the present study comprises four phases, namely (a) collection and analysis of the qualitative data (Phase 1); (b) development and pilot testing of the measuring instrument (Phase 2); (c) use of the outcomes of the first two phases to explore the phenomenon quantitatively (Creswell, 2014) and compilation of a list of pain-related vocabulary by means of which children who would benefit from AAC may communicate about their pain (Phase 3); and (d) social validation (by means of a stakeholder review of the proposed vocabulary list) by stakeholders from the specific population for whom it is intended (individuals who use AAC) (Kildea et al., 2011; Schlosser, 1999). The remainder of Chapter 3 will focus on Phases 1 and 2.

3.5 Phase 1

Phase 1 is described in terms of the aims; steps; participant selection and descriptive criteria; material and equipment used; data collection procedures; trustworthiness considerations; analysis and results, as well as implications for the next phase.

3.5.1 Aims of Phase 1

The aim of Phase 1 was to determine and describe common activities of South African English-speaking children (aged 4;0 to 12;11) that could result in physical pain experiences so as to develop a measuring instrument based on a set of hypothetical physical pain scenarios.

The following sub-aims were formulated:

(i) To collect drawings made by children of their pain experiences, and to discuss these drawings with the children;

(ii) To identify themes from the children's drawings and discussions by making a thematic analysis.

3.5.2 Steps of Phase 1

Figure 3.2 provides a schematic outline of the steps that were followed during Phase 1.

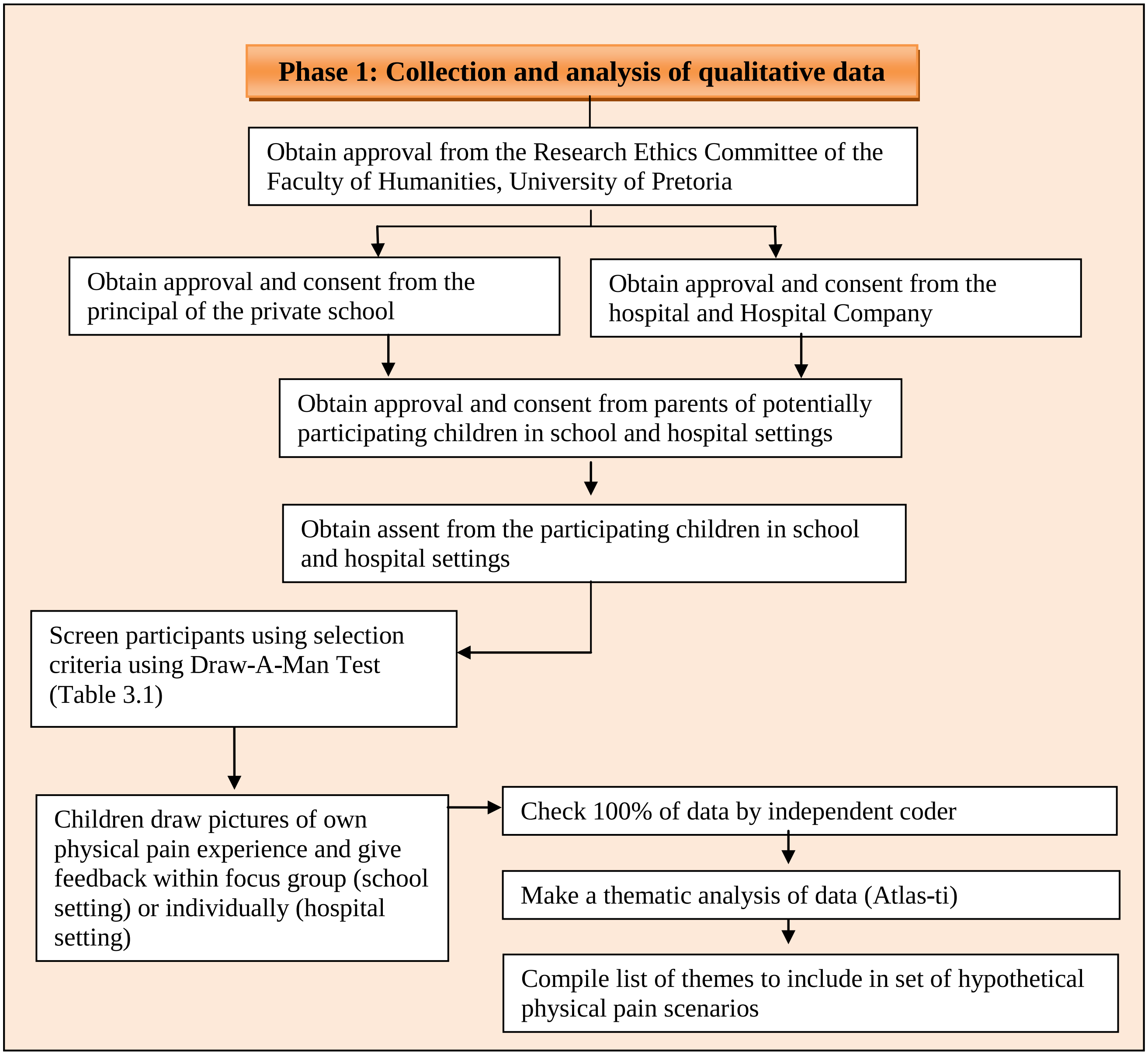


Figure 3.2. Overview of the steps followed in Phase 1.

Figure 3.2 outlines the steps that were included in the collection and analysis of the qualitative data of this study. After ethics approval had been obtained from the relevant authorities, parental consent was sought and provided, and children were requested to assent. The children were subsequently requested to draw pictures of activities they had been involved in that resulted in physical pain experiences and they discussed their drawings in focus groups (school setting) or individually (hospital setting). Verbatim transcriptions were made of all the children's discussions and all transcriptions were checked by an independent person (a qualified teacher with a postgraduate qualification in AAC) who listened to all the audio recordings and compared them for discrepancies with the transcriptions made by the researcher. A thematic analysis was done to compile a list of themes to be included in a set of hypothetical physical pain scenarios.

3.5.3 Participants

3.5.3.1 Selection Criteria

The criteria for the selection of the two different groups of participants in Phase 1, namely children with typical development in a school setting and paediatric patients in a hospital setting, are set out in Table 3.1. This table also provides a brief description of the methods used to ensure that the criterion was met, as well as a justification for each criterion.

Table 3.1

Criteria for Selection of Participants for Phase 1

Criteria	**Method**	**Theoretical justification**
	Children with typical development in a school setting	
Age: Participants had to be between 6;0 and 9;11 years old.	Biographical questionnaire (Appendix B)	Children with typical development aged 6;0 to 9;11 years already have sufficient vocabulary to express pain (Jerrett & Evans, 1986) and tend to use pain-related vocabulary more spontaneously than their older peers (Jerrett & Evans, 1986). Children between 12;0 and 14;11 tend to choose the fewest possible words to describe their pain, possibly because they do not want to be seen as "babies" by their peers (Azize et al., 2013). Therefore, for the purpose of this study, it was decided to include children in the foundation phase (6;0 – 9;11 years old) of government and private independent schools in the Tshwane South area of the Pretoria metropole.
Language: Participants had to be enrolled in a classroom where English is the language of learning and teaching (LoLT).	School records	The main aim of the study was to compile a list of English vocabulary related to physical pain for children who could benefit from AAC. As a result, the whole study was conducted in English and children needed to be able to express their own pain experiences in English. Due to the multi-lingual South African context, children probably had a different first language to their LoLT (Moodley, 2007).
Cognitive functioning:	The Goodenough	Children's cognitive abilities affect how they perceive,

Criteria	Method	Theoretical justification
Participants had to present with typical cognitive functioning.	Draw-A-Man Test (Harris, 1963) was used and interpreted by a trained psychologist.	understand, remember and report pain (Versloot, Veerkamp, & Hoogstraten, 2008). Typical cognitive functioning was interpreted as a cognitive (mental) age of no more than one year below their chronological age.
Paediatric patients in a hospital setting		
Age: Participants had to be between 4;0 and 12;11 years old.	Biographical questionnaire (Appendix B)	Literature indicates that children who were hospitalised had more pain-related vocabulary than peers who had not been hospitalised before (Franck et al., 2010; Jerrett & Evans, 1986; Merskey & Bogduk, 1994). The age range was wider than for children in school settings in order to include as many potential participants as possible, who would be able to contribute to the aim of the study.
Treatment: Participants in paediatric wards who had to overnight at minimum one night. Typically this includes children who were receiving cancer treatment or other medical procedures, such as surgery.	Hospital records	Experience of hospitalisations influences pain-related vocabulary (Franck et al., 2010). In order to ensure that participants were able to provide rich data, children in the cancer ward were also included as they typically have a range of hospital experiences, resulting in a larger vocabulary related to pain.
Language: The participants had to have conversational English skills to discuss the hypothetical physical pain scenarios.	Biographical questionnaire (Appendix B). Parents confirmed their children's ability to converse in English.	In order to maximise the number of potential participants, not only participants whose first language was English were included, but also those who were able to converse in English. This allowed multi-lingual children to participate.
Cognitive functioning: Participants had to present with typical intellectual functioning.	The Goodenough Draw-A-Man Test (Harris, 1963) was used and interpreted by a trained psychologist.	Same as children in the school setting.

Table 3.1 presents a clear outline of the selection criteria employed to obtain child participants in the school and hospital settings. It also justifies the criteria and indicates the methods employed to ensure that they were met.

3.5.3.2 Participant Recruitment

Before recruitment commenced, ethics approval was obtained from the Research Ethics Committee at the Faculty of Humanities, University of Pretoria (Appendix C); the executive head of the independent private school involved in Phase 1 (Appendix D); the chairperson of the

Research Operational Committee of the Hospital Company (Appendix E), as well as the hospital manager of the hospital (Appendix E) where data collection took place.

In order to achieve the main aim of Phase 1, two different participant groups who met the criteria outlined in Table 3.1 were recruited to participate. Thirty-eight 6;0 to 9;11 year-old potential participants were recruited from an independent private school in Tshwane South where English was the language of learning and teaching (LoLT) and a Grade R facility was part of the foundation phase. The executive head of the independent private school was contacted telephonically to request permission to conduct research at the school. This request was followed by a formal letter. The executive head, as well as all the teachers of the foundation phase at the school, consented that data could be collected from children in the foundation phase classes of the school. Thereafter the researcher visited the school to distribute consent letters via the children to their parents and inform them about the study (Appendix F). The parents completed the consent form and returned it to the school within a week. Teachers collected the consent forms. A total of 74 consent letters were sent out, 52 were returned (70% return rate), of who 42 gave consent. Four children were absent on the day of data collection, resulting in 38 participants. Before data collection commenced, all the children were asked to assent using a picture-based assent form (Appendix G).

Next, 12 children between the ages 4;0 and 12;11 years who were hospitalised during the time of data collection were recruited from a private hospital in the same geographical area as the school (Tshwane South). These children were recruited because they were able to mention activities related to pain. The hospital manager was first contacted telephonically and then a follow-up letter requesting permission to conduct research at the hospital was sent to her. She provided a letter of consent on condition that the Research Operational Committee (ethics board) of the hospital company would also approve the study. After a formal letter had been submitted to the Research Operational Committee, the chairperson consented that data may be collected at the hospital and stipulated that identifiable information on both the hospital and Hospital Company should be omitted to ensure confidentiality (Appendix E). Consent was granted by the hospital company before data-collection commenced. The parents were with their children at the hospital and were first asked verbally to indicate interest in the study, after which the aim of the research was explained in detail. Once they confirmed, parents received a parental information letter with a consent form (Appendix H) allowing them to consent in writing. All 12 parents consented but insisted that only audio and no video recordings were made, due to the invasiveness of a video recording in a context where the children were vulnerable. All the children assented on the same picture-based assent form used by the participants in the school setting.

3.5.3.3 *Sample size*

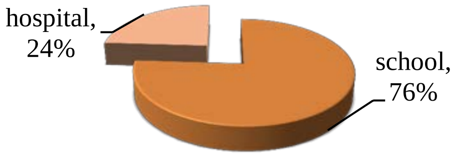
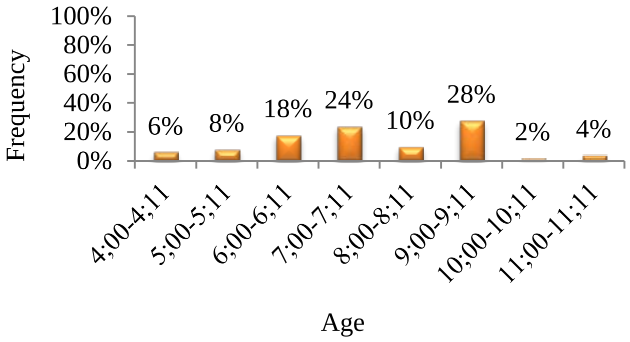
Thirty eight (38) children between 6;0 to 9,11 years of age in the school setting as well as 12 paediatric hospitalised patients between 4;0 to 12;11 years participated in Phase 1, resulting in a total sample size of 50 participants.

3.5.3.4 *Description of the sample*

The boy:girl gender ratio was 1:1.2 with the sample consisting of 23 boys and 27 girls. The child participants are described in Table 3.2 according to their recruitment settings, age, language(s) spoken at home, previous hospitalisation(s) and reason(s) for hospitalisation(s).

Table 3.2

Descriptive Summary Information on all the Child Participants in Phase 1

Description	Results (Total participants)
Recruitment settings (*N*-50) 76% participants in Phase 1 were recruited from the foundation phase of an independent private school and 24% from an independent private hospital in Tshwane South.	
Age (*N=50)* The average age of the participants was 7;4 with a range from 4;6 to 11;7. The younger (<6 years) or older (>9;11) participants were those who were hospitalised.	

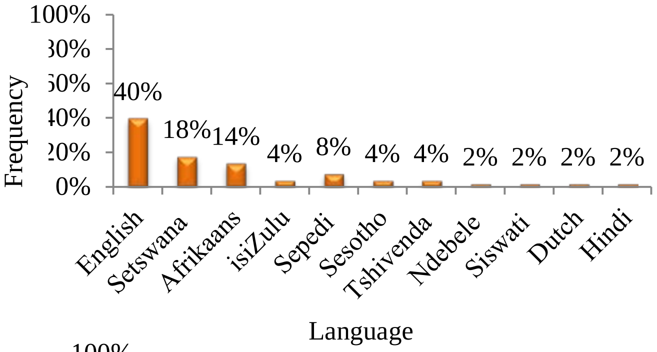
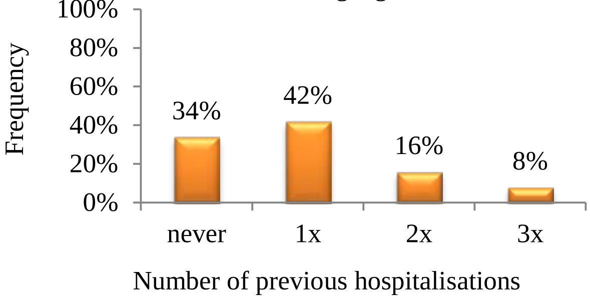
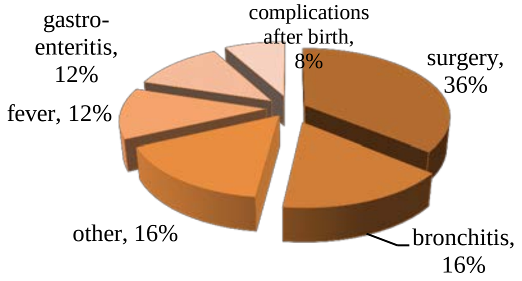
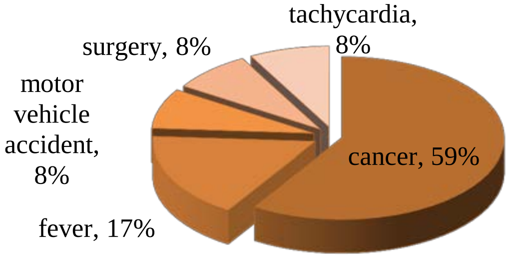
Description	Results (Total participants)
First language (*N*=50) As expected, English was the language most frequently spoken at home (40%). English was the LoLT in the school selected and the nurses mainly communicated in English with the children in the hospital setting. Although not all the participants used English as their first language, all understood and were able to discuss their pictures in English.	
Previous number of hospitalisations (school-based children) (*n*=38) According to the parents, 34% of the school-based children had never been hospitalised, whereas 66% had previous hospitalisations for various treatments as shown. Of the children with previous hospitalisations, 42% had been hospitalised only once, 16% twice and 8% had been admitted to hospital on three occasions.	
Reasons for hospitalisations (*n*=25) (school-based children) Reasons for previous hospitalisations varied from surgery (typically grommets and tonsillectomy) to bronchitis; fever; gastro-enteritis; complications after birth, and other reasons such as stitches, casts, concussion and allergies.	
Reasons for hospitalisations (hospitalised children) (*n*=12) The hospitalised children (*n*=12) received medical treatments for cancer (59%); fever (17%); a motor vehicle accident (8%); surgery (8%), and tachycardia (fast heart rate) (8%) during the time of data collection. 17% of the children (one who had been in a motor vehicle accident, and one with fever) were in hospital for a first time during the time of data collection. All the other children had been hospitalised at least once before.	

Table 3.2 shows that three quarters of the participants were children in a school setting while one quarter came from a hospital setting. The reasons for previous or current hospitalisations of the two groups of children varied, as did the number of previous hospitalisations. The average age of the participants was 7;4. Although only 40% of the

participants had English as their first language, they were all able to communicate and discuss their pictures in English. Their LoLT was English (participants from school setting) or their parents confirmed their conversational English skills (participants from hospital setting).

3.5.4 Material and equipment used during Phase 1

The following material and equipment were used during Phase 1:

3.5.4.1 Assent and consent forms

Each potential participant received a letter of consent that contained information about the study as well as a tear-off slip (Appendix F) to take home to their parents. Parents who agreed that their children could participate completed and returned the consent form to the classroom teacher. After consent had been obtained from their parents, children confirmed their willingness to participate by answering the questions on a symbol-based assent form (Appendix G).

3.5.4.2 Biographical questionnaire

A biographical questionnaire was developed to obtain background information from the parents of the children who participated in Phase 1 (Appendix B).

Seeing that children’s previous pain experiences influence their pain vocabulary (Franck et al., 2010), parents were asked about their children’s previous hospitalisations and/or exposure to activities that could have resulted in pain experiences. The focus was on physical pain and not on emotional pain (e.g. divorce).

Parents stimulate children’s language development and play an important part in the development of children’s pain vocabulary (Franck et al., 2010). If parents tell their child to “calm down” or “stop crying”, they may inhibit their child from learning to express pain during later pain experiences (Briggs, 2010). It was therefore important to obtain biographical information from parents because parental characteristics such as age, first language and qualifications may significantly influence the development of children’s pain vocabulary.

Table 3.3 reflects the compilation of the biographical questionnaire, featuring the question number, aspect, type of question, reason for inclusion and theoretical justification.

Table 3.3

Development of a Biographical Questionnaire to be Completed by Parents

Question number	**Aspect**	**Type of question**	**Reason for inclusion**	**Theoretical justification**
Section A1: Background information of the person completing the questionnaire				
1	Relation to the child	Multiple-choice question	To verify the relation to the child – mother, father or legal guardian.	The questionnaire needed to be completed by someone who knew the child well in order to comment on his/her pain experience.
2	Age	Open-ended question	To determine the age of the parent.	The parents’ age may influence the way in which they respond to children in pain. Younger parents may use different pain words compared to older parents (Turck et al., 1987).
3	Relationship status	Multiple-choice question	To determine if the child is raised by both parents or only by one.	Different stressors are involved in families with both or single parents and may influence parents’ reactions to their children’s pain experiences (Turck et al., 1987).
4	Nationality	Multiple-choice question	To determine the nationality of the parents.	Language and culture influence the use of pain-related words since upbringing is unique and the way one expresses pain is individual (Azize et al., 2013; Briggs, 2010).
5,6	First language and other languages spoken by parent	Multiple choice question	To determine the languages the parent speaks.	One of the selection requirements for this study was that participants should be able to converse in English.
7	Highest qualification	Open-ended question	To determine the level of the parent’s education.	A parent’s qualification influences the type of vocabulary he/she uses when their children are in pain (Hoff, 2003; Rowe, 2008)
8	Occupation	Open-ended question	To determine the current occupation of the parent.	Stress about finances (economic status of family) influences parents’ reaction to and coping with their children’s pain experiences (Turck et al., 1987).
9	Employment status	Multiple-choice question	To determine the socio-economic status	Increased stressors are imposed on parents when they have to take leave to care for a sick child at home (Turck et al., 1987) or if they do not have a medical aid to pay for the medical bills. Without a medical aid, high medical bills could place a financial burden and further stress on the family.
10	Income	Multiple-choice question	To determine the socio-economic status	

Question number	Aspect	Type of question	Reason for inclusion	Theoretical justification
11	Number and age of other children	Open-ended question	To determine if the child has older or younger siblings.	Presence of older siblings may influence pain-related vocabulary development (Craig, 2006; Franck et al., 2010).
Section A2: Background information of the child who will participate in this study				
12	Birthday	Open-ended question	To confirm age of child participant	Child's age influences vocabulary use (Franck et al., 2010; Versloot et al., 2008).
13	Gender	Multiple-choice question	To confirm gender of child participant	Girls have a larger pain vocabulary compared to boys (Azize et al., 2013; Jerrett & Evans, 1986).
14, 15	First language and other languages spoken by child	Multiple-choice question	To determine the first language(s) of the child participant as well as other languages he/she may be able to speak.	Children in South Africa often grow up in multi-lingual households. This may result in one language influencing the vocabulary of the other leading to words of the one language being used in the other language (code switching) (Moodley, 2007).
16	Birth order	Multiple-choice question	To determine if the participant has siblings and if they are older or younger than the participant.	Children with older siblings have a larger pain-related vocabulary than their peers without older siblings (Franck et al., 2010). This also confirmed the information obtained in Question 11.
17,18	Previous hospitalisation(s) of child participant and reasons	Multiple-choice and open-ended question	To determine if the child had previously been hospitalised.	Previous pain experiences such as previous hospitalisations influence pain-related vocabulary (Savedra et al., 1982).
19,20	Previous hospitalisations of siblings and reasons	Multiple-choice and open-ended question	To determine if the siblings had previously been hospitalised.	Pain-related vocabulary is influenced by older siblings' previous pain experiences and hospitalisations (Jerrett & Evans, 1986; Von Baeyer et al., 1998).
21	Extra mural activities and number of hours per week	Open-ended question	To determine potential risks for injuries	Physical activities, such as cricket, soccer and netball can pose potential injury to children (Fearon et al., 1996).

Table 3.3 justifies the inclusion of questions about the biographical information on parents as well as the children included in Phase 1. The biographical questionnaire was completed by parents in 10 minutes.

3.5.4.3 Goodenough Draw-A-Man Test

All the children who assented to participate in the study performed the Goodenough Draw-A-Man Test (Harris, 1963). This was interpreted by a psychologist registered with the Health Professions Council of South Africa (HPCSA), who was trained to interpret the test to determine the cognitive functioning of the child. A prerequisite for inclusion (Table 3.1) was that chronological age and cognitive age should not vary with more than a year. All participants met this criterion.

3.5.4.4 MONAMI Crayons, unruled paper

All participants received unruled A4 paper as well as a full set of MONAMI crayons to draw a personal physically painful experience. The children were allowed to add additional comments (and speech bubbles) to their drawings to describe their picture more clearly. They discussed their drawings afterwards in the focus groups (children in school settings) and individually (children in hospital settings) to provide background about their specific pain experience(s).

3.5.4.5 Recording equipment

A small video camera (Panasonic HC-V100) with tripod was used during the four focus groups with children in the school setting. An iPad was used to audio record the interviews with the children in the hospital setting. Recordings were only made if both the parent and child approved it. Two children in the school settings did not give permission to be recorded.

3.5.5 Data collection procedures

3.5.5.1 Ethical considerations

Approval for the study was obtained from the relevant authorities. Once permission had been granted, parents were approached.

Studying children's pain, which includes their vocabulary related to pain, is regarded as a difficult research procedure due to the ethical challenges related to informed consent, (i.e. voluntary participation, protection from harm, and privacy considerations) (Kortesluoma, Nikkonen, & Serlo, 2008). In Phase 1, each potential participant received a letter of consent with a tear-off slip (Appendix F) to take home for their parents to complete and return to school. After their parents' consent had been received, children confirmed their willingness to participate by answering the questions on a picture-based assent form (Appendix G). They were assisted by researcher who used the Talking Mats™ procedure (Cameron & Murphy, 2002). Talking Mats™ is a visual framework consisting of a textured mat or a piece of carpet of approximately 60cm x 30cm, on which graphic symbols can be displayed (Murphy, Tester, Hubbard, Downs, & MacDonald, 2005). In the present study a 3-point visual scale (e.g. yes, unsure, no) was used, and the participants had to indicate their choice on the visual scale, e.g. a symbol showing a video camera. For example, the child was asked "Will you allow me to video-record you?" and was expected to respond by placing the graphic symbol under the selected choice on the visual scale, e.g. yes/unsure/no. Parents were assured that the children would be protected from harm, and if this activity triggered any potential negative memories, the parents would be informed and the child would be referred for support. Privacy of the participants was ensured during the focus groups, as only the drawings were video-recorded and not the faces of the children to ensure that no identifiable information was captured during the recording process. No video recordings were made in the hospital setting, only audio recordings.

3.5.5.2 Settings

All focus groups and individual interviews involving the child participants were conducted at the schools or hospitals the participants attended. The independent private school and the hospital were situated in the same geographical area, Tshwane South. The four focus groups were conducted inside an empty classroom. The children were seated on a carpet on the floor when drawing and discussing their pictures. The individual interviews with the children in the hospital settings took place in the private paediatric wards where the children were admitted. These children were seated on their hospital beds during the interviews. Both settings were quiet to ensure that the children could concentrate during the procedures.

3.5.5.3 Procedures

The focus groups were organised according to the children's ages (6;0-6;11; 7;0-7;11; 8;0-8;11 and 9;0-9;11) since research shows that focus groups are suitable techniques for children of the same age (Mauthner, 1997). After written consent was received from each potential participant's parents, the researcher met the participants for each focus group at their classroom and escorted them to the empty classroom where the focus group discussions took place. First the child assent procedure was conducted and children completed the picture-based assent form. The researcher displayed larger versions of the assent form symbols (on laminated A4 sheets) on the black board as each aspect was addressed using the Talking Mats™ procedure (Cameron & Murphy, 2002). The children then drew pictures of their pain-related experiences. The use of drawings was a fun activity that helped the children not only to become better acquainted with the adult researcher (Punch, 2002), but also to visualise the scenarios that had caused them physical pain in the past and talk about the specific incidence that had caused them physical pain (Punch, 2002). Next they formed a circle to discuss their drawings within the groups. Specific questions were asked to elicit discussions: "What did you draw?" "Why did you choose to draw this picture?" "What happened?" If more clarification was needed, the researcher asked "Would you like to tell me more?" Each child was given the opportunity to talk about his/her picture and other participants were afterwards allowed to comment on their peer's pain experience. The drawing technique provided the children with a concrete focus whilst discussing the abstract topic of pain (Mauthner, 1997). These discussions were video-recorded (school setting, except for two children who did not agree to be recorded) or audio-recorded (hospital setting).

3.5.6 Trustworthiness considerations

Table 3.4 discusses specific techniques that were used to increase the trustworthiness of this research. Furthermore, reference is made to the link between qualitative and quantitative terms.

Table 3.4

*Increasing the Trustworthiness of the Qualitative Phase of this Research**

Strategy	Technique	How technique was addressed in present research
Credibility (in preference to internal validity) How similar are the findings to reality?	Member checking and confirming results with participants	First the children confirmed the different pain experiences as discussed in the focus groups discussion (member checking). Thereafter, the expert panel confirmed that the identified themes were a true reflection of the children's suggestions and that they could be included in the vignettes of the set of hypothetical physical pain scenarios – hence confirming the accuracy of the qualitative findings.
Transferability (in preference to external validity/generalisability) How applicable or useful are findings with regard to theory, practice and future use in various contexts or with other respondents?	Selection of information about the phenomena by stakeholders and an expert panel	The researcher attempted not to work in isolation, and frequently throughout the research project had meetings with experts in nursing, teaching and AAC fields, as well as children. For example, experts helped to confirm the themes identified from the data obtained during the focus group discussions; children confirmed the themes, and the research assistant, who was a qualified teacher with specialised training in AAC, assisted with the checking of transcriptions and the data analysis.
	Use of multiple cases or groups	Four focus groups in school settings as well as 12 individual interviews in hospital settings were used to guarantee rich descriptive data and to enhance the transferability of the data. Results from these sources were compared with one another as well as with the feedback from the expert panel and used to develop the measuring instruments.
	Ensure representativeness of participants	The background and biographical information of the participants for the child focus groups and expert panel was obtained by means of short questionnaires.
Dependability (in preference to reliability) How consistent are the results? Can the research be repeated?	Indirect method Look at the internal and external validity measurements	The above discussion on credibility and transferability is important for this section, as Lincoln and Guba (1985) argue that no validity is possible without reliability (and thus no credibility without dependability). A demonstration of the former is sufficient to establish the latter. The measurement instruments were piloted to determine if pain-related vocabulary had been elicited. The fact that the vignettes were developed from a child perspective ensured that the children could relate with the scenarios.
	Direct method Stepwise replication	In qualitative research, the researcher always aims to provide a "thick" or "rich" description of the context. Rigour was applied in describing the context, and how data was obtained, analysed (i.e. thematic analysis) and interpreted. The methodology should be explicit enough for an independent researcher to repeat.
Auditability (in preference to reliability) To what degree are research procedures	Use of peer debriefing	Throughout the research, the researcher involved peers (doctoral students) to review, interpret and ask questions about the qualitative phase of the study, thereby ensuring that the researcher addressed the research aim.

Strategy	Technique	How technique was addressed in present research
documented? Can someone outside the project follow and critique the research process?	Inter-rater reliability of coders	Verbatim transcriptions were made of all recordings (Poland, 1995). In order to improve the trustworthiness of the data, the reliability of the transcriptions was checked by an independent person (a qualified teacher with a postgraduate qualification in AAC). She listened to all the audio recordings, compared them to the transcriptions done by the researcher, and recorded all disagreements (Heilmann et al., 2008). The scoring was done as follows: If the transcription section was done 100% correct along with the audio recording, a score of 1 was given. If the transcription omitted words from the audio recording, or added words not present in the recording, a nil (0) score was given. For the purpose of the scoring process, the transcriptions were divided into the 50 individual responses obtained from the 50 participants (38 in the focus groups and 12 individual interviews). The percentage of agreement reflected the sum of agreements (a score of 1=100% correct transcription) divided by the total number of possible scores (50) available multiplied by 100. The independent person agreed that 46 of the 50 scores had been transcribed 100% correct: $\text{Percentage agreement} = \frac{46}{50} \times 100$ $= .92 \times 100 = 92\%$ agreement between the two transcribers The 92% percentage of agreement indicates an acceptable level of reliability (above 85%) of the transcriptions (Heilmann et al., 2008). Thereafter, the researcher worked together with the second coder and identified themes by consensus. In Phase 2, these themes were used to develop the vignettes for the set of hypothetical physical pain scenarios – with the assistance of an expert panel.
Confirmability (in preference to objectivity) How neutral is the research? Known as objectivity in qualitative research.	Use an external auditor to review the complete project (Creswell, 2014)	An independent knowledgeable researcher with experience in the field of qualitative research was asked to evaluate the degree to which the research process, including the raw data, data reduction and analysis products (transcriptions), data reconstruction (thematic categories), findings, interpretations and recommendations adhere to acceptable research practice. This researcher (the auditor) remained completely neutral to the research. It should be emphasised that neutrality was not seen as a way to avoid "contamination". Rather the researcher's characteristics, attitudes and feelings were recognised as influencing the research and hence made explicit.

*Conseptualised from Creswell (2014); Graneheim and Lundman (2004); Guba and Lincoln (1994); Lietz and Zayas (2010); Krefting (1991), and Shenton (2004).

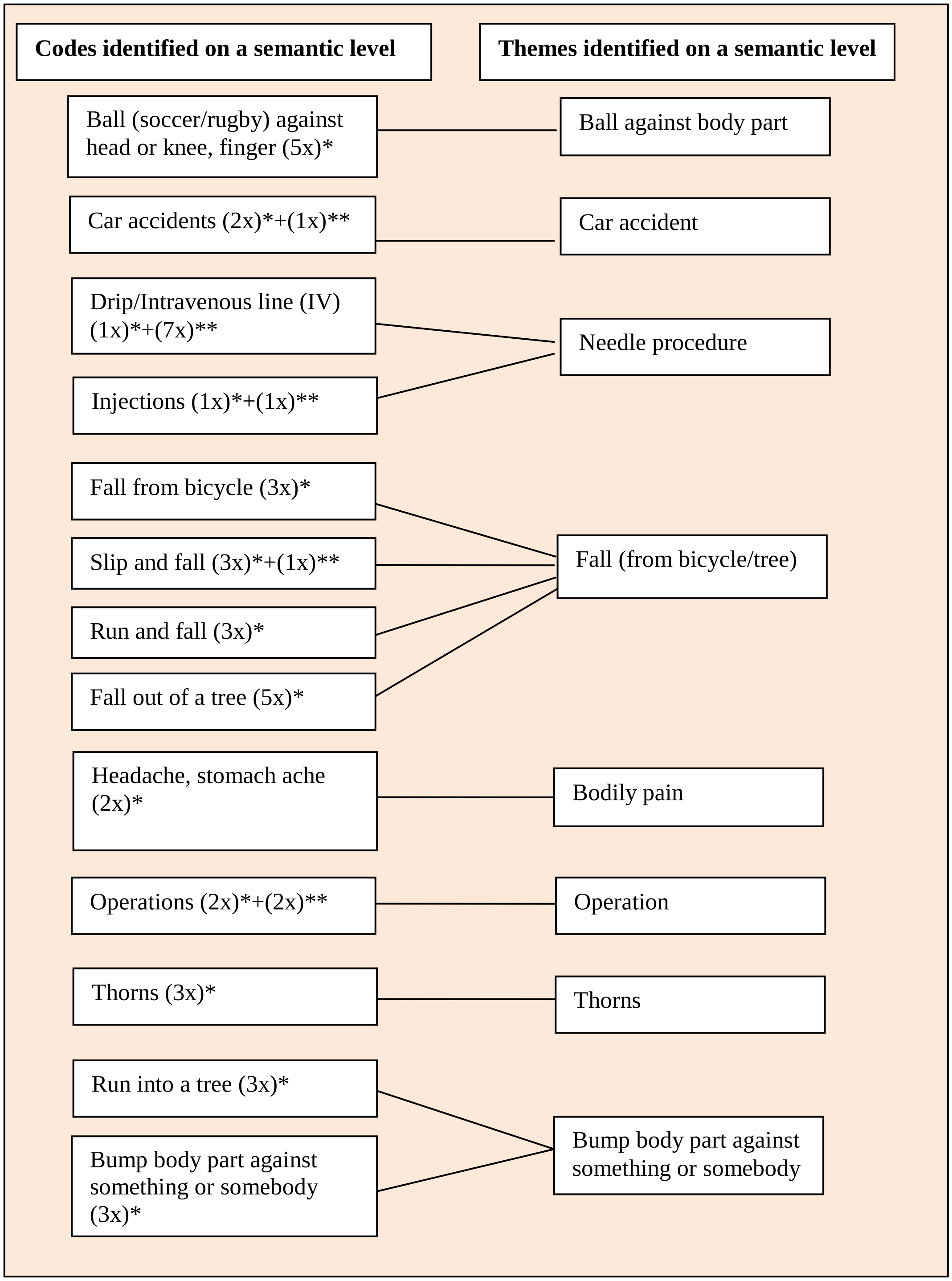
From Table 3.4 it is clear that various techniques were employed to enhance the trustworthiness of the qualitative phase of this study.

3.5.7 Data analysis

Verbatim transcriptions (Poland, 1995) were made of the recordings of the participant’s discussions of their pain experiences. These transcriptions were analysed using a thematic analysis (Braun & Clarke, 2006). The children’s drawings were not analysed and they merely served to help the children focus on the topic and recall their painful experiences during their discussions (Mauthner, 1997). Thematic analysis is an explanatory process whereby systematic data analysis is conducted to identify patterns (themes) in the data and provide an informative description of the phenomenon of children’s pain experiences (Braun & Clarke, 2006; Smith & Firth, 2011). The themes captured significant information, symbolised by some level of patterned response or meaning, within the data set in relation to the children’s pain experiences. The coding was done based on the prevalence of the themed pattern in the data set. Prevalence was determined in terms of the number of responses across the entire data set. Codes identified semantic content that provided information about the children’s pain experiences. The process of coding helped to organise the data into meaningful groups (Braun & Clarke, 2006), thereby enabling the researcher to analyse the data and determine the themes prevalent in the data set. Themed patterns repeated more than twice by different child participants during the focus group discussions or individual interviews were considered.

The themes or patterns relating to pain-eliciting scenarios in the data set were identified in an inductive way implying that the themes were strongly linked to the data. The thematic analysis was therefore data driven and the researcher did not attempt to fit the themes into a pre-existing coding frame (Braun & Clarke, 2006). Furthermore, the themes were identified on a semantic level, which implies that the themes could be identified directly from what the children said and no deeper meaning had to be looked for.

Consensus coding was used to identify the codes and themes related to pain-eliciting scenarios from the data provided by the children. The requirement for inclusion of a code was that it had to be mentioned twice or more by participants. Fifteen codes were identified within the semantic context. Two codes occurred only once, namely “cut foot open” and “somebody pushed me (child)”, and were thus excluded. The thirteen remaining codes that featured at least twice are depicted in Figure 3.3.



*Frequency (provided by child in school setting)
** Frequency (provided by child in hospital setting)

Figure 3.3. Codes and themes identified during thematic analysis.

From the thematic analysis as displayed in Figure 3.3, it is clear that five codes identified in the data retrieved from the children in hospital settings, resonated with the data of the children in school settings, namely “accidents”, “drip/intravenous line (IV)”, “injections”, “operations”, and “bodily pain”. In the discussion with the children in the hospital settings, they also referred to the IV as a “needle” while simultaneously pointing to the place where the IV was inserted in the arm or other body part. It was therefore decided to combine the IV and injection codes into one theme, namely “needle procedure”, as this was the pain experience that was mentioned most frequently (eight times in total) by both groups of children. Furthermore, four codes were included in the theme “falls”. “Fall out of a tree” was mentioned most frequently, followed by “slip and fall”; “fall from bicycle”, and “run and fall”.

3.5.8 Implications for next phase

The themes identified in Phase 1 were used to compile a measuring instrument (HPPS) in the next phase (Phase 2). The themes were used in all three versions of the measuring instrument (with some variance for the six respondent groups). Vignettes were written for each suggested theme (scenario) and a graphic artist developed illustrations to accompany each vignette.

3.6 Phase 2

Phase 2 comprises the aims; steps; authentication of the HPPS (i.e. participant selection and description; HPPS); material and equipment used; pilot study (i.e. aims, participant selection, description and recruitment; results and recommendations), as well as implications for the next phase.

3.6.1 Aims of Phase 2

The aim of Phase 2 was to develop and pilot test the measuring instrument (HPPS) to elicit pain-related vocabulary from the proposed six respondent and then to refine the instrument.

The following five sub-aims were formulated for Phase 2:

(i) To develop a set of hypothetical scenarios related to physical pain that are appropriate for South African children and to illustrate these scenarios by means of vignettes that would establish a measuring instrument to elicit pain-related vocabulary;

(ii) To validate the type and range of the hypothetical physical pain scenarios (HPPS) with the help of an expert panel and to judge their suggestions against published literature;

(iii) To develop and select a suitable character (appearance and name) for the vignettes;

(iv) To develop a measuring instrument (based on the vignettes) aimed at eliciting pain-related vocabulary from children, parents and teachers;

(v) To pilot test and refine both the measuring instrument and the method for data collection.

3.6.2 Steps in Phase 2

Phase 2 involved various steps. A brief overview is given in Figure 3.4.

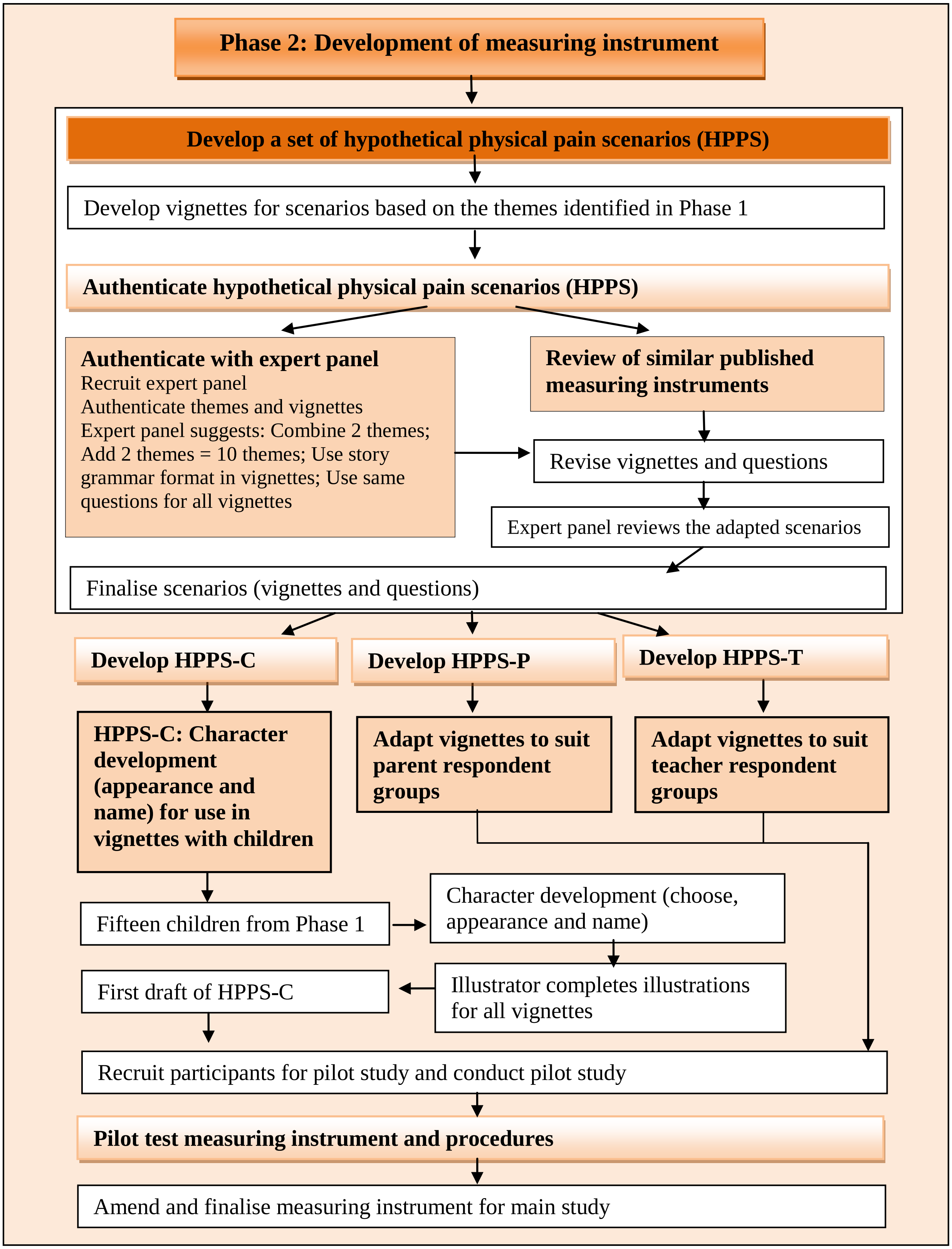


Figure 3.4. Overview of the steps followed in Phase 2.

3.6.3 Development of a set of hypothetical physical pain scenarios (HPPS)

Vignettes were developed and authenticated by an expert panel and published literature. Once the changes as suggested by the expert panel had been made to the vignettes, the latter were reviewed and confirmed.

3.6.3.1 Development of vignettes for scenarios

Vignettes were written based on the nine themes identified in Phase 1. These vignettes were a selection of some of the children's discussions about their pain experiences. Questions were added to all the vignettes to elicit pain-related vocabulary. The expert panel validated the vignettes and made suggestions for improvement.

3.6.3.2 Authentication of the HPPS

First the HPPS based on the themes identified in Phase 1, were validated by an expert panel to ensure the comprehensiveness of the scenarios for the South African context. This was done online on SurveyMonkey®. (Please see Table 3.9 for the example of the vignettes.) The outcome of the expert panel's findings was subsequently further authenticated against published literature on similar measuring instruments.

3.6.3.2.1 Recruitment of expert panel

In order to achieve the first two sub-aims of Phase 2, 11 experts in the field of childhood disability who worked in the geographical area where the study was conducted, were purposively selected and recruited to be part of the expert panel. The participants were contacted via email and provided with information about the research (Appendix I) (McMillan & Schumacher, 2001). Once they consented to participate, an invitation with a link to the online survey software was sent to them so that they could complete and submit their answers to the questions electronically (SurveyMonkey, 2014).

3.6.3.2.2 Selection criteria

Participants were selected based on their specific areas of expertise. The criteria for the selection of the expert panel are set out in Table 3.5. The table also provides a brief description of the initial screening method as well as a theoretical justification for each criterion.

Table 3.5

Selection Criteria for the Expert Panel

Criteria	Method	Theoretical justification
Professional registration: Healthcare professionals (such as speech language therapists, occupational therapists, medical doctors) must be registered with the HPCSA, nurses with the South African Nursing Council (SANC), social workers with the South African Council for Social Service Professions (SACSSP) and teachers with the South African Council for Educators (SACE)	Biographical questionnaire (Appendix J)	Be registered with the HPCSA; SANC; SACSSP, or SACE confirms that they are active (not retired) professionals, and that they have the required qualifications (HPCSA, 2013; SACE, 2011).
Experience of working with children: Must work with children on a daily basis	Biographical questionnaire (Appendix J)	Active healthcare professionals and teachers who work with children on a daily basis will have knowledge of daily painful experiences and scenarios that children may encounter (Davoudi, Afsharzadeh, Mohammadalizadeh, & Haghdoost, 2008; Herr et al., 2006).
Language: Must be competent in both spoken and written English	Self-report	Panel members should be able to read and understand English to give input on the hypothetical physical pain scenarios

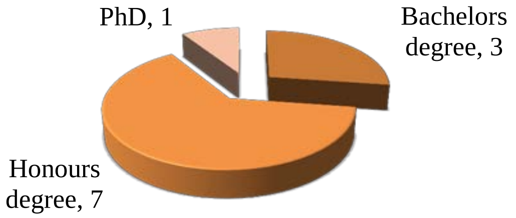
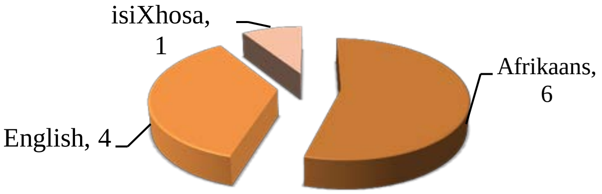
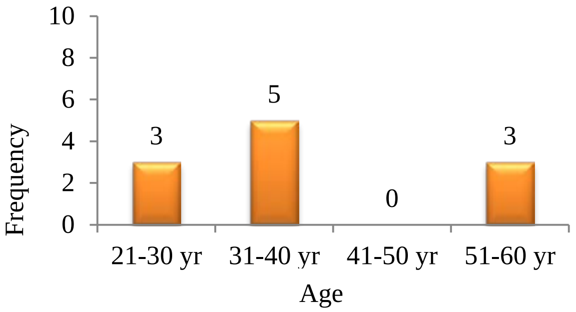
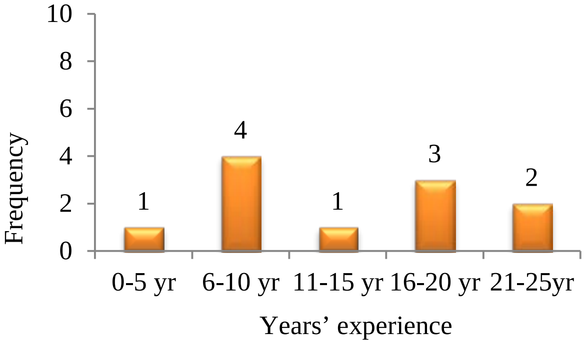
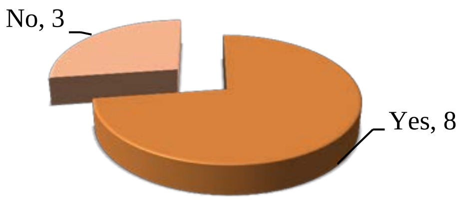
From Table 3.5, it is clear that the expert panel participants should be healthcare or educational professionals who work with children on a daily basis.

3.6.3.2.3 Participant description

Eleven female professionals (five teachers, two occupational therapists and one speech language pathologist, doctor, nurse and medical social worker), formed the expert panel. Table 3.6 describes the panel members in terms of their qualification, first language, age, years of experience of working with children, as well as experience of working with children with significant communication difficulties.

Table 3.6

Description of Expert Panel

Description	Results (*N* = 11)
Qualification Three participants had Bachelor's degrees as their highest qualification, while eight had post graduate qualifications in AAC, which included seven honours degrees and one PhD.	
First language Although the first language of the expert panel varied, they all used English as their professional language for communication with children and colleagues.	
Age The ages of the participants ranged from 27 years to 56 years, with a mean age of 38 years.	
Years' experience of working with children The years of experience of working with children ranged from three years to 25 years with an average 13 years' experience. This correlates with the participants' mean age of 38 years.	
Experience of working with children with significant communication difficulties (temporary or permanent) The eight participants who indicated that they had experience of working with children with significant communication difficulties stated that the communication difficulty was either due to illness or as a result of a disability. These participants explained that they observed the children's body language, interpreted facial expressions, listened to vocalisations and looked for non-verbal gestures, used pictures and faces pain	

Description	**Results (*N* = 11)**
scales, and also listened to the comments (or interpretations) of parents. AAC strategies that they used included picture cards, communication boards, auditory scanning, Picture Exchange Communication System (PECS), Picture Communication Symbols (PCS), writing on paper (older children) and signs.	

From Table 3.6, it is clear that all the members of the expert panel worked with children on a daily basis either in a school or in a medical setting, and had the required qualifications to do so. Their average age was 38 years, and they had an average of 13 years' experience. Eight of the participants indicated that they had experience of working with children with either permanent or temporary significant communication difficulties. Several AAC strategies were implemented to assist these children to communicate.

3.6.3.2.4 Questionnaire for expert panel on SurveyMonkey®

The expert panel completed an electronic questionnaire (Appendix J) supported by SurveyMonkey® to comment on the themes suggested for the hypothetical physical pain scenarios (HPPS) based on the experiences of the children as extrapolated in Phase 1 (SurveyMonkey, 2014). The questionnaire was constructed in two parts – Section A contained questions to obtain biographical information from the participants and Section B asked open-ended questions to comment on the pain scenarios based on the thematic analysis that followed Phase 1.

The first draft of the expert panel questionnaire was presented to an occupational therapist who works in the field of AAC and to a statistician, and they were asked to comment on its structure and conten. Where necessary, amendments were made before capturing the questionnaire and distributing it electronically via SurveyMonkey® to the participants (SurveyMonkey, 2014).

Table 3.7 provides information on the question number, the aspect targeted, type of question, reason for inclusion as well as theoretical justification for the inclusion of questions in the questionnaire. In addition to the questions in the biographical questionnaire discussed earlier (Table 3.3), this questionnaire also asked about the participant's current profession and work setting, gender, professional membership, number of years experience of working with children with and without significant communication difficulties, as well as strategies employed to obtain information from children with significant communication difficulties.

Table 3.7

Development of Questionnaire for the Expert Panel

Question number	**Aspect**	**Type of question**	**Reason for inclusion**	**Theoretical justification**
Section A: Background information of the person completing the questionnaire				
1, 2	Current profession and work setting	Multiple-choice question	To verify the profession and work setting of the participant	Professionals working with children on a daily basis have the experience to judge the hypothetical physical pain scenarios as suggested by the children themselves in Phase 1 (Davoudi et al., 2008; Logan, Coakley, & Scharff, 2007; Zhou et al., 2008).
3	Gender	Two-options question	To determine the participant's gender.	Female professionals often work with children in the age group 6;0 to 9;11 years.
4-7	First language, nationality, age			Refer to Table 3.3.
8	Number of years' experience of working with children	Open-ended question	To determine the extent of the professional's experience.	Professionals' experiences with children allow them to know and understand children's pain experiences (Davoudi et al., 2008; Logan et al., 2007)
9,10	Professional membership and membership number	Multiple-choice question	To determine if the professionals registered to practise their profession	According to SACE and HPCSA, all teachers and healthcare professionals should have an appropriate qualification and be registered with their specific Council to be employed as an educator or practise as a healthcare professional (HPCSA, 2013; SACE, 2011)
11	Employment	Multiple-choice question		
12	Qualification	Open-ended question	To determine the qualification(s) of the participant.	
13	Previous experience of working with children with significant communication difficulties, either due to illness or as a result of a disability	Yes/No option question	To determine if the participant has had previous experience(s) with children who cannot speak.	Professionals who have experience with children with significant communication difficulties can provide examples on how to deal with these children when they experience pain (Herr et al., 2006).
14	How to get information from a child with	Open-ended question	To determine how the participants dealt with children who cannot speak	See above.

Question number	Aspect	Type of question	Reason for inclusion	Theoretical justification
	significant communication difficulties			
Section B: Hypothetical physical pain scenarios				
	Vignettes for Scenarios 1 – 9 (Nine themes identified in Phase 1)	Open-ended questions	To introduce suggested vignettes to participants and ask their comments for improvement.	Experts had to confirm that children can relate to hypothetical scenarios (Azize, 2012) as this is a non-threatening way in which sensitive information can be obtained (Lollar et al., 1982).
	Add/suggest more themes of other activities that could result in pain-related experiences to be included as vignettes	Open-ended questions	To ask panel to expand on and/or delete themes/scenarios.	

All eleven participants in the expert panel completed the questionnaire. The expert panel ensured that the themes, which were identified by means of a thematic analysis in Phase 1 and represented as hypothetical physical pain scenarios were complete and relevant – thereby having a positive impact on their face validity. They made suggestions on the layout of the vignettes and also suggested changes to the vignettes and questions within each scenario, such as to follow a story grammar format for each vignette and to use the same questions after each vignette (See Table 3.9). The necessary changes were made to the set of hypothetical physical pain scenarios, the vignettes and questions as an outcome of the comments made by the expert panel (See Table 3.9). Face validity of the set of hypothetical physical pain scenarios was enhanced by these amendments based on comments on the vignettes and accompanying questions in each scenario.

3.6.3.3 Authentication by expert panel and support from published literature

Table 3.8 presents the themes for the set of hypothetical physical pain scenarios as extrapolated from the thematic analysis of the discussions of participant responses in Phase 1. It also gives the authentication of these themes, as well as additional themes suggested by the expert panel. The themes were furthermore authenticated by comparing them with two other existing measurements, namely the Charleston Pediatric Pain Pictures (CPPP) (Belter et al., 1988) and the Pediatric Pain Inventory (PPI) (Lollar et al., 1982) which include both hypothetical pain scenarios and illustrations to support the scenarios. The latter two measurements were used to determine how the results from the expert panel and thematic analysis compared to literature on existing hypothetical pain scenarios. Because the detail of the content of the CPPP and PPI are not available in the published research domain, the developers of these two hypothetical scenarios were contacted to obtain the original sets of scenarios with illustrations, and both agreed to assist.

Table 3.8

Themes for Vignettes Validated by Supported Literature

Themes extrapolated from Phase 1 data following a thematic analysis	Themes validated by expert panel	Themes in Charleston Pediatric Pain Pictures (CPPP) (Belter et al., 1988)	Themes in Pediatric Pain Inventory (PPI), (Lollar et al., 1982)
-	Add bee sting (suggested by two experts)	Bee sting	Bee sting
-	-	-	Finger in plug
-	-	-	Cut with knife
Thorns	Include	Nail in foot	-
-	-	-	Finger in door
-	Add burn wound (suggested by four experts)	Burn hand on stove plate	Burn hand on stove
Fall (out of tree)	Include	Fall carpet, stairs	Fall out of tree
	-		Bandages on leg
Fall (from bicycle)	Include		Fall from bicycle
-	-		Fall from skateboard
Bumped body part against something or somebody	Omit. Similar to ball against a body part (suggested by three experts)	Bump head against table	-
-	-	-	Remove Band-Aid from arm
-	-	Friend pinches you	-
-	-	Stubbed toe	-
-	-	Bully friend punch you	-
-	-	-	Stitches
Ball against a body part	Include	-	Ball against head (base ball)
Needle procedure	Include	-	IV
(Included in “needle procedure” theme)	-		Injection
Bodily pain	Include	-	-
Car accident	Include	-	-
Operation	Include	-	-

Table 3.8 shows that the expert panel confirmed eight of the nine themes or pain-related scenarios as extrapolated during the thematic analysis in Phase 1. Only one theme, namely “fall

out of a tree" was present in all four sources, whereas the "nail in foot" (in CPPP) featured as "thorns in foot/finger". Thorn injuries are typical in the South African context. The expert panel suggested that "ball against a body part" and "bump against something or somebody" were similar experiences and therefore, recommended that they be combined as a soccer ball against a body part. Two members of the expert panel were of the opinion that bee stings should be included, whereas four members suggested that burn wounds, such as "burn hand on stove" should be included in the vignettes that form part of the set of hypothetical physical pain scenarios. In their experience, many South African children suffered these injuries. Although the expert panel did not see the themes included in the CPPP or in the PPI prior to completing the questionnaire, both the CPPP (Belter et al., 1988) and the PPI (Lollar et al., 1982) included both of these themes. Five scenarios from the current data were also present in the PPI: "Fall out of the tree"; "fall from a bicycle"; "ball against head"; "drip"; "injection". Except for "nail in foot" only one other theme, namely "bump against something" featured in the CPPP. New themes that emerged from the current data and that were not included in either of the other inventories were "bodily pain"; "car accidents" and "operations". It is important to note that only physical pain themes were used and no emotional pain was included in the set of hypothetical physical pain scenarios.

3.6.3.4 Finalise scenarios

Table 3.9 provides a layout of the suggested scenarios, themes and vignettes that emerged from the thematic analysis in Phase 1, the expert panel's comments and suggested changed, as well as the updated changes to the vignettes based on the recommendations from the panel. Since the name of the story character had not yet been finalised at that stage, A in bold type (**A**) refers to the character. Note that the numbers of the scenarios changed from the initial suggestions in Phase 1 to the final measuring instrument in Phase due to the expert panel suggesting that the hospital-related scenarios should not follow one another – therefore the original Scenario 5 became Scenario 6, Scenario 8 became Scenario 5, and; Scenario 9 became Scenario 10.

Table 3.9

Development of the Set of Hypothetical Physical Pain Scenarios (HPPS) with Recommendation by Expert Panel and Updated Scenarios Using Story Grammar Structure for Vignettes

Suggested scenarios, themes and vignettes following the thematic analysis in Phase 1	**Recommendations by professionals in expert panel**	**Updated scenarios using story grammar structure for vignettes**	
		Story grammar structure	**Vignette**
Scenario 1 (*Theme:* Fall out of a tree) ***Vignette:*** It is holiday time. The sun shines brightly and **A** and his/her friend are playing outside in the garden. They are climbing a tree. Suddenly a branch breaks off and **A** falls out of the tree. His/her arm is very sore and he cannot move it. His/her friend runs to call **A**'s mommy. *Tell me what do you think **A** will tell his/her mommy about the pain in his/her arm? What will happen now?* He/she is going to the hospital and the doctor takes X-rays to see if the arm is broken. What do you think the doctor will find? The arm is broken and the doctor puts a cast on the arm and **A** feels much better.	• Explain the terms X-rays and cast to children. There are children who don't know what it is and who will not always ask. • Rephrase term X-ray with: "…picture taken of his arm" • Maybe cut out the "*Tell me what do you think*" and simply say "*What will **A** tell his/her mommy …?*" • Keep the flow of the action and movement clear by removing the question "*What will happen now?*" e.g. Mom takes him/her to the hospital. • Most children will be able to relate to this story.	**Title**	**Scenario 1: Ziggi falls out of a tree**
		Setting (Where and when)	It is holiday time. The sun shines brightly.
		Initiating event	Ziggi and his/her friend play outside in the garden. They climb a tree.
		Problem	Suddenly a branch breaks off. Ziggi falls out of the tree. His/her arm is very sore and swollen. He/she cannot move his/her arm.
		Plan or attempts	Ziggi's mommy comes to help.
		Questions	*What would Ziggi say?* *What would he/she say to his/her mommy?* *What would he/she say or do to feel better?* *What do you think will happen next?*
Scenario 2 (*Theme:* Fall from bicycle) ***Vignette:*** **A** is riding bicycle to the shop to buy some sweets. It is a gravel road. The bicycle skids on some sand, and **A** falls. There is blood all over his/her knees and the palms of his/her hands. *Tell me what do you think **A** will tell his/her mommy about the pain he/she may have. / Tell me more about the pain **A** may feel.*	• Scenario that all children can relate to. • Change gravel road to a dirt road. Some children may not know the term gravel. • *"Tell me more about the pain 'A' may feel."* • The location of the pain is quite important – sometimes after falling off a bicycle there is also internal pain that is not visible.	**Title**	**Scenario 2: Ziggi falls from his/her bicycle**
		Setting (Where and when)	Ziggi rides on his/her bicycle.
		Initiating event	He/she wants to buy some sweets at the shop.
		Problem	A dog runs across the road.
		Plan or attempts	Ziggi wants to brake. He/she pulls the brakes too hard. Ziggi falls.
		Questions	Same as in Scenario 1
Scenario 3 (*Theme:* Car accident) ***Vignette:*** **A** is very excited. It is his/her granny's birthday	• Don't localise the experience of pain, rather say "his whole body hurts". • It is not important that the child should have	**Title**	**Scenario 3: Ziggi is in a car accident**
		Setting (Where and when)	It is his/her granny's birthday. Ziggi is very excited.

Suggested scenarios, themes and vignettes following the thematic analysis in Phase 1	**Recommendations by professionals in expert panel**	**Updated scenarios using story grammar structure for vignettes**	
		Story grammar structure	**Vignette**
and the family on their way to her birthday party. Suddenly a car skips the robot and crashes into the side of the car where **A** is sitting. **A** is full of blood. There are cuts on his/her face and his body hurts –*Tell me about the pain **A** may have.*	had the experience since the essence of the whole scenario is hypothetical and playing to the children's imagination as well as real experience to elicit vocabulary at their level of understanding. • Part of the sentence (are on their way) is missing. • Children should know about this scenario as everybody uses transport daily. Especially public transport.	**Initiating event**	The family is in their car, on their way to the birthday party.
		Problem	Suddenly a big truck skips the robot. It crashes into the side of the car where Ziggi is sitting.
		Plan or attempts	His/her whole body hurts.
		Questions	Same as in Scenario 1
Scenario 4 (*Theme:* Ball against body part) ***Vignette:*** **A** is so glad to be at a game of his favourite soccer team. So far **A**'s team is winning. They have one goal to nil. Suddenly the ball comes directly to **A**! He/She is too slow to get out of the way of the ball or try to catch it. The ball hits him hard and strikes his finger. *Tell me what do you think **A** will tell his/her mommy about the pain he/she may have in his/her finger. / Tell me more about the pain in **A**'s finger.*	• Good scenario that all children can relate to. • Would a child think that this 'accident' was a big deal? What about the ball hitting the face, or chest? Or is this supposed to be a 'little pain' scenario? • A sentence should be added before the questions: He cannot move his/her finger.	**Title**	**Scenario 4: Ziggi is hit by a ball**
		Setting (Where and when)	Ziggi's is very happy to be at the soccer game.
		Initiating event	His/her favourite team is playing – and guess what? They are winning! They have one goal to zero.
		Problem	Suddenly the ball comes directly to Ziggi!
		Plan or attempts	He/She is too slow to get out of the ball's way. He/she can't even catch it! The ball hits him/her hard on his/her finger.
		Questions	Same as Scenario 1
Scenario 5 (*Theme:* Thorns) ***Vignette:*** It is break time at school. **A** and his/her friends are playing with a tennis ball. One of the children throws the ball very hard. **A** runs to catch it while keeping his/her eyes on the ball. Oh oh – do you see what I am seeing? Yes, there is a thorn bush and **A** doesn't see it! He/she runs into the thorn bush. The thorns scratch his/her arms and some even get stuck under his/her skin. *Tell me more about the pain*	• It is a good idea to ask what he/she will tell someone else (like the teacher) about what it feels like. • What kind of pain does **A** have from the thorns in his arm? • Better question: *"Tell me what **A** will tell his/her teacher about the pain he/ she might have."* • Must **A** stand still or move around? • Change to a thorn tree (Akasia).	**Title**	**Scenario 6: Ziggi runs into a thorn tree**
		Setting (Where and when)	It is break time at school. Ziggi and his/her friends are playing "catch" with a tennis ball.
		Initiating event	Someone throws the ball very hard. Ziggi runs to catch it and keeps his/her eyes on the ball the whole time.
		Problem	Ziggi does not see the thorn tree! He/she runs into a branch of the thorn tree. The thorns scratch his/her arms and some even get stuck under his/her skin.
		Plan or attempts	-

Suggested scenarios, themes and vignettes following the thematic analysis in Phase 1	Recommendations by professionals in expert panel	Updated scenarios using story grammar structure for vignettes	
		Story grammar structure	**Vignette**
*that **A** may have./ Tell me what do you think **A** will tell his/her teacher about the pain he/she may have.*		**Questions**	Same as in Scenario 1
Scenario 6 (*Theme:* Bumped body part against something or somebody) ***Vignette:*** **A** is playing soccer with his/her friends during break. **A** runs to kick the ball. His/her friend also runs to kick the ball. They do not see each other and bump their heads. *Tell me what do you think **A** will tell his/her friend about the pain he/she may have? Tell me what you think **A** would say to you to describe his/her pain.*	• Remove this scenario as it is similar to "ball against body part". • Combine this story with the other soccer story.	-	-
Scenario 7 (*Theme:* Bodily pain) ***Vignette:*** **A** is not feeling well today and struggles to work in class. His/her teacher wants him/her to do maths in his/her workbook, but he/she just can't. He/she has a headache, his/her back is sore and his/her stomach aches so much that he/she thinks he/she is going to vomit. *Tell me what you think **A** would say to you to describe his/her pain.*	• *Tell me what you think **A** would say to his teacher or friend?* Children can sometimes just answer: "But I am not there" or "I have cancer and I cannot go to school." • You can ask the child to describe the pain more specifically with examples or to compare it to something he knows. • This one is tricky since it is hidden pain and in describing the scenario you are already giving vocabulary which you don't want the children to simply repeat as you'll be leading them. • You only have to ask: "*What would **A** say to you when he is not feeling well?*" Using words like "describe his pain" might be difficult for the target age. • In this scenario you already describe all the pain.	**Title**	**Scenario 7: Ziggi has a headache**
		Setting (Where and when)	Ziggi struggles to do his work in class. He/she is really not feeling well
		Initiating event	His/her teacher wants him/her to work in his/her book. He/she just can't.
		Problem	He/she has a headache. He/she wants to vomit.
		Plan or attempts	He/she walks to the teacher.
		Questions	Same as in Scenario 1

Suggested scenarios, themes and vignettes following the thematic analysis in Phase 1	Recommendations by professionals in expert panel	Updated scenarios using story grammar structure for vignettes	
		Story grammar structure	**Vignette**
Scenario 8 (*Theme*: Operation) ***Vignette:*** **A** wakes up in his/her hospital bed after the doctor removed his/her tonsils. He/she thought the doctor was going to take the pain in his/her throat away. But still he/she doesn't feel well. *Tell me more about the pain **A** has.* His/her mommy and the nurses tell him/her that he/she will feel much better after a few spoons of ice cream or jelly...	• **A** needs special pain medicine to be better. • It is good to tell him that the operation is to make him better but it is important to also tell him that the pain will not be away immediately but that it will take a few days. This prepares him. If you don't tell them, they will think everyone lied to them about getting better. • Adding extra info about ice cream/jelly might redirect the child's attention and he may not answer appropriately. Maybe child must answer first and then in conclusion, just to give the story a happy ending the jelly/ice cream can be added. • Maybe leave out the bit about his expectations for after the surgery. • The whole process should be well explained to the child. The caregiver must also be sure to say there will be pain and explain where it will be. The child might also be dizzy or feel nauseous after the operation.	**Title**	**Scenario 5: Ziggi had an operation**
		Setting (Where and when)	Ziggi wakes up in his/her hospital bed.
		Initiating event	The doctor removed his/her tonsils.
		Problem	He/she still doesn't feel well.
		Plan or attempts	He/She struggles to speak to his/her mommy.
		Questions	Same as in Scenario 1
Scenario 9 (*Theme:* Needle procedure) ***Vignette:*** **A** is very sick in hospital because the doctor says he/she has an illness that can make other people also sick. **A** needs to get medicine to make him/her better. The medicine is given to him/her through a drip – this is when a needle is put into your vein so that the medicine can flows directly into your blood. This way **A** can become better much faster. The nurse tries to puts a drip in **A**'s arm but keeps missing and has to try again and again. It is very sore. *Tell me more about the pain **A** may have.* Once the drip is in his vein, the pain is better!	• You should use the term "arm" not "vein". Children will understand it better. • **A** experienced physical pain but also psychological pain because of the trauma of inserting the drip. Here it is also important to explain to the child what he will be experiencing. Don't tell him it won't hurt or it will only be one prick. Use distraction methods to take his attention away from the procedure. • **A** is very sick. He has to go to hospital. (Maybe leave out the infectious to other people bit as it doesn't add anything to the story). **A** needs medicine to make him better. The medicine is given through a drip. They have to put a needle	**Title**	**Scenario 10: Ziggi gets a drip**
		Setting (Where and when)	Ziggi is very sick in hospital.
		Initiating event	Ziggi needs medicine to make him/her better. The medicine is given to him/her through a drip – They have to put a thin needle in his/her arm to get the medicine into his/her body.
		Problem	The nurse tries to puts a drip in Ziggi's arm. She keeps missing the vein where she has to put the needle in.
		Plan or attempts	She has to try again and again.

Suggested scenarios, themes and vignettes following the thematic analysis in Phase 1	**Recommendations by professionals in expert panel**	**Updated scenarios using story grammar structure for vignettes**	
		Story grammar structure	**Vignette**
	in his arm to get the medicine in his body. (Leave out 'This way **A** can become better much faster'). The nurse tries to put a drip in **A**'s arm. She keeps missing. She has to try again and again. It is very sore. What kind of pain does **A** feel? • This scenario can be very traumatic, especially the needle and drip part. I would rather suggest the needle be explained as a small prick not shown as a long scary needle. It can also be suggested that the child looks away while the needle is put in.	**Questions**	Same as in Scenario 1
Other	• Add theme: **Burn wound**	**Title**	**Scenario 8: Ziggi gets a burn wound**
		Setting (Where and when)	Ziggi's mommy cooks supper.
		Initiating event	Ziggi is very hungry. He/she wants to look in the pot to see what they will eat tonight.
		Problem	When he/she lifts the lid, the warm lid burns his/her hand.
		Plan or attempts	He/she drops the lid and sees the blister on his/her hand.
		Questions	Same as in Scenario 1
	• Add theme: **Bee sting**	**Title**	**Scenario 9: Ziggi is stung by a bee!**
		Setting (Where and when)	It is a hot summer's day.
		Initiating event	Ziggi drinks cold drink from a can. Suddenly a bee stings him/her.
		Problem	He/she does not see the bee! Suddenly the bee stings him/her on the lip.
		Questions	Same as in Scenario 1

The expert panel suggested that the vignettes should follow the grammar structure of children’s stories (Montague, Maddux, & Dereshiwsky, 1990). Story grammar refers to a formal set of rules used in children’s stories when joining events together in a specific and predictable way (Hayward & Schneider, 2000; Whaley, 1981). Using a story grammar structure for the vignettes pitched at the school-age level ensured that the children were able to relate to the vignettes (Montague et al., 1990). Furthermore, previous research found that the use of the story-grammar structure assisted children in focusing their attention on various aspects of the story, thereby enhancing their comprehension and enabling them to answer questions afterwards (Whaley, 1981).

According to the story grammar structure, the setting should first be introduced by describing the time and place of the event, followed by initiating the event, setting the problem, and finally the planning by the character to address the problem (Montague et al., 1990; Whaley, 1981). Because the aim of the vignettes was to elicit pain-related vocabulary, the last two elements of story grammar structure, namely direct consequences and reactions related to the outcomes were incorporated into the questions that were asked at the end of each story (Montague et al., 1990). Table 3.9 illustrates on how each scenario was presented using the story grammar structure.

Furthermore, the expert panel suggested, similar to the procedure that was followed by Azize (2012), that all stories should end with the same questions. The questions were formulated based on the categories identified by Franck et al. (2010), Azize (2013), Ely (1992), Jerret and Evans (1986) and Johnson et al. (submitted). The four questions were “*What would Ziggi say?”* (to elicit exclamations or vocabulary to describe pain or unpleasant sensations;)*; “What would he/she say to his/her mommy?” (*to elicit vocabulary to describe unpleasant sensations; causes of pain or pain locations)*; “What would he/she say or do to feel better?”* (to elicit vocabulary to comfort child in distress, cope with pain, request help or manage pain)*;* and “*What do you think will happen next?”* (to elicit vocabulary to comfort child, but this question was mainly included to incorporate the last two elements of story grammar structure [Montague et al., 1990], namely direct consequences and reactions related to outcomes). The panel’s suggestions were implemented and tested during the pilot study.

The expert panel also suggested changing the word “pain” to “hurt” because some children may not have a clear concept of the word “pain”. Another important recommendation by the panel was to change the sequence of the vignettes and scenarios, to ensure that all the hospital-related scenarios (i.e. operation and drip) did not follow each other. The recommendations were incorporated as shown in the last column of Table 3.9.

Based on the recommendations of the expert panel, a total of 10 vignettes were developed using a story grammar format. The updated version of each vignette was reviewed and confirmed by the expert panel.

3.6.4 Material and equipment used in Phase 2

One measuring instrument was developed, namely the Hypothetical Physical Pain Scenarios (HPPS). The HPPS was adapted for the six respondent groups with the two child respondent groups completing the HPPS-C, the two parent respondent groups completing the HPPS-P and the two teacher respondent groups completing the HPPS-T.

This section commences with a discussion of the character development and biographical section of the HPPS-C, followed by the development of the HPPS-P and HPPS-T.

3.6.4.1 HPPS-C

The HPPS-C consists of ten vignettes as discussed in Table 3.9 together with a set of illustrations to visually support the vignettes, and a biographical section that the children’s parents completed. A discussion of the character development follows.

3.6.4.1.1 Character development

Once the changes suggested by the expert panel had been made to the content of the vignettes, illustrations were made for the HPPS-C by a professional graphic artist. Four characters were created who were not ethnically, age or gender biased as those factors have been shown in the literature to have an impact on perception (Belter et al., 1988; Lollar et al., 1982). Furthermore, the characters did not show any facial features that suggested emotion as this could have influenced the children’s responses when relating to the vignettes (Belter et al., 1988). Fifteen of the 38 children in the school setting, who also participated in Phase 1 were randomly selected and asked to select the one character they preferred. Children from different cultures were included in the group. Figure 3.5 displays the four options, as well as the frequency with which each one was selected.

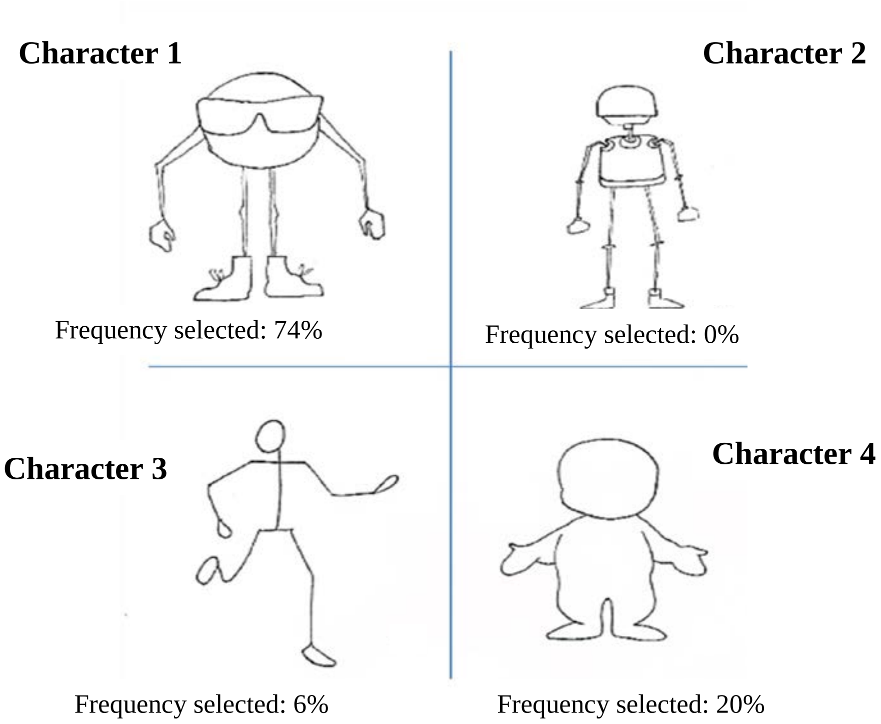


Figure 3.5. Frequency with which each specific character was selected (*n*=15).

Figure 3.5 clearly shows that the majority (74%) of child participants selected Character 1 to represent the character in the hypothetical physical pain scenarios, with 20% selecting Character 4; 6% selecting Character 3 and none selecting Character 2. The fact that no children selected Character 2 and only 6% selected Character 3 is supported by research where it was reported that South African children do not prefer stick man illustrations (Dada, Huguet, & Bornman, 2013).

The children who were involved in the selection of the character were also given the opportunity to suggest a name for the character. Only six children suggested possible names for the character, namely DJ, Kwele, Max, Ziggi, Zimbo, and Zog. Max, DJ and Zog were not considered as options as these names were possibly more related to boys. From the remaining three names (Ziggi, Kwele and Zimbo), the children (*n*=15) were again asked to select the name they prefer. Ziggi was selected by 60% of the children; while 26% opted for Kwele and 14% for Zimbo. The name Ziggi did not show a bias towards any gender or ethnic group.

Once the character’s name and appearance had been finalised, the professional graphic artist developed illustrations for all ten vignettes.

3.6.4.1.2 Biographical section

The biographical section (Appendix B) included in the HPPS-C was the same as the questionnaire that parents completed in Phase 1. The parents of participating children were asked to complete this section.

3.6.4.2 HPPS-P

The HPPS-P (Appendix K) was compiled for the two parent respondent groups. It comprised two sections: Section A (Questions 1-13) dealt with biographical information and was the same as the biographical questionnaire (Appendix B) mentioned earlier; Section B contained the same ten vignettes as well as questions that asked parents to indicate the words and/or phrases they thought their children would use (a) to describe pain; (b) to request help or assistance; (c) to express their pain (exclamations); (d) to describe the causes of their pain; and (e) to comfort themselves. These questions were based on categories identified in previous research (Franck et al., 2010; Jerrett & Evans, 1986; Johnson et al., 2015). The HPPS-P was developed online using SurveyMonkey®. Table 3.10 provides information on the question number, aspect, type of question, reason for inclusion as well as theoretical justification for the inclusion of questions in the online parent survey-questionnaire.

Table 3.10

Development of the HPPS-P

Question number	**Aspect**	**Type of question**	**Reason for inclusion**	**Theoretical justification**
SECTION A: Background information of the person completing the questionnaire				
1-13	Questions 1-7 in this questionnaire are identical to those in the questionnaire described in Table 3.3, except for the fact that questions 4 (nationality), and 6 (other languages) of the original questionnaire were omitted and question 10 (income) was replaced with question 8 (method of payment of medical bills) in the current questionnaire. Questions about the children’s ages and birth order as well as previous exposure to hospitalisations were also added, because older siblings and experiences of previous hospitalisations were considered to influence the development of pain-related vocabulary (Franck et al., 2010)			

Question number	Aspect	Type of question	Reason for inclusion	Theoretical justification
SECTION B: Information on children's pain vocabulary as reported by parents				
Scenarios	Describe pain	Open-ended question	To determine parents' perceptions regarding the words their children would use to describe their pain.	Franck et al. (2010) identified various categories in children's use of physical pain-related vocabulary. The words South African children use to describe pain, request help, comfort themselves, exclaim as well as describe causes of pain are important. It is also important to determine which words should be included in an AAC system for children with complex communication needs or for individuals who are vulnerable in terms of communication to express their pain for a specific period (e.g. following a surgery).
	Request help	Open-ended question	To determine parents' perceptions regarding the words their children would use to request help.	
	Exclamations	Open-ended question	To determine parents' perceptions regarding the exclamations their children would use when they got hurt.	
	Causes of pain	Open-ended question	To determine parents' perceptions regarding the reasons their children would give to explain why they got hurt.	
	Comfort themselves	Open-ended question	To determine parents' perceptions regarding what words their children would use to comfort themselves.	

Once the HPPS-P had been developed, it was pilot tested and revisions were made.

3.6.4.3 HPPS-T

The HPPS-T in SurveyMonkey® (Appendix L) was the same as the HPPS-P, save for the fact that three scenarios were excluded as they were deemed not relevant for teachers, namely burn wounds, needle procedures or recovering after surgery. Table 3.11 presents information on the question number, aspect, type of question, reason for inclusion as well as theoretical justification for the inclusion of questions in the HPPS-T.

Table 3.11

Development of the HPPS-T

Question number	Aspect	Type of question	Reason for inclusion	Theoretical justification
SECTION A: Background information of the person completing the questionnaire				
1,2	Work place and grade teaching	Two-options question (government/ private school)	To determine teaching context	The participant should currently be working as a Gr R-3 teacher in either a private or government school.
3, 6, 7, 8	The same as for the questionnaire for the expert panel (Table 3.7).			
4,5	First language and other language(s) spoken	Open-ended question	To determine the first language of the teacher	Although teacher participants taught in English, it may not be their first language. Hence their first language may influence their choice of pain-related words (Briggs, 2010).
9	Experience as teacher for specific grade	Open-ended question	To determine the number of years' experience the teacher has in specific grade.	Professionals' experiences with children of a specific age will allow them to know and understand these children's pain experiences (Davoudi et al., 2008)
10	The same as Question 12 in the questionnaire for expert panel (Table 3.7).			
11	Are you a parent of 6- to 9-year-old child?	Two-option question (yes/no)	To determine if the teacher is a parent of a child in the age groups involved in this study besides his/her teaching responsibility.	Refer to Question 1 in Table 3.3 on the influence of parents on their children's pain-related vocabulary.
SECTION B: Information on children's pain vocabulary as reported by teachers				
Scenarios	Identical as discussed in Table 3.10. Three scenarios (surgery, needle procedures and burn wounds) were omitted as these scenarios most likely happen outside the school context.			

The HPPS-T was pilot tested and revisions were made based on the results and recommendations.

3.6.4.4 *Scripted interview guide for HPPS-C*

A scripted interview guide (Appendix M) was developed to ensure that the same script and procedures were followed during the in-depth interviews with the child participants using the HPPS-C (Boyce & Neale, 2006). This guide ensured that the researcher would remain consistent in initiating the interview (introducing herself and asking the child's name, obtaining the child's assent, completing the PPVT-IV, introducing the character [Ziggi, featured in the vignettes]; introducing the vignettes, posing the questions and concluding the child participant interview). Adherence to all the steps in the scripted interview guide thus heightened the procedural reliability of the study (McMillan & Schumacher, 2001).

3.6.4.5 Procedural checklist

The procedural checklist (Appendix N) was developed based on the scripted interview guide and used by an independent observer to score the videos of the in-depth interviews of the pilot study to ensure procedural reliability. To calculate procedural reliability, the number of correctly completed steps (agreements) was divided by the total number of steps (agreements + disagreements) and then multiplied by 100 to express the percentage of procedural reliability (Coleman-Martin, Heller, Cihak, & Irvine, 2005; McMillan & Schumacher, 2001). Each in-depth interview involved a total of 95 procedural steps.

3.6.4.6 Peabody Picture Vocabulary Test (PPVT-IV)

The Peabody Picture Vocabulary Test, 4th Edition (PPVT-IV) (Dunn & Dunn, 2007) was used to evaluate the child participants' receptive English language skills and determine their verbal ability. Although the PPVT-IV is not standardised for the South African context, it has been used successfully to determine South African children's receptive English language skills (Tönsing, Dada, & Alant, 2014). The PPVT-IV Standard Score was used as a selection criterion for participants – child participants who obtained a Standard Score of less than 86 were excluded as their vocabulary acquisition was below average. The time each test took to be executed was also recorded.

3.6.4.7 Recording equipment

A small Panasonic HC-V100 video camera was placed at an angle to video-record the interviewer and not the child in order to make it possible for the independent coder to score the interview procedure for procedural integrity by using the procedural checklist. A digital voice recorder (Olympus DM650) was used to audio-record interviews. These audio recordings were used during the transcriptions of the in-depth interviews as they were clearer than those on the video camera. All the audio recordings of the pilot study (100%) were scored by the independent coder to check the transcriptions of the interviews. The independent coder agreed that the transcriptions by the researcher were 100% accurate as no differences were identified.

3.6.4.8 iPad tablet with illustrations/Laptop computer with PowerPoint presentation

The illustrations of the vignettes were presented and prepared for display on an iPad tablet. Research shows that adding illustrations as additional visual stimuli can capture the children's attention, serve as a mental scaffold (by building on previous knowledge), promote their creativity and motivate them to attend better than when only listening to the stories (Carney & Levin, 2002; Fang, 1996). Furthermore, the use of the iPad to display illustrations has been shown to motivate the children to participate and engage in story-activities (Godzicki, Godzicki, Krofel, & Michaels, 2013). A Toshiba laptop with a PowerPoint presentation of the same illustrations as displayed on the iPad was used as backup in case of technical problems when using the iPad.

3.6.5 Pilot study

The final step in the material development process was to pilot test the material. In order to do this, all the procedures, material and, equipment proposed for Phase 3 were included in a pilot study. Consent was obtained from the Gauteng Department of Education to approach the selected government schools to recruit participants (see Appendix O).

3.6.5.1 Aims of the pilot study

The main aims of the pilot study were to test the measuring instrument; the procedures proposed in the quantitative phase (Phase 3); the equipment suggested for the administration of the HPPS-C in Phase 3; and the ease and accuracy of the data analysis process.

3.6.5.2 Participants

Three distinct participant groups were included in the pilot study, namely children, parents and teachers. Each group will be described in detail in this section.

3.6.5.3 Selection criteria and recruitment

Except for the language criterion, which was amended so that all the children had to be English first language speakers, the same selection criteria as stipulated in Table 3.1 were used for the selection of the child participants for the pilot study. The Peabody Picture Vocabulary Test (PPVT-IV) was administered (Dunn & Dunn, 2007) to determine the children's English receptive language skills. To avoid data contamination, participants were from different but comparable schools to those included in the main study. No children from a hospital setting participated in the pilot study in order to reserve all possible many participants from this setting for the main study. Initially four children, representing different age ranges (6;0–6;11; 7;0–7;11; 8;0–8;11; 9;0–9;11) were recruited. Seeing that Participant 1's PPVT-IV indicated a language delay, another 6-year-old participant was recruited, resulting in five participants for the pilot study. Table 3.12 provides a summary of the child participants in the pilot study.

Table 3.12

Description of Child Participant in the Pilot Study (n=5)

Category	**Participant 1***	**Participant 2**	**Participant 3**	**Participant 4**	**Participant 5**
Gender	Female	Male	Male	Female	Female
Chronological age	6;2	6;6	7;4	8;0	9;0
PPVT-IV age	5;0	6;8	8;5	8;5	9;5
PPVT-IV Standard Score	85*	101	134	103	103
Number of siblings	1	2	1	1	2
Birth order of child	First born	Second	Second	First born	First born
Previous hospitalisation(s)	Yes	Yes	No	No	Yes
Reason(s) for hospitalisation(s)	Tonsillectomy	Tonsillectomy Stitches to hand	n.a.	n.a.	Oromaxilla surgery post facial injury
Previous hospitalisation(s) of sibling(s)	No	Yes	No	No	Yes
Who? Reason for hospitalisation?	n.a.	Sister, Teeth corrected; stitches on mouth	n.a.	n.a.	Brother, Tonsillectomy

*Participant 1 did not meet this selection criterion (<86 PPVT-IV Standard Score).

Table 3.12 shows that two boys and three girls were recruited for the pilot study with a participant in each of the four age range categories (6;0–9;11 years). Participant 1 did not meet the selection criterion regarding language skills (i.e. a Standard Score of 86 or above on the PPVT-IV) and she was therefore excluded. Hence another 6-year-old child (Participant 2) was included to ensure that the youngest children in the study understood the hypothetical physical pain scenarios and would be able to answer the questions posed. The fact that the PPVT-IV could pick-up the discrepancy in Standard Scores, confirmed that the use of the PPVT-IV was effective as part of the selection criteria.

The parent participants in the pilot study were parents of 6;0 to 9;11-year-old English first language speaking children with typical development. Although the parents consented that their children may participate in the pilot study, the parents themselves were not available to participate in the pilot study. Therefore, it should be noted that the parents who participated in the pilot study were not the parents of the child participants. Table 3.13 depicts a summary of the biographical information of the five parent participants who completed the online parent survey-questionnaire in the pilot study.

Table 3.13

Description of Parent Participant Description in the Pilot Study (n=5)

Category	**Participant 1**	**Participant 2**	**Participant 3**	**Participant 4**	**Participant 5**
Age	41	32	42	46	43
Gender	Female	Female	Female	Female	Female
First language(s)	English	Afrikaans and English	English	Afrikaans and English	English
Highest qualification	Diploma	Matric (Gr 12)	Bachelor's degree	Bachelor's degree	Bachelor's degree
Occupation	Hotel manager	Sales representative	Director	Occupational therapist	Manager
Employment status	Full time	Full time	Full time	Full time	Full time
Pay medical bills	Medical aid	Hospital plan	Medical aid	Medical aid	Hospital plan
Number of children	2	1	3	2	2
Birth order of child in target age group	First born	First born	Second	Second	Second
Age of child in target age group	8;7	6;1	9;0	9;11	8;5
Recent exposure to hospitalisation	Yes, mother and brother had few operations	Yes, child was once hospitalised for rota virus	Yes, child and grandmother	No	No

Table 3.13 shows that only mothers participated in the pilot study and that three of the four age ranges for children were included. Although two parents were bilingual, they confirmed that English was their children's first language. The results from the pilot study confirmed that the biographical section was effective and yielded important information.

For the third participant group, four teachers (who taught Gr R to 3 children) from two schools in the relevant geographical area were recruited. However, neither the Gr 2 nor the Gr 3 teacher completed the online HPPS-T, claiming that they did not have email access at home and that extramural commitments kept them from completing the online HPPS-T after hours at school within the agreed time frame. Table 3.14 therefore describes only the two remaining teacher participants. The same selection criteria used for the expert panel (Section 3.6.3.2) were used. The teachers were all teaching at schools where English was the LoLT.

Table 3.14

Description of Teacher Participants in the Pilot Study (n=2)

Category	**Participant 1**	**Participant 2**
Current context	Private school: Gr R	Government school: Gr 1
Age	60	48
Gender	Female	Female
First language(s)	English	Afrikaans
Other language(s)	-	English
Teaching qualification	Diploma level 5 ECD	Teacher Diploma (4 years); Further Diploma in Education
Teaching experience	30 years	25 years
Teaching experience for specific grade	30 years	6 years

Only two teachers completed the , highlighting the fact that online surveys might not be a feasible data collection strategy for this participant group. Although one of the teachers did not speak English as a first language, both were teaching at schools where English was the LoLT.

3.6.5.4 Results and recommendations of the pilot study

The specific aims, materials and procedures used, as well as the results and recommendations for the main study are presented in Table 3.15.

Table 3.15

Aims, Materials, Procedures, Results and Recommendations Following the Pilot Study

Aims	Materials	Procedures	Results	Recommendations for main study
1. Testing the measuring instrument				
1.1 Scripted interview guide with vignettes				
1.1.1 To determine the relevance and appropriateness of the questions in the scripted interview guide.	Scripted interview guide (Questions were included in this guide – Section 3.6.4.4) (Appendix M)	In-depth interviews were conducted with the children using the questions included in the scripted interview guide. Observations were made on how the children reacted to the questions.	Child participants understood the questions and gave appropriate answers to all four questions. Some children seemed to answer some questions with information not directly related to pain. Participant 3 commented on question 2 for Scenario 10 (“*What would Ziggi say to her mommy?*”) “Fire her (“fire” is a South African colloquialism which means in this context to dismiss the nurse), because she doesn’t work properly!” Participant 4 responded to the last question by giving another pain-experience that Ziggi may encounter. Prompting questions had to be used to ensure that the participants gave information related to the scenario.	Questions should be adapted as follows: *“What would Ziggi say about his/her hurt?”* (Prompting questions: “*How does the hurt feel? Tell me more*.”) *“What would Ziggi say to his/her mommy about his/her hurt?”* *What would Ziggi say or do to make it better?”* *“What do you think will happen next in this story?”* (Prompting question*: “If you would like to end this story, how will it end?”*)
			Some participants wanted to add their own experiences and if not given the opportunity to do so, persevered.	A prompt for a personal story should be added:*“Has something like this* (add example of scenario such as ‘when a thorn got stuck in your skin’) *ever happened to you before? ...Would you like to tell me more about it?”* (Prompting questions: *How did it feel? “What did you do or say to make it better?”*)
1.1.2 To evaluate whether children understood the vignettes	Scripted interview guide (Section 3.6.4.4) (Appendix M)	Children’s responses and reactions to the vignettes were noted during the in-depth interviews.	Children understood all 10 vignettes and responded appropriately. Comments like “this happened to my brother or me” were made, indicating that they associated with the character, Ziggy.	The language of the vignettes should remain the same for Phase 3.
1.1.3 To ascertain the clarity of	Scripted interview guide (Section 3.6.4.4)	Children’s responses and reactions to the vignettes	All instructions were clear and well understood, judging by the type of	The instructions in the hypothetical physical pain scenarios should be kept the same for

Aims	Materials	Procedures	Results	Recommendations for main study
instructions in the scripted interview guide.	(Appendix M)	and illustrations were noted during the in-depth interviews.	answers provided. No clarification questions were needed.	Phase 3.
1.1.4 To determine whether the vignettes elicited the required information.	Scripted interview guide (Section 3.6.4.4) (Appendix M)	Transcriptions were made of the children's responses.	Relevant vocabulary was provided by children in their responses as the instrument elicited pain-related vocabulary across the different categories and age groups. For example: "Look Mommy, I have a eina"; "Ouch!"; "Oh!"; "It is very, very sore".	Small amendments should be made to some questions (see 2.1.1) to ensure relevant answers.
1.2 Online HPPS-P and HPPS-T				
1.2.1 To determine the relevance and appropriateness of the instructions in the HPPS-P or HPPS-T.	Online HPPS-P or HPPS-T supported by SurveyMonkey® (Section 3.6.4.3) (Appendices K, L)	Participants received invitations to participate in this study via email. Once they consented, a link to the electronic HPPS-P or HPPS-T was sent to them. They were asked to complete the measuring instrument within a week of receiving it. Possible recommendations to improve the HPPS-P or HPPS-T were requested from the participants.	All instructions were clear and well understood as the participants answered all the questions appropriately.	The instructions within the HPPS-P and HPPS-T should remain the same in Phase 3.
1.2.2 To determine whether the required information was obtained from the online HPPS-P or HPPS-T.	Online HPPS-P or HPPS-T supported by SurveyMonkey® (Section 3.6.4.3) (Appendices K, L)		Pain-related vocabulary was provided by parent and teacher participants in their responses. Both parents and teachers suggested that a shorter version of the HPPS-P or HPPS-T with fewer scenarios should be used in Phase 3. Parents and teachers chose to repeat some of the answers for various scenarios.	Ten scenarios should be used for the children. The scenarios for the HPPS-P should be reduced from the original 10 to eight scenarios with "fall from a tree" and "with a bicycle" that were combined to read "Your child falls and hurts him/herself", and with "car accident" being excluded. The same scenarios that were reduced in and/or excluded from the parent questionnaire, should also apply for the teacher questionnaire (hence reducing seven scenarios to five for Phase 3).
1.2.3 To determine any problems with the procedure of completing the online HPPS-P or HPPS-T.	Follow-up email to ask about respondents' experiences while completing the online HPPS-P or HPPS-T.	Participants were requested to comment on which process they found easy or difficult to follow in the completion of the online HPPS-P or HPPS-T.	Parents did not report any challenges in completing the online HPPS-P. Teacher 1 experienced Internet connectivity problems and could at first not complete the whole HPPS-T. She then had to continue at a later stage and indicated that she is not experienced in	Parents completed the online HPPS-P effectively, and this same format is suggested for Phase 3. For teachers, a choice between a paper-based and an online HPPS-T should be given to increase the response rate.

Aims	Materials	Procedures	Results	Recommendations for main study
			computer skills and would have preferred to rather complete a printed HPPS-T. Two other teachers who were recruited could not complete the online HPPS-T as they had no internet access at home.	
1.2.4 To determine the estimated time required to complete the HPPS-P or HPPS-T.	Participants (parents and teachers) were asked to record how long it took them to complete the HPPS-P or HPPS-T.	Participants had to complete the questions in the HPPS-P or HPPS-T in their own time and were asked to record the time it took them to complete the questions.	Completion times for the parent participants were as follows: Participant's number – Time it took to complete online HPPS-P/HPPS-T Parent 1 – 33:10 Parent 2 – 34:45 Parent 3 – 27:15 Parent 4 – 29:00 Parent 5 – 32:55 Teacher 1 – 65:34 Teacher 2 – 28:10 An average completion time of 31:25 minutes for parents. Parents complained about the long completion time. Teacher's inadequate computer skills and Internet connectivity resulted in caused long completion times.	The scenarios for parents and teachers should be reduced to cut the completion time for both groups.
1.2.5 To determine the return time for the completed online HPPS-P or HPPS-T.	Online HPPS-P or HPPS-T (Section 3.6.4.3)	The processes followed to request participants to complete the online HPPS-P or HPPS-T were: • Email was sent with request to participate • Participant gave consent • Receive received link to HPPS-P/HPPS-T • Participants were asked to complete the online HPPS-P or	The majority of participants submitted the completed HPPS-P or HPPS-T within the scheduled time framework. However, two parents took five and seven days respectively to respond to the initial email request for participation as they were on leave during the commencement of the pilot study or did not read their emails on a daily basis and therefore did not request the link. Two teachers completed the HPPS-T within the week. Furthermore, two other teachers who were approached to participate did not do	The link to the HPPS-P or HPPS-T should be sent together with the email requesting participation in order to improve the return rate. Printed copies of the HPPS-T should be made available to the teacher participants with a set time of one week to complete the questions.

Aims	Materials	Procedures	Results	Recommendations for main study
		HPPS-T within a week from receipt of the survey link • Follow-up email was sent with reminder	so because they claimed that they did not have internet access at home and could not access the HPPS-T at school after hours due to extra mural responsibilities.	
2. Testing the data collection procedures as stipulated in the scripted interview guide				
2.1 To determine the suitability of the Peabody Picture Vocabulary Test (PPVT-IV) (Dunn & Dunn, 2007) to: • establish rapport between the researcher and child participants; • reduce possible stress that may be experienced by some participants; • confirm age equivalent language skills and Standard Scores for each participant.	PPVT-IV (Dunn & Dunn, 2007) (Section 3.6.4.6)	The implementation of the evaluation was done as prescribed by the PPVT-IV manual (Dunn & Dunn, 2007).	Rapport was established by using the PPVT-IV as it requires only non-verbal responses and no corrective feedback was provided. This put the children at ease. One child, who was very shy, became increasingly relaxed as she continued with the PPVT-IV. Except for Participant 1, all the children were functioning on or above their chronological age level. Participant 1 presented with a Standard Score of 85 (PPVT-IV age of 5.00). The PPVT-IV test was therefore successful to highlight differences between chronological ages and PPVT-IV age and Standard Score.	The PPVT-IV should be implemented during the main data collection as the required response mode (non-verbal) will assist in establishing rapport and decreasing tension in the children (Dunn & Dunn, 2007). Children with Standard Scores below 86 will be excluded as their vocabulary acquisition is below average.
2.2 To determine the estimated time to complete PPVT-IV and HPPS-C.	Timer (on audio recorder)	The timer was as soon as the interviewed commenced.	Recording times were as follows: Participant nr — Recording times (minutes & seconds): PPVT-IV / HPPS=C / Total 1 — 14:10 / 16:06 / 30:16 2 — 20:04 / 25:41 / 45:45 3 — 11:23 / 14:04 / 25:27 4 — 14:18 / 22:02 / 36:20 5 — 21:36 / 22:09 / 43:45 On average the interviews took 36 minutes (PPVT-IV and vignettes).	The researcher should aim to restrict the in-depth interviews to 30 minutes per child as that was the time allocated per child by the school. The interviews should be paced to ensure at least 15 minutes to complete the questions related to the vignettes. As the researcher became more experienced in administering the PPVT-IV did not exceed 15 minutes completion time of the child assent form and the PPVT-IV, and hence the pilot study increased the researcher's skill in keeping to the allotted

Aims	Materials	Procedures	Results	Recommendations for main study
				time.
2.3 To evaluate the effectiveness of the administrative procedures to be used during data collection with the child participants	Scripted interview guide (Section 3.6.4.4) (Appendix M)	The suggested scripted interview guide was followed.	The clear layout of the scripted interview guide assisted the researcher to focus and follow the same procedure with each individual interview.	Administrative procedures were clear and should be kept the same for Phase 3. A printed scripted interview guide should be available during the interviews to increase the procedural reliability of data collection.
2.4 To ensure procedural reliability	Procedural checklist for in-depth interviews with child participants (Section 3.6.4.5) (Appendix N) Video recordings	An independent observer screened all five video recordings and completed the procedural checklist.	An independent observer checked 100% of the videos of the pilot study's in-depth interviews, and found that 423 out of a possible 475 steps were followed resulting in an agreement of 89% of the procedures followed during the in-depth interviews.	The same procedural checklist should be used in Phase 3 with 30% randomly selected video recordings screened as this can effectively be used to determine procedural reliability.
3. Determining the suitability of equipment used during the administration of the HPPS-C				
3.1 To determine the suitability of the recording equipment used during the administration of the HPPS-C	Panasonic HC-V100 -video camera; Olympus DM650 digital voice recorder (Section 3.6.4.7)	Both video and audio recordings were made.	The sound of the audio recordings was clear and as the focus was not on non-verbal cues, the audio recordings were effective as a back-up measure. The video camera was placed to not record the face of the child (to protect the identity of the child), but rather to record the procedure.	For consistency, audio recordings should be used during all the in-depth interviews and the video recordings could serve as a back-up for the audio recordings. During the video recordings the focus should be on the procedure to allow for the completion of the procedural checklist by an independent coder. The audio recordings could be used to transcribe all the in-depth interviews and to confirm the transcriptions by an independent coder.
3.2 To determine the suitability of the display equipment used in the in-depth interview.	iPad and Toshiba laptop with PowerPoint presentation (Section 3.6.4.8)	The iPad was used during the in-depth interviews with the child participants to display the illustrations that accompany the vignettes. The Toshiba laptop with PowerPoint presentation was at hand as a back-up.	In one of the interviews, the iPad did not work effectively and the laptop was used as an efficient backup system. The children enjoyed working with the iPad. Their engagement was high and they were focused on the task at hand.	The iPad should be used during the interviews, but the laptop should be available as a back-up system should the iPad fail in any way.

Aims	Materials	Procedures	Results	Recommendations for main study
4. Testing the ease and accuracy of the data analysis process				
4.1 To evaluate transcription rules.	Verbatim transcriptions of participant responses given during administration of the HPPS-C	Transcription rules were developed and implemented (Appendix P).	An independent second coder checked all five transcriptions and confirmed a 100% agreement.	Transcription rules that were developed should be used to clean the data for Phase 3.
4.2 To test the ease and accuracy of analysing the data offered by the children.	Transcriptions of responses to HPPS-C (for the purpose of this exercise, only the words and phrases that were pain-related within the transcriptions were used); Atlas-ti (word cruncher); Word Cloud	Atlas-ti and Word Cloud software were used to determine the frequency of the pain-related words in the interview transcripts.	Atlas-ti word cruncher made word counts of individual words but did not identify phrases. Word Cloud only focused on individual words and no phrases (Cui et al., 2010).	An alternative coding system should be used to allow for coding of both words and phrases, e.g. “very, very sore”; “go to the hospital”; “please help” in the main study. Individual words lost context, therefore words and/or phrases should be included in the main study.

The recommendations of the pilot study as stipulated in Table 3.15 were implemented to refine the methodology and reduce threats to internal and external validity before commencing with Phase 3.

Although not a customary step in pilot studies, the results obtained were analysed to determine possible ways in which to do this, as no existing traditional approaches were available. The word cruncher function in the qualitative software program, Atlas-ti was used to make a word count of the words in the transcriptions made from the children's responses to the HPPS-C. The words and/or phrases not related to pain or answers that were misinterpreted were first removed from the transcriptions to include only pain-related words and/or phrases. Table 3.16 presents the 28 words used four times or more by all the child participants in the pilot study. These words are represented in alphabetical order in Table 3.16. It was decided to sort the words into a number of categories, namely

(i) core vocabulary: Words that is needed to build sentences or that are often used when communicating (e.g. a, take, put, stop) and that are based on the children's or toddlers' core vocabulary lists compiled by Banajee et al. (2003), Marvin et al. (1994), and Trembath et al. (2007);

(ii) pain-related vocabulary: Words that are needed to describe and discuss feelings of pain and pain intensity; and

(iii) other words: Words that are not included in (i) or (ii) discussed above.

Table 3.16

Total Word Count and Categories of Pilot Study Results of Child Participants

Words	Total count	Category	Words	Total count	Category	Words	Total count	Category
a	9	core	it	19	core	stop	4	core
and	19	core	like	5	core	swollen	4	pain-related
arm	5	other	me	5	core	the	13	core
be	6	core	mommy	9	core	they	5	core
better	5	core	my	16	core	to	10	core
day	4	core	on	6	core	very	15	core
he	5	core	one	5	Core	was	5	core

Words	Total count	Category	Words	Total count	Category	Words	Total count	Category
I	9	core	ow	4	pain-related	will	13	core
ice	4	other	put	8	core			
is	19	core	sore	15	pain-related			

From Table 3.16 it is clear that on a one-word level, three broad categories could be identified, namely core, pain-related and other. However, these results showed that it was important to know the context in which the words were used to enable their categorisation into the five pain-related categories identified by Franck et al. (2010). The implications of this result were that words and/or phrases had to be coded and categorised in Phase 3, as context was important. Employing a method such as Word Cloud (Figure 3.6) alone would not be sufficient. However, the possible use of core and fringe words related to pain should be investigated for the main study to ensure that the person has more messages to convey than only one-phrase messages. Figure 3.6 contains a visual representation of the words presented in Table 3.16.

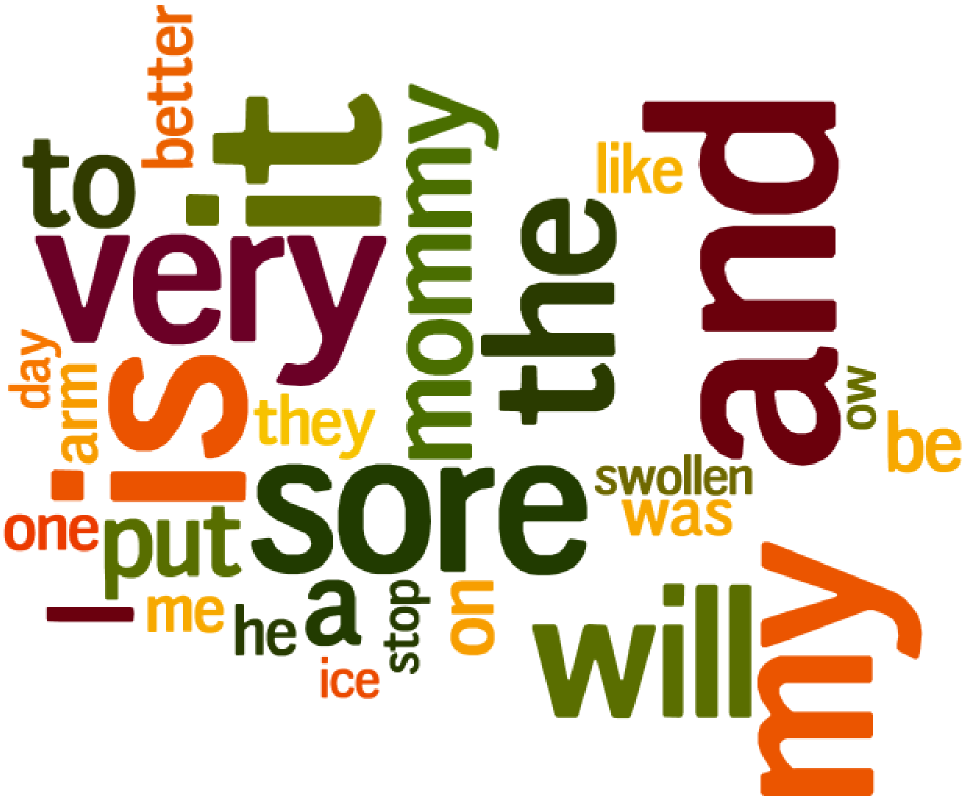


Figure 3.6. Word Cloud of the child participant responses.

Furthermore, it should be kept in mind that all the hypothetical physical pain scenarios were based on common childhood pain experiences as reported by typically developing children themselves. Children with disability may for example not have experiences of “running into a thorn tree” and these words and/or phrases suggested by typically developing children could therefore be excluded from the personal word lists of children with disabilities. The specific needs of each individual child should always be the focus when determining individualised vocabulary for a child.

3.6.6 Implications for the next phase

The HPPS with the accompanying vignettes and illustrations were applicable to elicit pain-related vocabulary from typically developing 6;0 to 9;11-year-old children. The HPPS-P and HPPS-T used the same scenarios and were effective to determine parents’ and teachers’ perspectives of the vocabulary they thought children in the above age group would use to describe and express pain, however, parents were requested to complete only eight scenarios and teachers five. The pilot study was effective in evaluating the custom-designed measuring instrument (HPPS) and the procedures developed to gather data. Furthermore, the three respondent groups (children, parents and teachers) collectively provided a rich data source to determine children’s pain-related vocabulary.

3.7 Conclusion

This chapter focused on the aims of the study and the research design employed. It also described the data collection, analysis and results of Phase 1 (Qualitative) as well as on the development of the measuring instrument in Phase 2. Not only did it describe the development of the HPPS, but it also included a description of the pilot study in which the study was executed on a small scale as proposed for the main study.

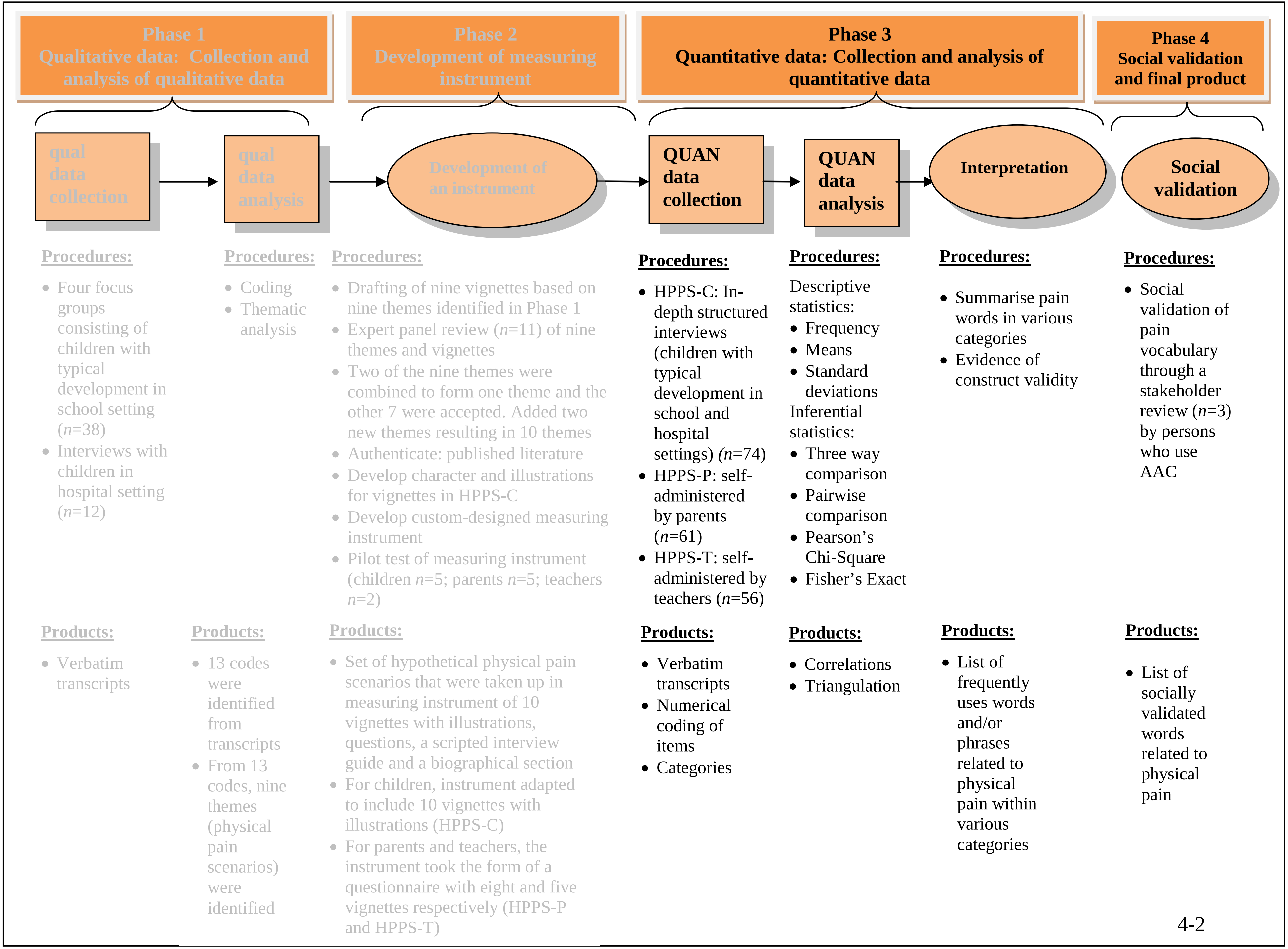
CHAPTER 4

RESEARCH METHODOLOGY: QUANTITATIVE PHASE

4.1 Introduction

As discussed in Chapter 3, this study used a sequential exploratory mixed methods design. In Chapter 3, the first two phases were discussed in detail. Chapter 4 will now focus on the Quantitative phase (Phase 3) and the Social Validation phase (Phase 4). It commences with a discussion of the aims of Phase 3 (the Quantitative phase), followed by a description of the steps followed, participants, material and equipment, as well as the data collection procedures, data analysis and validity and reliability. Next the Social Validation phase (Phase 4) is discussed in terms of its aims, a description of the steps followed, participants, the material and equipment, as well as the data collection procedures for the validation process. Phase 4 concludes with a description of the data analysis.

Figure 4.1 provides an outline of the flow of this design, that highlights Phases 3 and 4, but it also includes Phases 1 and 2 in order to give a comprehensive overview of the complete study.



Phase 1
Qualitative data: Collection and analysis of qualitative data

qual data collection

Procedures:

- Four focus groups consisting of children with typical development in school setting (*n*=38)
- Interviews with children in hospital setting (*n*=12)

Products:

- Verbatim transcripts

qual data analysis

Procedures:

- Coding
- Thematic analysis

Products:

- 13 codes were identified from transcripts
- From 13 codes, nine themes (physical pain scenarios) were identified

Phase 2
Development of measuring instrument

Development of an instrument

Procedures:

- Drafting of nine vignettes based on nine themes identified in Phase 1
- Expert panel review (*n*=11) of nine themes and vignettes
- Two of the nine themes were combined to form one theme and the other 7 were accepted. Added two new themes resulting in 10 themes
- Authenticate: published literature
- Develop character and illustrations for vignettes in HPPS-C
- Develop custom-designed measuring instrument
- Pilot test of measuring instrument (children *n*=5; parents *n*=5; teachers *n*=2)

Products:

- Set of hypothetical physical pain scenarios that were taken up in measuring instrument of 10 vignettes with illustrations, questions, a scripted interview guide and a biographical section
- For children, instrument adapted to include 10 vignettes with illustrations (HPPS-C)
- For parents and teachers, the instrument took the form of a questionnaire with eight and five vignettes respectively (HPPS-P and HPPS-T)

Phase 3
Quantitative data: Collection and analysis of quantitative data

QUAN data collection

Procedures:

- HPPS-C: In-depth structured interviews (children with typical development in school and hospital settings) (*n*=74)
- HPPS-P: self-administered by parents (*n*=61)
- HPPS-T: self-administered by teachers (*n*=56)

Products:

- Verbatim transcripts
- Numerical coding of items
- Categories

QUAN data analysis

Procedures:

Descriptive statistics:
- Frequency
- Means
- Standard deviations

Inferential statistics:
- Three way comparison
- Pairwise comparison
- Pearson’s Chi-Square
- Fisher’s Exact

Products:

- Correlations
- Triangulation

Interpretation

Procedures:

- Summarise pain words in various categories
- Evidence of construct validity

Products:

- List of frequently uses words and/or phrases related to physical pain within various categories

Phase 4
Social validation and final product

Social validation

Procedures:

- Social validation of pain vocabulary through a stakeholder review (*n*=3) by persons who use AAC

Products:

- List of socially validated words related to physical pain

Figure 4.1. The flow and stages of the sequential exploratory design used in this study.

4.2 Phase 3

Phase 3 is described in terms of the following elements: aims; participant selection and recruitment; participant description; material and equipment used; data collection procedures and analysis; implications for the next phase.

4.2.1 Aims of Phase 3

The main aim of Phase 3 was to identify and describe the vocabulary suggested by the six respondent groups (children aged 6;0 to 7;11; children aged 8;0 to 9;11; parents of children aged 6;0 to 7;11; parents of children aged 8;0 to 9;11; teachers of children aged 6;0 to 7;11 and teachers of children aged 8;0 to 9;11) as the words and/or phrases that typically developing children aged 6;0 to 9;11 would use to describe physical pain and/or pain-related experiences. The 6;0–7;11-year-olds are referred to as the younger children and the 8;0–9;0-year-olds as the older children.

The following sub-aims were formulated:

(i) To determine the total number of pain-related words and/or phrases occurrences per respondent group per scenario;

(ii) To identify and compare the total number of pain-related words and/or phrases related to physical pain elicited by the six responded groups;

(iii) To categorise the pain-related vocabulary elicited by the six respondent groups through a process of deductive and inductive coding;

(iv) To compare the pain-related vocabulary suggested by the younger and older groups of children;

(v) To develop a composite list of common pain-related vocabulary items in various pain-related categories and sub-categories;

(vi) To determine the impact of other factors namely gender, previous hospitalisations, presence of older siblings, parents' age, and parents' qualifications on the use of pain-related vocabulary by children aged 6;0 to 9;11.

4.2.2 Steps of Phase 3

Phase 3 consisted of various stages as shown in Figure 4.2.

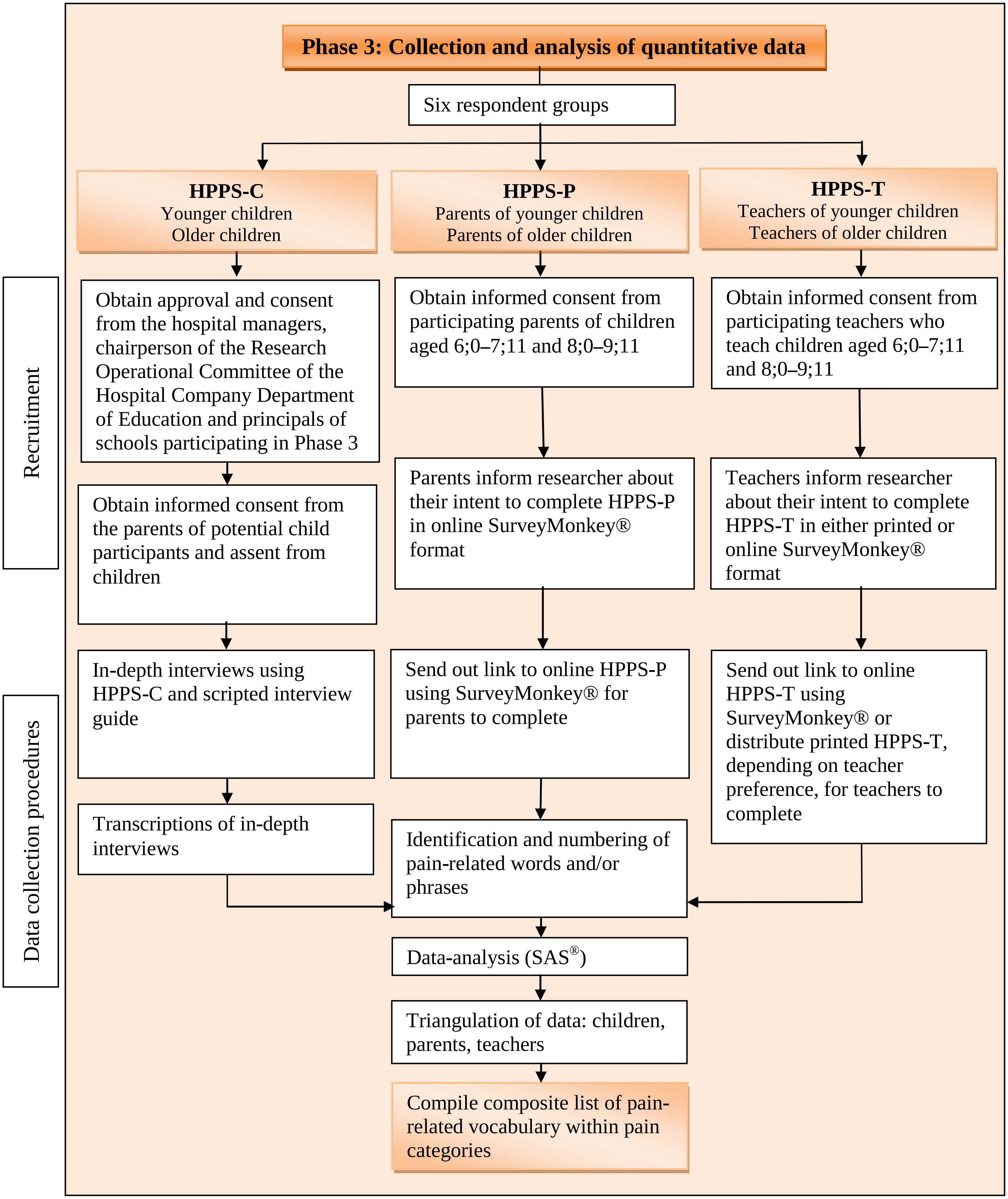


Figure 4.2. Overview of the steps followed in Phase 3.

Figure 4.2, provides a clear layout of the steps that were followed in Phase 3. After ethics approval had been obtained from the relevant authorities, all children whose parents gave informed consent and who then assented participated in the in-depth interviews. Thereafter clear transcription rules (Appendix P) were used to make verbatim transcriptions of all the interviews (*n*=74) and the data analysis was done. Parents who consented, completed the online HTTP-P using SurveyMonkey® (Appendix K) and teachers who consented completed either a printed or online HPPS-T (Appendix L), depending on their preference. Regarding the data of all the participant groups, a process was followed to identify pain-related words and phrases in the transcriptions or in the written answers provided. These words and/or phrases will be discussed in more detail in Section 4.2.6. Next, numbers were allocated to the words and/or phrases to enable inferential statistical procedures. Inferential statistics were calculated using the Statistical Analysis Software (SAS®) programme (SAS Institute Inc., 2011). The data was then compared between the two age groups of children, as well as between the six respondent groups.

4.2.3 Participants

Phase 3 included six respondent groups, namely children aged 6;0 to 7;11 (the younger group) and children aged 8;0 to 9;11 (the older group); parents of these two children groups and teachers who teach 6;0 to 7;11-year-olds (typically Gr 1 children) and 8;0 to 9;11-year-olds (typically Gr 3 children).

The same selection criteria described in the pilot study (Phase 2) for the selection of the typically developing children, were used to select the child participants for Phase 3 (refer to Section 3.6.5.3), as was done for the adult participants.

4.2.3.1 Recruitment of participants

Consent was obtained from the Gauteng Department of Education (Appendix O) to recruit participants from schools in the Tshwane South region as this was a region that contained both schools and hospitals. Principals of 16 primary schools (11 government and five independent private schools) with English as the language of learning and teaching (LoLT) in the specific region were contacted telephonically. Principals of six schools (four government and two independent private schools) indicated that they were not interested to have their schools participate in the study. At 10 schools (seven government and three independent private schools) the principals and staff from the foundation phase requested more information about the study in order to give informed consent. Follow-up letters with additional information about the research were then sent to the principals of these schools (Appendix Q). Upon receipt of the letters, they consented that the researcher may recruit potential children, parents and teachers at the school. Children and parents were recruited from only seven (four government and three independent private schools) of the 10 schools but teachers were recruited from all 10 said schools so as to reach the minimum target of 25 participants per respondent group.

First, two groups of children with typical development were recruited from the target schools, namely children aged 6;0 to 7;11 and children aged 8;0 to 9;11 years with English as first language. The Gr 1- and Gr 3-teachers at these schools were asked to identify potential children who met the selection criteria. A total of 262 consent letters (Appendix F) were distributed to the parents or primary caregivers via their children to inform them about the aim of the study. Of the 262 letters that were distributed, 78 (30%) were returned and indicated that consent was granted for the child to participate in the study; 59 (22%) were returned refusing consent, and 125 (48%) were not returned. The response rate of 52% is similar to the average response rate of 48,3% reported in literature (Baruch & Holtom, 2008). All 78 children provided written assent on a symbol-based assent form (Appendix G).

Furthermore, English-speaking children who were hospitalised during the time of data-collection were recruited from two private hospitals in the identified region. The hospital managers were contacted telephonically and follow-up letters requesting permission to conduct research at the hospital were sent to them. Letters of consent were provided and the chairperson of the Research Operational Committee of the Hospital Company amended the original approved research done in Phase 1 to enable the researcher to conduct research at more hospitals that are part of the Company in an attempt to reach more potential paediatric patients. The two hospitals – one is the hospital with the biggest paediatric ward in Tshwane – are situated in the same geographical area as the schools involved in Phase 3. The children in the hospital setting were recruited because they were information-rich participants regarding the specific topic and hence their experiences would enhance the study. The medical social worker at the hospitals acted as the hospital contact person and informed the researcher when patients were admitted who met the selection criteria (as stipulated in Section 3.6.5.3) and who would thus be potential participants. Although the aim was to recruit more paediatric patients for the study, the researcher was unfortunately not always informed by the contact persons at the hospitals when new patients who may be potential participants were admitted, despite numerous follow-ups by the researcher. During a period of three months, the researcher was informed nine times about children who were hospitalised and who would possibly meet the selection criteria. Upon further investigation, only four of these nine children (44%) met the selection criteria. The other five children's first language was not English. The parents of these four children were with their children in the hospital and were approached in person to ask their permission to allow their child to participate in the research. All four parents consented in writing after which the children provided written assent on a symbol-based assent form (Appendix G). The data obtained from this group of children was combined with that of the children in the school setting as per age range.

Before commencement of the in-depth interviews, the researcher explained the process to the children and discussed the questions on the assent form with them. The children then completed the assent form with the assistance of the researcher. All 82 children gave written assent on a symbol-based assent form.

Second, parents of the participating 82 typically developing children between 6;0 and 9;11 years in the school and hospital settings were contacted via email (e-mail addresses were indicated on the consent letters), requesting them to complete an online HPPS-P. Of these 82 possible parents, 19 (23%) consented (Appendix R) and returned their online HPPS-P and 63 (77%) did not respond to the request. Of the 50 parents who previously consented that their child may participate in Phase 1, and who provided their email addresses, 16 (32%) indicated their willingness to complete the online HPPS-P themselves and 34 (68%) did not respond. A further 26 parents were recruited by a snowball sample (McMillan & Schumacher, 2001) when the participating parents forwarded the link to family or friends with children who met the selection criteria. The parents who consented (61 in total) were divided into two respondent groups, namely 29 parents with children aged 6;0 to 7;11 and 32 parents of 8;0 to 9;11-year-olds. The link to the online survey software, SurveyMonkey® was emailed to the parents and they could complete and submit the HPPS-P electronically at a time convenient for them (SurveyMonkey, 2014).

Third, two respondent groups of teachers were recruited, namely Gr 1 teachers (teaching typically developing children between 6;0 and 7;11 years old) and Gr 3 teachers (teaching 8;0 to 9;11-year-old children). A total of 65 Gr 1 teachers were approached. Of these, 30 (46%) consented, 9 (14%) returned their consent letters (Appendix S) but preferred not to participate and 26 (40%) did not return their consent letters. A total of 59 Gr 3 teachers were approached, of whom 26 (44%) consented, five (8%) submitted their consent letters, but refused to participate and 28 (47%) did not return their consent letters. All of these teachers were recruited from the seven schools from which child participants were recruited, but in order to meet the targeted numbers of teachers (minimum 25 per group), three additional government schools in the Tshwane South area were also included. All 56 Gr 1 and Gr 3 teachers who agreed to participate worked at schools where English was the language of teaching and learning or in dual-medium schools where there was a focused English stream of instruction. Before recruitment of the teachers commenced, consent was obtained from the principals of the targeted schools. Teachers received written information about the study, requesting their consent to participate. They could choose to either complete an online HPPS-T or a printed HPPS-T. Of the 56 teachers who consented, 13 requested the online HPPS-T and 43 the printed HPPS-T. The 13 teachers who consented and requested the online HPPS-T, were contacted via email and provided with the link to the online survey software, SurveyMonkey®, which allowed them to complete and submit the HPPS-T electronically at their own pace (SurveyMonkey, 2014).

4.2.3.2 Sample size

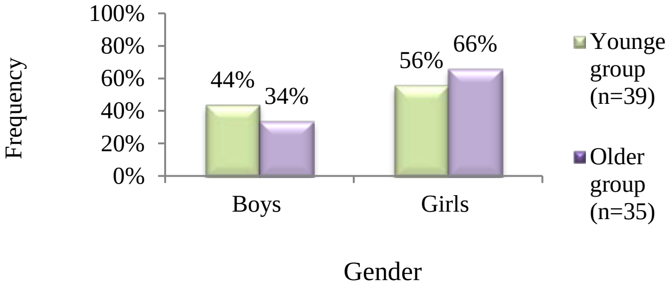
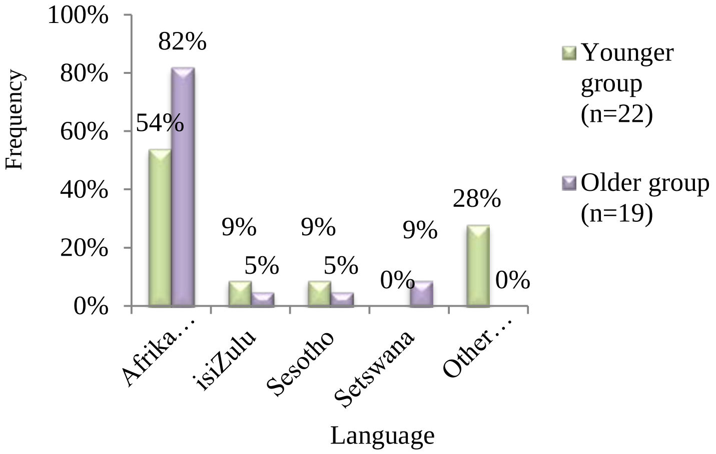
Eighty two children (78 from school settings and four from hospital settings) agreed to participate following their parents' consent. Eight children did not meet the selection criteria as stipulated in Section 3.5.3.1 (three children were too young; two did not speak English as a first language and three obtained a Standard Score of below 86 in the PPVT-IV). This resulted in a total of 74 child participants – 39 in the younger group (6;0 to 7;11) and 35 in the older group (8;0 to 9;11). Sixty one parents (29 younger and 32 older) completed the online HPSS-P and 56 Gr 1 and Gr 3 teachers (30 for younger and 26 for older children) successfully completed the HPPS-T (13 online and 43 in printed format).

4.2.3.3 Description of sample

The child participants are described in Table 4.1 according to the following characteristics: their age; gender; other languages they spoke apart from English; their parents' ages; one or two parents in household; number of children in household; previous hospitalisations, and reason(s) for hospitalisation(s). Throughout the thesis, the younger group representing the 6;0 to 7;11-year-olds is indicated in green and the older group (8;0 to 9;11-year-olds) is indicated in purple.

Table 4.1

Description of Child Participant Group in Phase 3

Description	Results (All participants *N*=74)
Age of child participants The mean age of the younger children was 6;4 years (*n*=39) and for the older children 8;3 years (*n*=35).	
Gender In both groups more girls than boys participated with a boy girl ratio of about 1:1.6.	
Other languages (*n*=41) More than half of the children in both groups spoke a second language. The percentages in the graphs represent the percentage per group, e.g. in the younger group, 54% spoke Afrikaans; 9% isiZulu and 9% Sesotho; while 5% each spoke other African languages such as Sepedi and Xitsonga. There were three children who spoke non-South African languages at home, labelled as "other" namely Serbian, Croatian and Malayalam. In the older group, 82% of the children spoke Afrikaans – an indication that the older children already had two years of Afrikaans (second language) instruction in their school curriculum. 9% children spoke Setswana and 5% isiZulu and Sesotho respectively.	

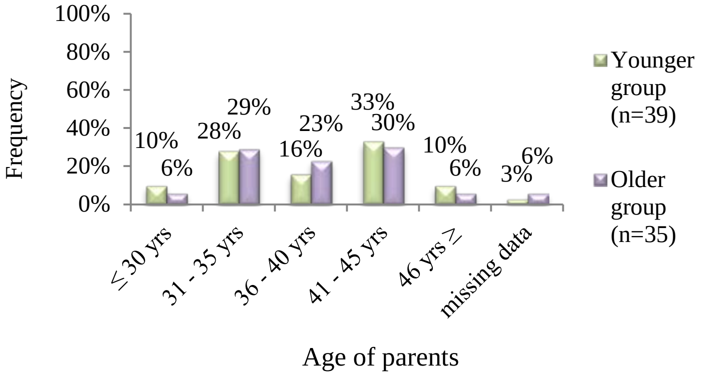
Description | **Results (All participants *N*=74)**

Parents' age

This data refers to the parents of the two child respondent groups. In the two groups, three parents opted not to indicate their age (missing data).

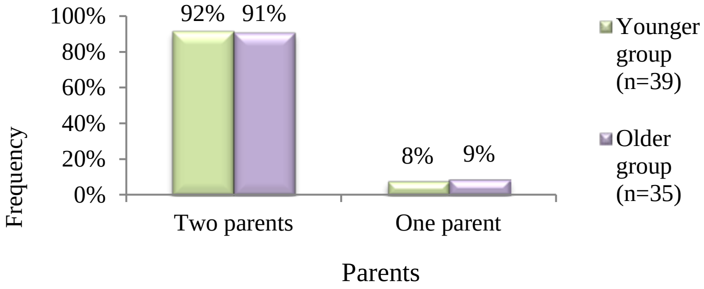
The mean age of the parents of the younger group was 38,3 years and that of the older group was 38,4 years.

The majority of parents in both groups were between 41 and 45 years-old (33% in the younger group and 32% in the older group) which indicate that these parents were in their late thirties when their children were born.



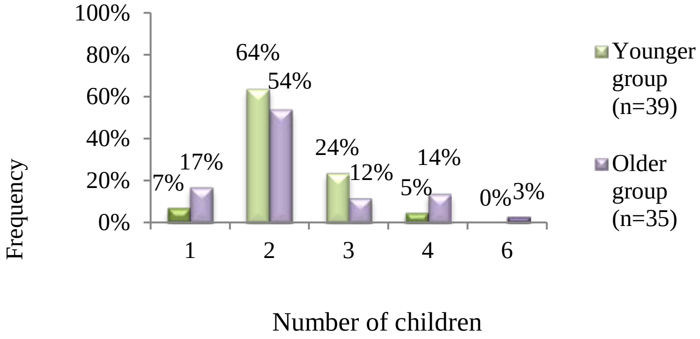
Parents in household

The majority of children in both groups lived in homes where both parents were present.



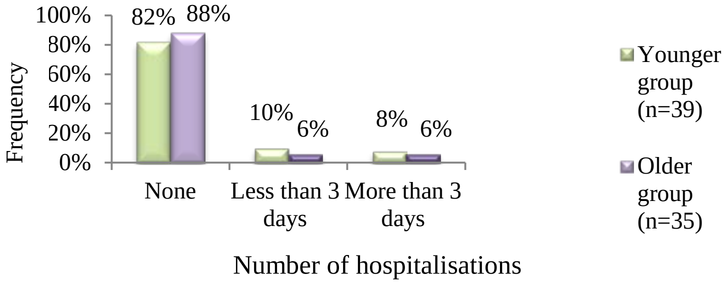
Number of children per household

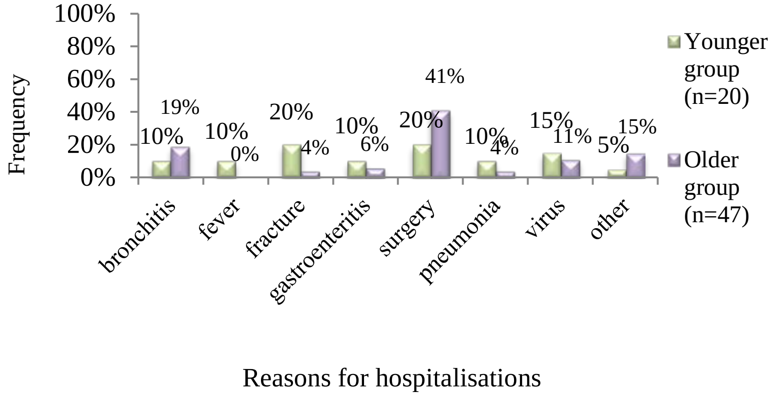
Seven percent children in the younger group were a single child; 64% had at least one other sibling; 24% had two siblings; and 5% had three siblings. The majority of children in the older group (54%) had one additional sibling, and a larger number compared to the younger group were the only child (17%); 12% of the older group had two siblings; 14% had three siblings and 3% had a large family with five siblings.



Previous hospitalisations (past two years)

The majority of the children in both groups (82% and 88% respectively) were neither hospitalised at the time of the study nor had been within the two years prior to the study. Of the younger group, 10% had experienced hospitalisations of 3 days or less, 8% children experienced hospitalisations of more than three days – 4% children had been admitted more than five times and 4% multiple times (no numbers were specified). In the older group, 6% children reported having been hospitalised for three days or less and 6% for more than three days – 3% children had been hospitalised more than five times and 3% multiple times. This graph shows the importance of the dual



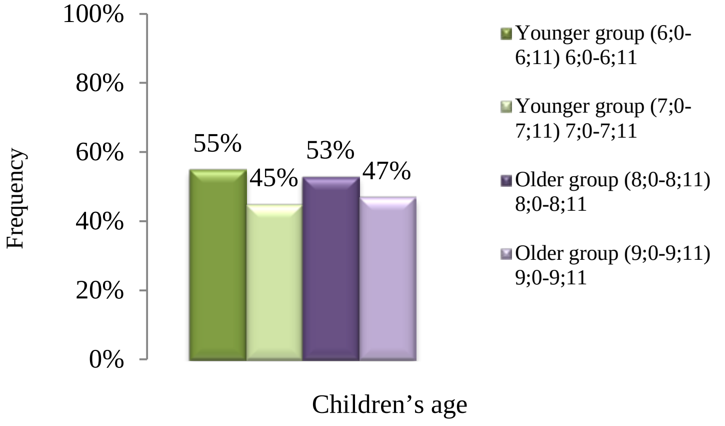
Description	Results (All participants *N*=74)
recruitment strategy (school and hospital context) as a significant proportion of the children from school had not had any previous hospital experience.	
Reason(s) for hospitalisation(s) Reasons for hospitalisations for the younger and older groups were mainly surgery (20% and 41% respectively), such as tonsillectomy, oromaxilla, and adenoidectomy. Children were also hospitalised for fractures (20% and 4% respectively) and bronchitis (10% and 19% respectively). Compared with older children, more children from the younger group had been hospitalised for virus-related reasons (15% and 11%respectively); gastroenteritis (10% and 6% respectively) and pneumonia (10% and 4% respectively). Only children from the younger group were hospitalised when they had fever (10%), whereas older children (15%) were hospitalised more for other reasons, such as meningitis and encephalitis. Two children, one from each age group, had cancer.	

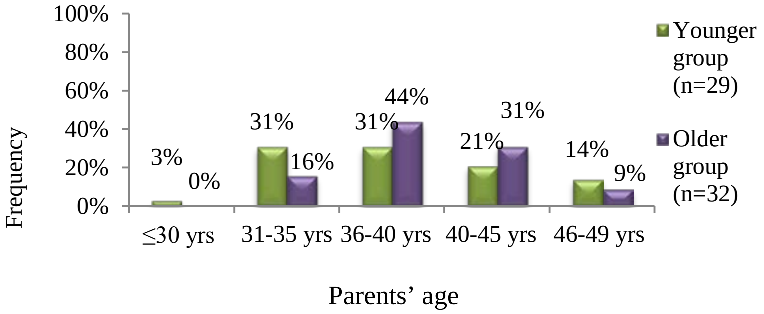
In summary, Table 4.1 shows that more girls than boys participated in the study; that the majority of children in both groups were multi-lingual, and that they lived in homes with two parents and one sibling – the mean was two children per household. The majority of the children in the younger group had an older sibling whereas the majority of the children in the older group were first born. Furthermore, only 18% of children in the younger group and 12% in the older group had experiences of hospitalisations during the past two years. All of these factors influence children’s use of pain-related vocabulary (Franck et al., 2010).

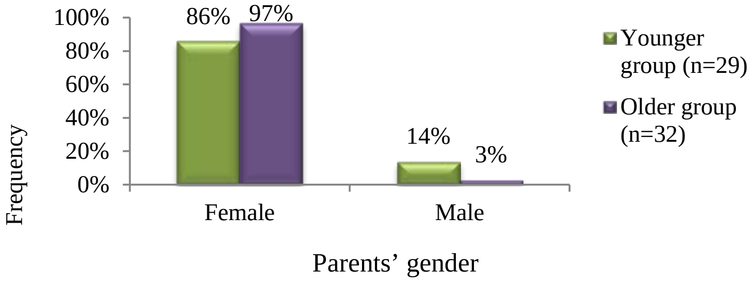
Table 4.2 describes the parent respondent groups of this study according to their children’s age, their own age, gender, employment status, and access to medical services. In Table 4.2, the younger group represents parents of the 6;0 to 7;11-year-olds (dark green) and the older group those of the 8;0 to 9;11-year-olds (dark purple).

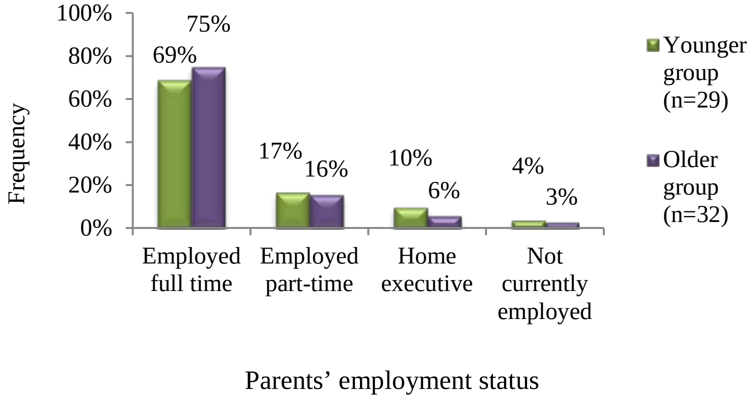
Table 4.2

Description of Parent Participant Group in Phase 3

<table>
<tr><th>Description</th><th>Results (All participants <i>N</i>=61)</th></tr>
<tr><td>Age of children between 6;0- and 9;11 years-old
48% of the parents had children in the younger group and 52% in the older group. The younger group consisted of 55% children who were 6;0–6;11 years old, and 45% who were 7;0–7;11 years old, while the older group consisted of 53% children who were 8;0–8;11 years old and 47% who were 9;0–9;11 years old.</td><td>


</td></tr>
<tr><td>Age of parent participants
The average age of the parents of children in the younger group was 34;3 years ranging from 29 to 49 years compared to those who had children in the older group whose mean age was 39;5 years ranging from 30 to 49 years.</td><td>


</td></tr>
<tr><td>Gender
The majority of the parents in the two groups who completed the HPPS-P were female (mothers) (86% and 97% respectively). Only five were male (fathers) (14% in the younger and 3% in the older group respectively) completed the HPPS-P.</td><td>


</td></tr>
<tr><td>Employment
The majority of parents in both age groups (69% and 75% respectively) were employed full time while 4% and 3% per age group respectively were not employed during the time of data collection. One mother stated that she had to resign from her full-time employment to take care of her sick child with cancer. 17% and 16% per age group respectively had part-time jobs and 10% in the younger group and 6% in the older group were home executives (house wives).</td><td>


</td></tr>
</table>

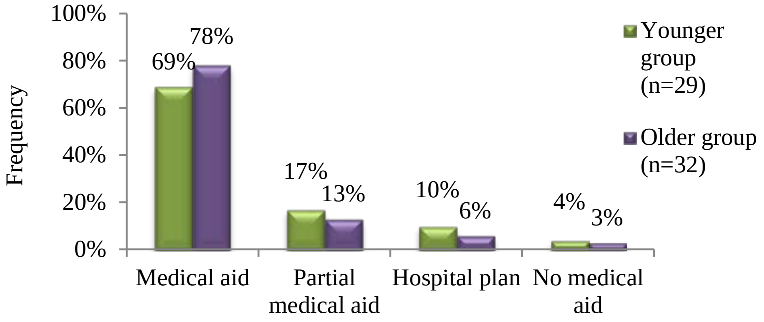
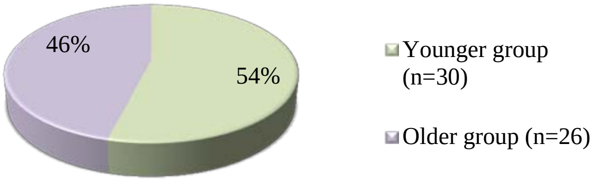
Description	Results (All participants *N*=61)
Access to medical aid The majority of the participants in both groups (69% and 78% respectively) had medical aids that paid for their medical expenses, while 17% in the younger group and 13% in the older group indicated that their medical expenses were partially covered by the medical aid. 10% in the younger group and 6% in the older group had a hospital plan (medical aid only pays when the person is hospitalised). Only 4% and 3% respectively per age group went to a government hospital for medical treatments because they had no access to a medical aid. This data suggests that the majority of participants were financially able to afford a medical aid implying a middle or higher socio-economic status.	 Possible access options for medical treatments

Table 4.2 shows that the mean age of the parents in the two parent respondent groups was 34;3 years and 39;5 years respectively with a range 29 to 49 years and that the parents were mostly in full-time employment, which allowed access to a medical aid to pay for medical expenses.

Table 4.3 portrays the biographical information of participants in the two teacher respondent groups who completed the HPPS-T according to the grade they teach; their overall teaching experience; years' experience in the specific grade they were currently teaching; their age and their first language. Two age groups were included with the younger group (light green) referring to Gr 1 children (typically 6;0–7;11-year-olds) and the older group (light purple) to Gr 3 children (typically 8;0–9;11-year-olds).

Table 4.3

Description of Teacher Participant Group in Phase 3

Description	Results (All participants n=56)
Grade taught 54% teachers taught Gr 1 children (younger group) and 46% taught Gr 3 children (older group). Gr 1 represents the entry and Gr 3 the exit points of the foundation phase.	

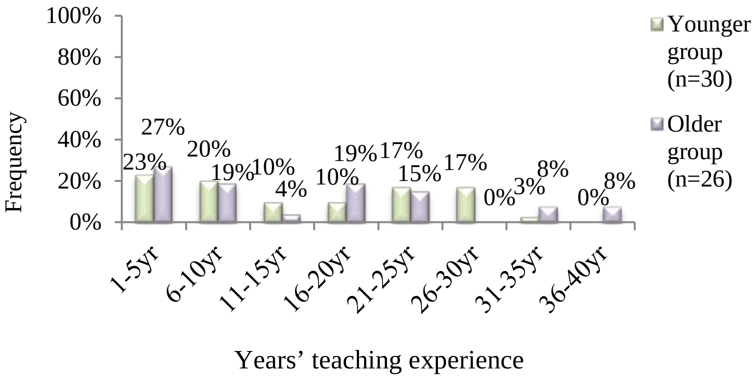
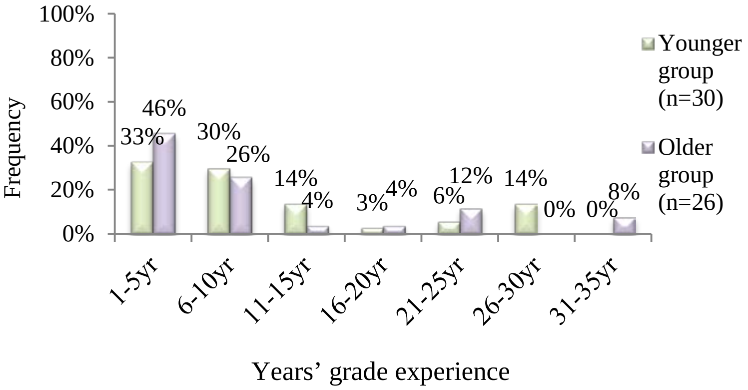
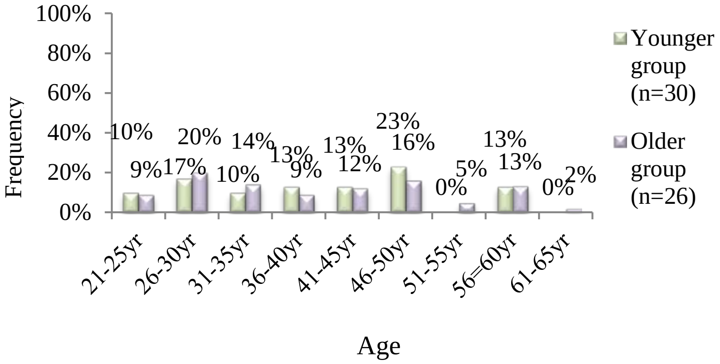
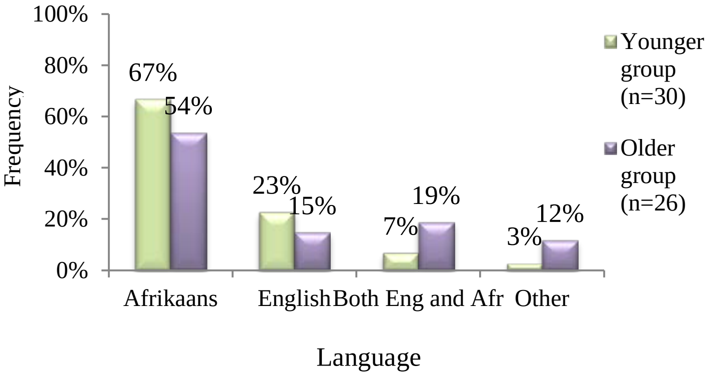
Description	Results (All participants n=56)
Years of overall teaching experience The mean overall teaching experience for the Gr 1 teachers was 15;2 ranging from 1;0 to 34;0 years. The Gr 3 teachers' overall teaching experience was 15;7 years, ranging from 1;0 year to 40;0 years.	
Years of experience teaching current grade The majority of the teachers in both groups had 1 to 5 years' experience teaching the specific grade (33% and 46% respectively). The mean experience of the Gr 1 teachers with the specific grade was 12;9 years, and ranged from 2;0 to 30;0 years. Gr 3 teachers had an average of 10;9 years' experience (ranging from 1 to 35 years).	
Age of teachers The mean age of the Gr 1 teachers was 39;9 years. The youngest Gr 1 teacher was a beginner teacher, aged 22, while the oldest teacher was 60 years old. The mean age of the Gr 3 teachers was 39;5 with the youngest aged 24 years of age and the oldest 62 years old.	
First language of teachers All the teachers taught in schools where English is the LoLT. It became clear that teachers from various language backgrounds taught at English schools. The majority of the teachers were Afrikaans speaking (67% and 54% respectively), followed by English (23% and 15% respectively). The other language category comprised of Sesotho sa Leboa (3%), isiXhosa (3%), isiZulu and Portu-guese (3%), for the older group, with 3% speaking Tshivenda in the younger group.	

Table 4.2 summarises the biographical information of the teachers who participated in the study. The mean age of the teachers in both groups was almost equal namely 39;9 and 39;5 years of age respectively, and their mean years of teaching experience in the specific grade were 15;2 and 17;7 respectively, which indicate that they were experienced teachers. The majority of the teachers in both groups spoke Afrikaans as a first language, although they worked at schools where English was the LoLT.

4.2.4 Material and equipment used in Phase 3

4.2.4.1 Assent and consent forms

The same assent and consent forms as discussed in Section 3.5.4.1 were used.

4.2.4.2 Set of hypothetical physical pain scenarios

The set of hypothetical physical pain scenarios with accompanying vignettes and illustrations, which was adapted as per the pilot study recommendations, was used in Phase 3 (see Section 3.6.5.4). The number of scenarios differed for the six respondent groups following the recommendations from the pilot study. The HPPS-C completed by the children contained 10 scenarios; the HPPS-P completed by the parents contained eight scenarios and the HPPS-T completed by the teachers contained five scenarios.

4.2.4.3 Peabody Picture Vocabulary Test (PPVT-IV)

The same procedure and interpretation of test scores as discussed in Phase 2 (Section 3.6.4.6) were followed.

4.2.4.4 Scripted interview guide

The same scripted interview guide as discussed in Section 3.6.4.4 was used during data collection from the child participants by means of an in-depth interview using the HPPS-C.

4.2.4.5 Procedural checklist

The same procedural checklist as discussed in Section 3.6.4.5 was used by an independent observer to score 30% randomly selected videos of the in-depth interviews to ensure procedural reliability.

4.2.4.6 Recording equipment

Both a video camera (Panasonic HC-C100) and an audio recorder (Olympus DM650 digital voice recorder) as discussed in Section 3.6.4.7 were used. The audio recording was used to make the verbatim transcriptions and the video recordings served to check for procedural integrity.

4.2.4.7 iPad tablet with illustrations/Toshiba laptop with PowerPoint presentation

An iPad tablet with illustrations and a Toshiba laptop that served as a back-up system (see Section 3.6.4.8) were used.

4.2.5 Data collection procedures

4.2.5.1 Ethical considerations

Ethical principles, namely respect for persons, beneficence and justice should be obeyed when involving human participants in a research study (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Respect for persons involves both autonomy (which implies that participants should be informed of all aspects of the study as well as of their freedom to decide whether they would like to participate in the study or not) and entitlement to protection (Rossi, Reynolds, & Nelson, 2003). Children are typically regarded as a vulnerable research population, and thus need specific protection when included in research (Rossi et al., 2003). Therefore, parental consent as well as child assent was required. Once ethics approval had been granted by all relevant authorities and parents had consented, parents' informed consent was obtained by providing them with a letter with detailed written information on the study. They were requested to give their written response to indicate their consent or refusal for their child to participate in the study (Appendix R). The word "assent" differentiates the child's agreement from the legally valid consent provided by parents (Jonsen, 1978). Although children mature in their ability to understand and engage themselves in various activities, the ethical principle of respect acknowledges that this is a developing skill (Jonsen, 1978). The reason for obtaining child assent is to show respect for the child's developing autonomy and therefore children's objection to participate should be binding. In the current study, only children whose parents gave consent were included in the study. After the parents had given their consent, children also gave written assent using a symbol-based assent form on which they could indicate whether they wanted to participate in the study or not, and whether they knew that they could withdraw at any time from the study without any negative consequences.

The principle of beneficence involves doing no harm to the participants and to maximise possible benefits and minimise possible harms. During data collection, the children were not exposed to any risk or harmful situations and they all understood that this study was to benefit children with significant communication difficulties, as the children would be given access to the suggested vocabulary list.

By adhering to the scripted interview guidelines, all children were treated equally, thus acknowledging the principle of justice (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).

4.2.5.2 Data collection: Child participants

The researcher fetched the individual children from their classrooms and accompanied them to an empty office where the interviews took place. The child sat next to the researcher at a small table to enable the child to see the PPVT-IV pictures as well as the iPad. The children in the hospital settings were interviewed while they sat in their hospital beds with the researcher standing next to the bed, displaying all the materials on the hospital tray in front of the child. The complete interview was video-recorded without including the child to only focus on the procedure for procedural integrity. The interviews did not exceed 30 minutes on average.

In-depth interviews were conducted using the scripted interview guide (Appendix M). The participants were welcomed and the researcher introduced herself. Informed assent was obtained from each child who completed a symbol-based assent form (Appendix G). The researcher explained the study to the child by working through the assent form item by item. By implementing a symbol-based assent form and discussing all items with the child participants, the researcher accommodated those younger children who probably did not yet have the literacy skills needed to complete assent forms by independently.

4.2.5.3 Data collection: Parent participants

Parents received a letter of request (Appendix R) to participate in the study via email. All the parents who consented received a link to the online HPPS-P on SurveyMonkey® with a request to complete the questionnaire within a week upon receipt of the link. Follow-up emails were sent to parents who did not complete the HPPS-P within the set time. Thereafter all the parents who consented were asked by means of a snowball procedure (McMillan & Schumacher, 2001) to forward the link to the HPPS-P to parents whom they knew to reside in the same geographical area and who had children between 6;0 and 9;11. In total 61 parents successfully completed the online HPPS-P.

4.2.5.4 Data collection: Teacher participants

After approval was obtained from the relevant authorities, Gr 1 and Gr 3 teachers from the same seven schools as the child participants, received letters outlining the study and requesting their participation. The teachers had the option to complete the HPPS-T online or to receive it in hard copy print format. Only 13 of the 56 teachers (10 Gr 1 teachers and three Gr 3 teachers respectively) chose to complete the online HPPS-T. The remaining 43 teachers (20 Gr 1 teachers and 23 Gr 3 teachers respectively) completed the printed HPPS-T. The researcher arranged to collect the completed forms at the different schools after a week.

4.2.6 Data Analysis

Raw data obtained from the child respondents was transcribed from the audio recordings. These transcriptions, as well as the written responses from the adult respondent groups were transformed into a data set through the process of identification of relevant words and phrases, entering and coding the data.

First of all, all of the recorded in-depth interviews with the children were transcribed verbatim (Poland, 1995) using a word-processing program and adhering to a predetermined set of transcription rules (Appendix P). Once the data set had been checked by the second person for consistency of the transcription rules, it was transferred to an Excel-format for further analysis. The same procedure to determine transcription consensus as described in Section 3.5.6 was followed. A second person checked and compared 30% (22) randomly selected transcriptions made by the transcriber (researcher) against the audio recordings. This second person agreed that 19 of the 22 total possible scores (a score of 1 was allocated for a 100% correct transcription) were transcribed correctly and that no obvious errors were made during the transcription process:

$$\text{Percentage agreement} = \frac{\text{19 number of agreements}}{\text{22 number of agreements plus disagreements}} \times 100$$

$$= .86 \times 100$$

$$= 86\% \text{ agreement between two transcribers}$$

The 86% percentage of agreement reached between the two transcribers signified an acceptable level of reliability (85%) of the transcriptions (Heilmann et al., 2008). The transcriptions were transferred to an Excel-format.

Next, the researcher and second coder identified pain-related words and phrases within all verbatim transcriptions of children's data, keeping in mind the questions asked and the five categories of pain-related words and phrases that these questions attempted to tap (see Section 3.6.3.4). For example, one participant gave this answer to one of the questions ("*What would Ziggi say or do to make it better?*"): "Tell his mother and he would lie in bed." The pain-related phrases extracted from this transcribed answer were [Tell his mother] and [lie in bed] as these relate to vocabulary to request help or manage pain and to cope with pain. Each unique phrase and/or word was given a unique number. Identical phrases/words were given identical numbers. In this way, the total number of unique pain words and phrases could be determined. A total of 549 words and/or phrases were identified within the children's data set.

Subsequently, the parents' and teachers' data sets were transferred to an Excel format. Identical procedures were followed to identify pain-related words and/or phrases. The same numerical codes allocated to the children's data set were assigned to the same pain-related words and/or phrases in the parents' or teachers' data sets. If there were new pain-related words and/or phrases within the parents' or teachers' data sets that did not appear in the children's data, new numerical codes were added. Altogether 80 new words and/or phrases were identified in this manner, which brought the total number of words and/or phrases to 629.

The researcher then worked together with the second coder, employing a deductive thematic analysis approach (Braun & Clarke, 2006). This resulted in six mutually identified and agreed upon categories based on earlier research (Ely, 1992; Franck et al., 2010), and the results of the systematic review conducted for this study (Johnson et al., 2015). A six category was also created to capture all the responses that did not fit the specific categories. All the identified pain-related words and/or phrases were then categorised into these pain-related categories (Appendix T), namely:

(a) vocabulary to describe pain (Azize et al., 2013; Franck et al., 2010; Johnson et al., 2015);

(b) vocabulary to direct the actions of others in response to the pain/injury (Azize et al., 2013; Ely, 1992);

(c) vocabulary to describe the location of pain (Ely, 1992; Franck et al., 2010);

(d) vocabulary to describe the causes of pain (Franck et al., 2010);

(e) vocabulary to describe strategies to cope with pain (Johnson et al., 2015);

(f) other. (Words and/or phrases that could not be categorised into any of the five categories above were allocated in this sixth category.)

The words in the sixth category were then coded by consensus (between two coders) means of an inductive thematic analysis approach (Braun & Clarke, 2006). The two coders agreed that these words could be categorised into two new pain-related categories, namely (f) vocabulary to reflect on strategies of how the pain could have been prevented, and (g) vocabulary to indicate the consequences or influence of the pain or injury on activities and participation. Table 4.4 provides a clear layout of the seven pain-related categories and their definitions. In order to categorise the pain-related words and/or phrases more easily, the researcher and independent coder worked together to identify and define a further 23 sub-categories as displayed in Table 4.4. A reference related to the different constructs within the socio-communication model of pain is also provided as theoretical justification for each pain-related category.

Table 4.4

Categories, Definitions, Sub-Categories, Definitions of Pain-Related Vocabulary

Seven main categories of pain-related vocabulary and their definitions	**23 Sub-categories and definitions**
A Vocabulary to describe pain: Words or phrases that explain the physical feeling of how the pain is experienced *(Pain expression – socio-communication model of pain)*	A1 ***Exclamations***: A sudden cry or remark, to specifically express surprise, anger, or pain A2 ***Vocalisations and verbalisations***: Utterances/noises to express pain A3 ***Descriptors***: Vocabulary used to describe a pain experience or feelings of pain A4 ***Sensory words***: Vocabulary related to sensation or the physical senses; transmitted or perceived by the senses A5 ***Intensifiers***: Vocabulary that indicates the intensity/severity of the pain experience A6 ***Comparisons or metaphors***: Vocabulary used to compare the feeling of pain with something else, i.e. “like ....” or “feels as if ...” A7 ***Evaluative words***: Vocabulary to evaluate/assess the pain experience
B Vocabulary to direct others' actions in response to the pain/injury/illness: Words or phrases that specify to others what to do, or not do when the child is in pain – these include requests for help or assistance; specifications of how treatment should be done; protests from the child and remedies to be given to ease the pain *(Decoding – socio-communication model of pain)*	B1 ***Actions***: Vocabulary to indicate to others’ what to do, or not to do when child is in pain B2 ***Places***: Vocabulary to indicate where the child wants to/should go when in pain B3 ***Remedy***: Vocabulary to indicate what medicine or treatment should be provided when child is in pain
C Vocabulary to describe the pain location and visible signs to the actual tissue damage as a result of the physical injury: Words or phrases to give an account of all characteristics or features of the place of injury – both internally and externally as well as what the injury looks like and how this injury affects the body structure and functions of the child. *(Encoding – socio-communication model of pain)*	C1 ***Site of injury***: Vocabulary to indicate the place of injury on the body C2 ***Visible signs of injury***: Vocabulary to give an account of the characteristics and features – both internally and externally – of the actual tissue damage as a result of physical injury
D Vocabulary to describe the causes of the pain: Words or phrases that describe the incident that led to the pain experience, including reasons and explanations of actions that resulted in the injury *(Intrapersonal and encoding – socio communication model of pain)*	D1 ***Internal causes of pain***: Vocabulary to describe the incident due to own mistake that led to the pain experience (could have avoided injury/cause of pain) D2 ***External causes of pain***: Vocabulary to describe the incident inflicted by others – thus outside of own control – that led to the pain experience (could not have avoided injury/cause of pain)
E Vocabulary to describe strategies used to cope with pain: Words and/or phrases of attempts or actions to deal with pain *(Intrapersonal factors– socio-communication model of pain)*	E1 ***Self-talk***: Vocabulary used as a form of self-regulation to deal better with pain E2 ***Actions to cope with pain***: Vocabulary used to indicate what to do to deal effectively with pain E3 ***Positive outcomes***: Vocabulary to affirm that the pain will become better

Seven main categories of pain-related vocabulary and their definitions	23 Sub-categories and definitions
	E4 ***Distractions***: A thing/action that deflect attention from pain
F **Vocabulary to reflect on strategies of how the pain could have been prevented:** Words or phrases that show that the child thought carefully about how the pain could have been avoided or about lessons learnt for the future. *(Encoding – socio communication model of pain)*	F1 ***Reflect on what happened*** (past): Vocabulary to reflect on how what happened that caused the pain could have been prevented F2 ***Reflect on how to prevent pain***: Vocabulary to indicate how the pain can be avoided in the future
G **Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation:** Words or phrases that indicate the outcome(s) or results of the pain or injury that affect (a) the child's participation in activities; (b) rewards received as a result of the injury; and (c) emotional responses and reflections as a result of the pain/injury (*Encoding – socio-communication model of pain)*	G1 ***Physical outcome***: Vocabulary to indicate the physical consequences or influence of participation in activities as a result of pain (Can't do something as a result of pain/pain denies child of something) G2 ***Secondary gain***: Vocabulary to explain the extra "rewards" received as a result of the pain experience (such as getting attention or receiving some consolation as a result of pain) G3 ***Emotional response as result of pain***: Vocabulary to describe emotions due to pain experience

Table 4.4 highlights the seven pain-related categories and 23 sub-categories that were identified and mutually agreed upon by the researcher and second coder. Next, the researcher and second coder mutually agreed on the categorisation of all the words and/or phrases in these said categories. The numerically coded data were subsequently entered into the SAS® software programme (SAS, 2011) for statistical analysis.

Descriptive and inferential statistics were calculated in SAS® (SAS, 2011). Frequencies, means and standard deviations were used to organise the data of the six respondent groups (children, parents and teachers). The number of different words/phrases was determined; percentage of participants using words/phrases from different categories was determined and compared among the various respondent groups. In order to meet the sub-aims of Phase 3, data derived from the HPPS-C, HPPS-P and HPPS-T were compared using three-way as well as pairwise comparisons. Statistical inferences were made by using either the Pearson's Chi-Square Test or Fisher's Exact Test to compare data in the six respondent groups. Pearson's Chi-Square Test was used when the expected frequencies within the cells were 5 or more. If 50% of the cells had expected counts less than 5, Fisher's Exact Test was performed. Furthermore, words and/or phrases that occurred 10 times or more in all six respondent groups were determined. A composite list of pain-related words and/or phrases that occurred in all six respondent groups was compiled. The pain-related words and/or phrases derived from this process were categorised according to the pain-related categories (Franck et al., 2010; Jerrett & Evans, 1986; Johnson et al., 2015).

4.2.7 *Issues of validity and reliability*

The following strategies were implemented to ensure validity and reliability of the quantitative phase (Phase 3) of this research.

Procedural integrity (Creswell, 2009) was ensured since a scripted interview guide was adhered to (Appendix M) in the in-depth interviews when the HPPS-C was completed with the children (Creswell, 2009). The second coder, who worked independently, used the procedural checklist (Appendix N), and looked at a randomly selected 30% (22) of the video recordings. She evaluated all the steps (97) as indicated on the checklist to ensure that the exact same standard interview procedure was followed during the different interviews (Creswell, 2014), thereby heightening procedural integrity. The percentage of adherence to the procedures was calculated by the following formula:

$$\text{Percentage agreement} = \frac{\text{2014 number of steps correctly executed}}{\text{2134 total number of steps}} \times 100$$

$$= .94 \times 100$$

$$= 94\% \text{ adherence}$$

Across the 22 interviews (30% randomly selected videos) that were checked, 2014 out of a possible 2134 steps were completed correctly, resulting in a procedural reliability of 94%.

A verbatim transcript was made of each interview following the transcription rules developed and tested in Phase 2 (see Appendix P). To ensure reliability, an independent person listened to 30% of randomly selected audio recordings, and compared them to the researcher's transcriptions (see Section 3.5.6). By using the following formula, a transcription agreement of 86% was noted, indicating that the transcriptions were correct:

$$\text{Percentage agreement} = \frac{\text{19 number of agreements}}{\text{22 number of agreements plus disagreements}} \text{ x } 100$$

$$= .86 \text{ x } 100$$

$$= 86\% \text{ agreement}$$

Using a deductive thematic analysis (Braun & Clarke, 2006), the researcher and second coder worked together to discuss and evaluate the pain-related vocabulary in order to agree on clearly defined categories (A, B, C, D, and E) as well as the “other” category that emerged from the HPPS-C, HPPS-P and HPPS-T data (Leedy & Ormrod, 2010). The researcher consistently ensured that there was not a drift in the definition of the categories or sub-categories that could possibly result in a shift in the meaning of the categories during the categorising process (Creswell, 2014). This was done by constantly comparing the data with the definitions of the categories or sub-categories and by writing memos about the categories and their definitions (Creswell, 2014). The researcher and second coder then used an inductive thematic analysis to categorise those words and/or phrases that had been categorised in the “other” category into two new and mutually agreed categories, F and G (see Section 4.3.6). The same process was followed for the categorisation of the data into the sub-categories.

Validity of the data was enhanced by exploring the phenomenon from the multiple perspectives of the six respondent groups (Kildea et al., 2011).

4.3 Phase 4: Social validation

As the outcome of this study was to develop a socially valid composite list of pain-related vocabulary for children who could benefit from AAC (for a temporary or permanent period), three literate adults who use AAC were requested to participate in a stakeholder review. The involvement of persons who use AAC in the development of this list may improve its quality because these stakeholders could consider the suitability and functionality of the selected vocabulary (Balandin & Iacono, 1998a; Beukelman et al., 1991). Hence, the voices of these persons who use AAC were heard through this stakeholder review. This should result in the improved identification and management of this vulnerable population’s pain as seeing that the stakeholder group have lived experiences and intimate insider knowledge of the vocabulary that would be required (Kildea et al., 2011). Persons with significant communication difficulties experience challenges in expressing their painful experiences (Cano et al., 2009) and need to be able to report their pain. One way to achieve this is to provide them with access to the relevant vocabulary either on low or high technology AAC systems. The purpose of the stakeholder review with persons who use AAC was to determine if the compiled composite list of pain-related vocabulary, which may be incorporated into an AAC system, was appropriate for use in specific contexts related to pain.

4.3.1 Aims of Phase 4

The main aim of Phase 4 was to determine by means of a stakeholder review of literate adults who use AAC – whether the compiled list of pain-related vocabulary (words and/or phrases) would be appropriate for use in scenarios that result in physical pain in order to socially validate the composite list of pain-related vocabulary (words and/or phrases).

The following four sub-aims were formulated:

(i) Determining the appropriateness of the compiled list to answer questions based on three hypothetical physical pain scenarios;

(ii) Determining the extent to which words and/or phrases from the pain-related main and sub-categories were used;

(iii) Gathering participants' suggestions on how to improve the vocabulary list (words and/or phrases) as well as gathering their perceptions about the display and presentation of this vocabulary on an AAC system for children;

(iv) Suggesting a final list of socially validated pain-related vocabulary (words and/or phrases) that would fulfil the main aim of the study.

4.3.2 Steps of Phase 4

Figure 4.3 provides a schematic outline of the steps followed during Phase 4.

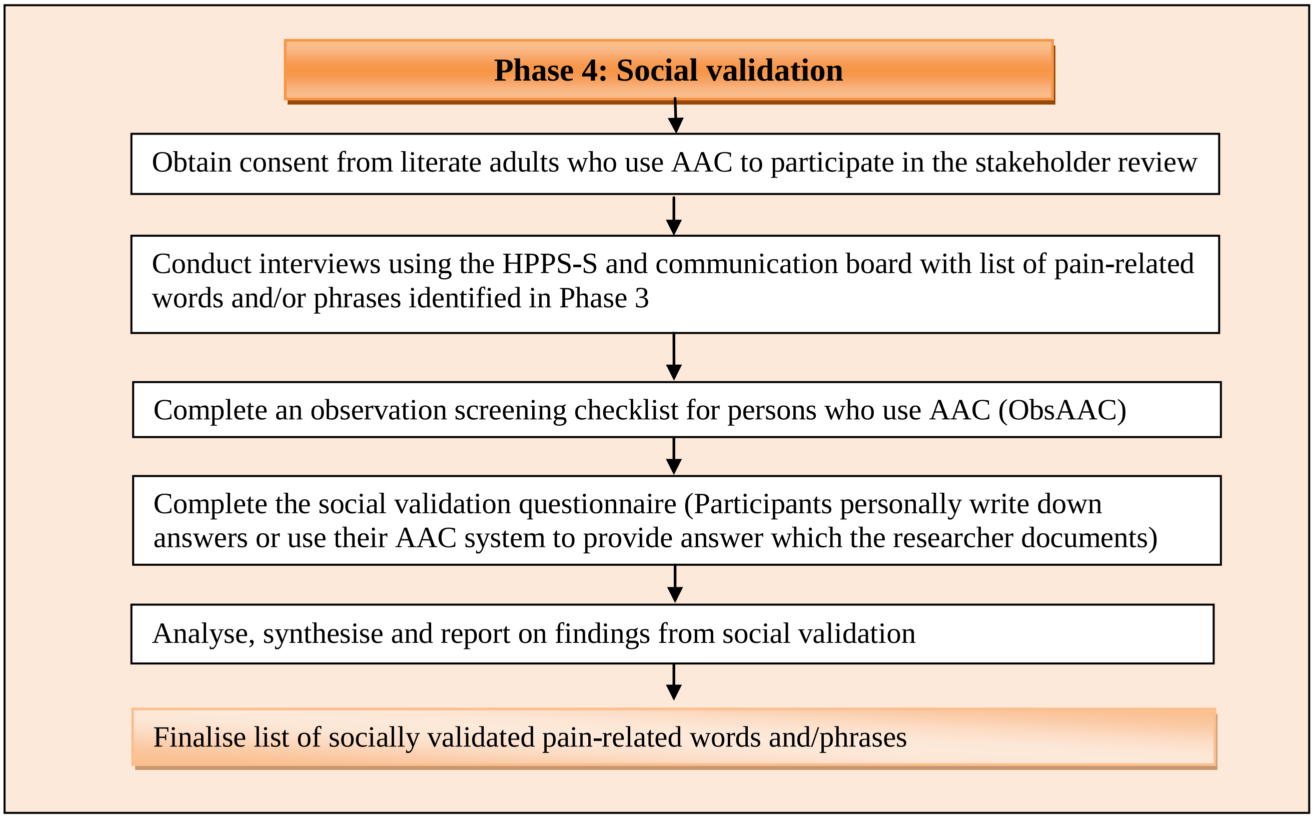


Figure 4.3. Overview of the steps followed in Phase 4.

4.3.3 Participants

Adults, who use AAC and who are literate in English, were purposively selected and recruited based on the premise that they would be able to provide rich data that would be appropriate to participate in the social validation of the composite pain-related vocabulary list. They were selected due to their literacy skills in English, which would enable them to participate beyond the suggested vocabulary list, and also because of their personal experiences of using AAC and understanding the benefits and challenges of vocabulary availability.

4.3.3.1 Selection criteria

The criteria for the selection of the participants for the stakeholder review are set out in Table 4.5. This table also includes a brief description of the screening method as well as a justification for each criterion.

Table 4.5

Selection Criteria for Adults who use AAC

Criteria	Method	Theoretical justification
Communication boards: Should be familiar with the use of low-technology communication boards	Self-report	Persons who use AAC have experience of preselected vocabulary on communication boards to enable them to socially validate vocabulary for inclusion in an AAC system (Lollar et al., 1982).
Language: Should be competent in English (receptive and expressive language)	Self-report	The study aimed to identify a list of English words useful to English-speaking children in South Africa who need AAC.
Auditory and visual skills: Should be within normal parameters (including corrected vision or hearing)	Self-report	The participants have to listen to vignettes and search for the answers on a communication board.
Literate: Should be able to use traditional orthography receptively and expressively	Self-report	The participants should be able to read the words and comment on them where applicable, by using text on the provided communication board or on their current AAC system.
Hospitalisation: Should have been hospitalised at least once before in the past five years	Self-report	Previous hospitalisations influence the use of pain-related vocabulary (Franck, et al., 2010). Participants needed to provide feedback on specific hospital procedures.

Table 4.5 presents a clear layout of the five criteria used for selecting literate adults who use AAC to participate in the stakeholder review process in Phase 4 of the study.

4.3.3.2 Participant recruitment

The potential participants who met the selection criteria and resided in the same geographical area from where participants had been recruited for Phases 1 to 3 (Tshwane South) were contacted via email or short message systems (SMS). All participants were known to the researcher as they were part of an empowerment programme for adults who use AAC, namely Fofa, which is the only programme of its kind in South Africa. All three potential participants gave informed consent to participate after they had received a letter with detailed information about the study (Appendix U).

4.3.3.3 Description of participants

The adults who use AAC are described in Table 4.6 according to their current age and age at onset of the injury; gender; disability type; language (first language and language of speech-generating system) as well as their speech ability. Their highest qualification and employment status are also given, followed by a description of their hospitalisation history. Finally, the challenges they experience due to their disability, as well as their gross and fine motor skills, mobility, and AAC system, are described.

Table 4.6

Adults who use AAC who Participated in the Social Validation Phase (Phase 4) (N=3)

Category	Participant 1	Participant 2	Participant 3
Age	28 years	30 years	35 years
Age at injury	11 years	12 years	25 years
Gender	Female	Male	Male
Disability type	Neurological damage due to unknown medical condition (Acquired)	Head injury (Acquired)	Head injury with mobility impairment (Acquired)
First language	SiSwati	Afrikaans	Afrikaans
Language of speech generating device	English	English	English
Speech ability	Uses vocalisations, gestures, uses no speech; Uses AAC	Uses gestures and some speech, but unintelligible; Uses AAC	Uses no speech; Uses AAC
Highest qualification	Gr 12	Gr 6	4 years post-school
Employment status	Part-time employed	Not employed	Not employed
Last hospitalisation (during past 5 years)	Monthly for one day	2012	2011
Reasons for hospitalisation	Unclear diagnosis – currently receiving monthly treatment for stomach ulcer	Surgery to remove his wisdom teeth (2012) Two surgeries to add steel plates with screws to broken collar bone (he twice fell out of wheel chair) (2010; 2012)	Gall bladder surgery - complications Spleen surgery
Number of times hospitalised over the past 5 years	Multiple times – was in hospital the last time for 2½ weeks of treatment	Multiple times	Multiple times – for example 3 months in hospital due to severe complications after surgery
Challenges due to disability	No speech. Difficulty to communicate so that unfamiliar people can understand	Difficulty to speak so that unfamiliar people can understand; Difficulty to concentrate, remember or make decisions; Frequent worry,	No speech. Difficulty to communicate so that unfamiliar people can understand; Frequent worry, nervousness or anxiety;

Category	Participant 1	Participant 2	Participant 3
		nervousness or anxiety	
Gross motor skills level according to GMFCS*	Level I	Level V	Level V
Fine motor skills functioning level according to the BFMF**	Level II	Level V	Level IV
Mobility	Ambulatory	Uses wheelchair	Uses wheelchair
AAC system	AAC low-technology communication system (Alphabet communication board or pen and paper); Non-dedicated device (Android tablet) with AAC software using text-to-speech technology	AAC low-technology communication system (Alphabet communication board); Non-dedicated device (Windows-based laptop) with AAC software using text-to-speech technology	AAC low-technology communication system (Alphabet communication board or pen and paper); Dedicated AAC device with voice output (Lightwriter)

*Gross Motor Function Classification System (Palisano et al., 1997).
** Bimanual Fine Motor Function (Beckung & Hagberg, 2002; Himmelmann, Beckung, Hagberg, & Uvebrant, 2006).

It is clear from Table 4.6 that all three participants (one female and two males) used low-technology communication boards as well as high-technology devices (one a dedicated and two non-dedicated speech-generating devices) with English as voice output. All of the participants had acquired conditions. The two male participants, who were in wheelchairs, were severely physically impaired with poor gross and fine motor skills, while the female participant was ambulatory and consequently had better gross and fine motor skills, than the male participants.

4.3.4 Material and equipment used in Phase 4

The following material and equipment were used during Phase 4:

4.3.4.1 Consent form

The same consent form that was described in Section 3.5.4.1 was used. All participants were able to independently read and sign it.

4.3.4.2 HPPS-S

The HPPS-S consisted of three vignettes namely Scenario 5 (Ziggi had an operation), Scenario 7 (Ziggi has a headache – bodily pain) and Scenario 10 (Ziggi gets a drip). The reason for using only three scenarios was that participants were selected on the basis that they would be able to relate to the medical-related scenarios and would therefore be able to provide feedback. Scenarios 5, 7 and 10 also focussed most closely on the main aim of the study. In addition, only the first three questions of the original vignettes from the HPPS-C were asked to the adults to avoid fatigue due to the number of keystrokes each answer necessitated. The questions used were: *"What would Ziggi say about his/her hurt?"; "What would Ziggi say to mommy about his/her hurt?* and *"What would Ziggi say or do to make the hurt better?"*

4.3.4.3 iPad tablet with illustrations

The same iPad tablet as described in Phase 3 was used.

4.3.4.4 Pain-related and alphabet communication board

In order to socially validate the composite list of pain-related vocabulary pertaining to physical pain, a communication board was compiled that consisted of the 87 words and/or phrases extrapolated from the data in Phase 3. The board was an A4 size (30.3 x 40.6cm) laminated cardboard. The pain-related communication board was printed on the front and an alphabet board on the reverse side.

The layout of the pain-related words and/or phrases was done according to the seven pain-related categories as discussed in Section 4.2.6. Each main category was randomly colour-coded for organisational reasons as colour-coded backgrounds could help a user to find target locations more easily (Thistle & Wilkinson, 2009). Colour coding also assisted the user to communicate more accurately and at a faster rate (Alant, Kolatsis, & Lilienfeld, 2010) as research has shown that grouping objects of the same colour made it easier for the user to locate the object in the display and to do so in less time (Wilkinson, Carlin, & Jagaroo, 2006). Therefore, the different categories were grouped together in the same location of the board. The colour coding did not follow the Fitzgerald key (Goossens et al., 1994) since the word list did not contain core words in different word classes, and hence that type of coding (e.g. yellow colour for nouns and pink for verbs) was inappropriate.

On the current communication board, the words against the pink background were words that described pain (Category A). The words against the blue background were words that informed other people what to do when the participant was in pain (Category B) while the orange background had words that indicated where the pain was and what the injury looked like

(Category C). The words against the green background were words indicating causes of pain – either internally or externally (Category D) and against the yellow background were words that could be used to cope with pain (Category E). The purple background contained words that participants could use to reflect on how they could have prevented the pain (Category F). Finally, the words against the brown background indicated the consequences of the pain and how it influenced the person's participation (Category G).

The shades of the specific colour within each main category indicated the sub-categories. The differences in the shades of the specific colours were not discussed with the participants and were only used during the interview to assist the researcher to quickly see in which sub-category the selected words and/or phrases chosen by the participants were. Using different shades increased the accuracy of documenting the participant responses.

The option of "I don't know" or "not on this board" was added to the pain-related communication board to assist the participant to indicate if he/she could not answer the question. Hence, an alphabet board was provided on the reverse side of the pain-related communication board, should the participants not find an answer on the pain-related board. However, no participants deemed it necessary to use the alphabet board to answer any of the questions, as they were able to find answers for all the questions posed on the pain-related communication board. The example of the pain-related communication board (front) is displayed in Figure 4.4. Please note that the font size of the example provided on the next page differs from that on the original board that was larger than the A4 size of the thesis. A larger font size was used on the original pain-related communication board that was used during the social validation process, to ensure the participants could easily see and read the words and/or phrases.

A1	A2	A3	A4	A5	A5	A7
• eina • ouch • ouchie • ouwa • ow • owie	• cry/cries/crying • I screamed • moan	• blood/bleeding • hurt (my body part) • I feel sick • it pains/paining • it is sore • the sore aches/aching	• hot • the sore sting(s)/is stinging • the sore was burning	• feels really bad • hurts very bad/hurt a lot • It was painful • really hurt • very painful/so painful	• very sore/really sore/so sore • very, very sore/ extremely sore/really, really sore	• I don’t feel well • it feels not nice/ • don't feel nice
E1 E2	**B1**	**B2**	**B3**	**C1, C2**	**D1**	**D2**
• I am okay • I’m fine/it is fine • it is not sore at all/ • wasn't that sore E2 • do nothing • hold it/hold on hurt • I want to go home • I want to sleep/go to sleep • lie down • lie in bed • I rub it • rest for a little bit	• clean it • give me a hug/ • I need a hug • hold my hand • make it better • please help • stop hurting/ • poking me • take it (thorns/ • splinter) out • wait until it is better • I am okay • I’m fine/it is fine • it is not sore at all/ • wasn't that sore	• go to the doctor • go to the hospital • go to sickroom/ office/principal	• drink water/ • put water on the sore • medicine/ medication • put cold water on it • put on bandage • put on cast • put on cream/ • special cream • put on ice/ice pack • put on ointment • put on plaster • put on something	C1 • There are thorns in my … (body part) C2 • it is swollen • break (body part) • I have a blister • my skin has scratches	• I fell • I have a headache	• a dog ran across • the street • ball hit me • I was hit by a ball • I touched the warm pot/kettle/iron • it was him • the bee stung me • there is a splinter in my skin • they gave injection/ inject
E3	**E3, E4**	**F1**	**F2**	**G1**	**G1, G3**	
• it will feel better/will be better • doctor will help to make it better	• pray to God/Allah to make it better E4 • let's play	• I pulled the brakes too hard	• be more careful	• can't move (body part) • facial expressions • I can't talk/speak (it is sore)	• I want to vomit • point at place of injury • G3 • I am sorry Mom (that I got hurt)	I don’t know Not on this board

Figure 4.4. Example of the pain-related communication board used in Phase 4.

4.3.4.5 Social validation questionnaire

Table 4.7 reflects the compilation of the social validation questionnaire (Appendix V) featuring the question number, aspect investigated, type of question, reason for inclusion and theoretical justification.

Table 4.7

Development of Social Validation Questionnaire

Question number	Aspect	Type of question	Reason for inclusion	Theoretical justification
Section A1: Background information				
1-5	Questions 1-7 in this questionnaire are identical to those in the questionnaire described in Table 3.3, except that questions 4 (nationality) and 6 (other languages) of the original questionnaire were omitted.			
Section A2: Information about the abilities of the person who uses AAC				
6-8	Challenges experienced due to disability	Multiple-choice question	To determine the challenges the person who uses AAC experiences due to his/her disability.	Persons who use AAC are often exposed to needle procedures, (blood sampling, IVs, surgery) as a result of their disability (Dubois et al., 2010) and should be able to comment on high frequency pain-related vocabulary for inclusion in a final list.
9	AAC system	Multiple-choice question	To determine the type of AAC system the person uses.	One of the selection criteria is that the person should be familiar with the use of a low-technology communication board with preselected vocabulary.
10	Previous hospitalisations and reasons for hospitalisation	Open-ended question	To determine if the person who uses AAC have had previous hospitalisations over the past five years	Previous experiences of hospitalisations influence the use of pain-related vocabulary (Franck et al., 2010), and persons who use AAC may have experiences in hospital where they may not have been able to communicate their pain.
Section B: Information about the pain-related words and/or phrases on the communication board				
11-17	Perceptions of the participants regarding the use of the words and/or phrases on the pain-related communication board	4-point Likert scale Open-ended question	To determine the perception of the person who uses AAC regarding the use of the pain-related words on the communication board.	In the past, AAC systems did not have the capacity to include a large number of vocabulary items (Lollar et al., 1982), which caused persons who use AAC to experience the impact of having insufficient or incorrect vocabulary to meet their communication needs.

4.3.4.6 Observation screening checklist for persons who use AAC (ObsAAC)

An observation screening checklist (ObsAAC) (Appendix W) was compiled to observe the persons who use AAC and make notes about the following: their communication/speech ability; the AAC system used (e.g. type of system and language on speech-generating device); mobility; their gross and fine motor abilities based on the GMFCS (Palisano et al., 1997) and the BFMF (Beckung & Hagberg, 2002) respectively; their accuracy in pointing and rate of retrieving target objects, and their rate of successfully retrieving target objects (see Appendix W). To determine the participants’ pointing accuracy they were asked to point at five different words and/or phrases that were in different locations on the communication board, namely “eina” (top left corner), “I don’t feel well” (top right corner), “put on cast” (centre of board), “doctor will help to make it better” (bottom left corner) and “not on this board” (bottom right corner). A 100% accuracy rate was achieved by all three participants. The rate at which selections were made,was an average of 1 second for Participant 1; 22 seconds for Participant 2 (range 12 to 31 seconds), and 19 seconds for Participant 3 (range 7 to 23 seconds).

4.3.4.7 Scripted interview guide for HPPS-S

The script described in Section 4.2.4.4 was amended (Appendix X) to reflect the HPPS-S. Each participant was visited individually and after exchanging greetings, the researcher explained the aim of the validation process. The layout of the communication board was explained in terms of colours and categories. It was explained that the board consisted of all the words and/or phrases that had been used or suggested 10 times or more by children, parents and teachers in Phase 3 of the study. The researcher discussed all the colours on the board and then read out the words and/or phrases with the participant to ensure the participant was familiar with the range of words that were included in the board. Finally the three scenarios of the HPPS-S were discussed.

4.3.4.8 Recording equipment

A video camera (Panasonic HC-V100) with tripod was used to video-record the procedure. This visual recording focused on the communication board and not the individual. The researcher confirmed each participant’s selection orally to ensure that his/her choice was correctly documented. Audio recordings were deemed inappropriate for this activity where the communication board was used as all non-spoken communication attempts (e.g. pointing) would be missed.

4.3.5 Data collection procedures

4.3.5.1 Ethical considerations

Ethics approval was obtained from the Research Ethics Committee, Faculty of Humanities, University of Pretoria, and after the participants consented, the social validation phase of the study commenced.

4.3.5.2 Procedures

Once they consented to participate, an example of the pain-related communication board was emailed to the participants to allow them to familiarise themselves with the layout and content (words and/or phrases) of the board before the interview. The researcher visited the two male participants at their homes as they were not employed. The female adult was met at her place of employment.

All the participants sat either in their wheelchair or on a chair next to the researcher at a table. The communication board was placed in front of the participant on the table where it could easily be seen, and where the participant could have easy access to it, given the unique motor skills of each. During the interview, the participants used direct selection (pointing with a finger or a pencil) to indicate their choices on the communication board. The researcher verbally confirmed the word or phrase that was indicated to ensure that the correct response was captured.

It was explained to the participants that the colours had been selected randomly merely to enhance visual discrimination. For example, blue and green were not placed next to each other to make it easier for the participants to locate the different types of words and/or phrases that he/she was looking for.

The iPad with the illustration of Ziggi was positioned next to the communication board. After discussion of the vocabulary items and colour coding on the communication board, the vignettes of the three scenarios (Scenarios 5, 7 and 10) were shared and questions were asked. All participants had to answer the questions using the communication board that was supplied to them (Figure 4.5). Thereafter, the participants completed the social validation questionnaire. The female participant independently wrote down her answers while both males participants used their own AAC systems to answer the questions. This provided all participants the opportunity to provide novel answers. The researcher recorded the answers of the two male participants on the questionnaire.

4.3.6 Data analysis

Following the data collection, the researcher worked together with a second coder and watched all three videos. They captured and mutually agreed on which pain-related words and/or phrases the participants pointed to in response to each of the questions posed for each of the scenarios. No disagreements were noted between the researcher and second coder. Data was analysed to determine which of the pain-related categories and sub-categories were used by the participants for the different questions in each scenario. It was also documented which categories were not used.

4.4 Conclusion

This chapter discussed and justified the methodology selected to investigate the aims of Phases 3 and 4. First the aims and sub-aims used in the Quantitative phase (Phase 3) were discussed. Next, the steps followed, participants, material and equipment and data collection procedures were considered, followed by a discussion of the data analysis as well as aspects of validity and reliability. The Social Validation phase (Phase 4) with literate adults who use AAC followed next. Finally, the chapter was concluded by a discussion of the steps followed, participants, material and equipment, data collection procedures and the data analysis strategies.

CHAPTER 5

RESULTS

5.1 Introduction

Chapter 5 presents the results of the Quantitative (Phase 3) and Social Validation (Phase 4) phases to address the main research aim, namely to determine a social valid composite list of pain-related vocabulary to be incorporated into an AAC system for allowing children who could benefit from AAC to communicate their pain. Figure 5.1 gives a schematic outline of the flow of Chapter 5.

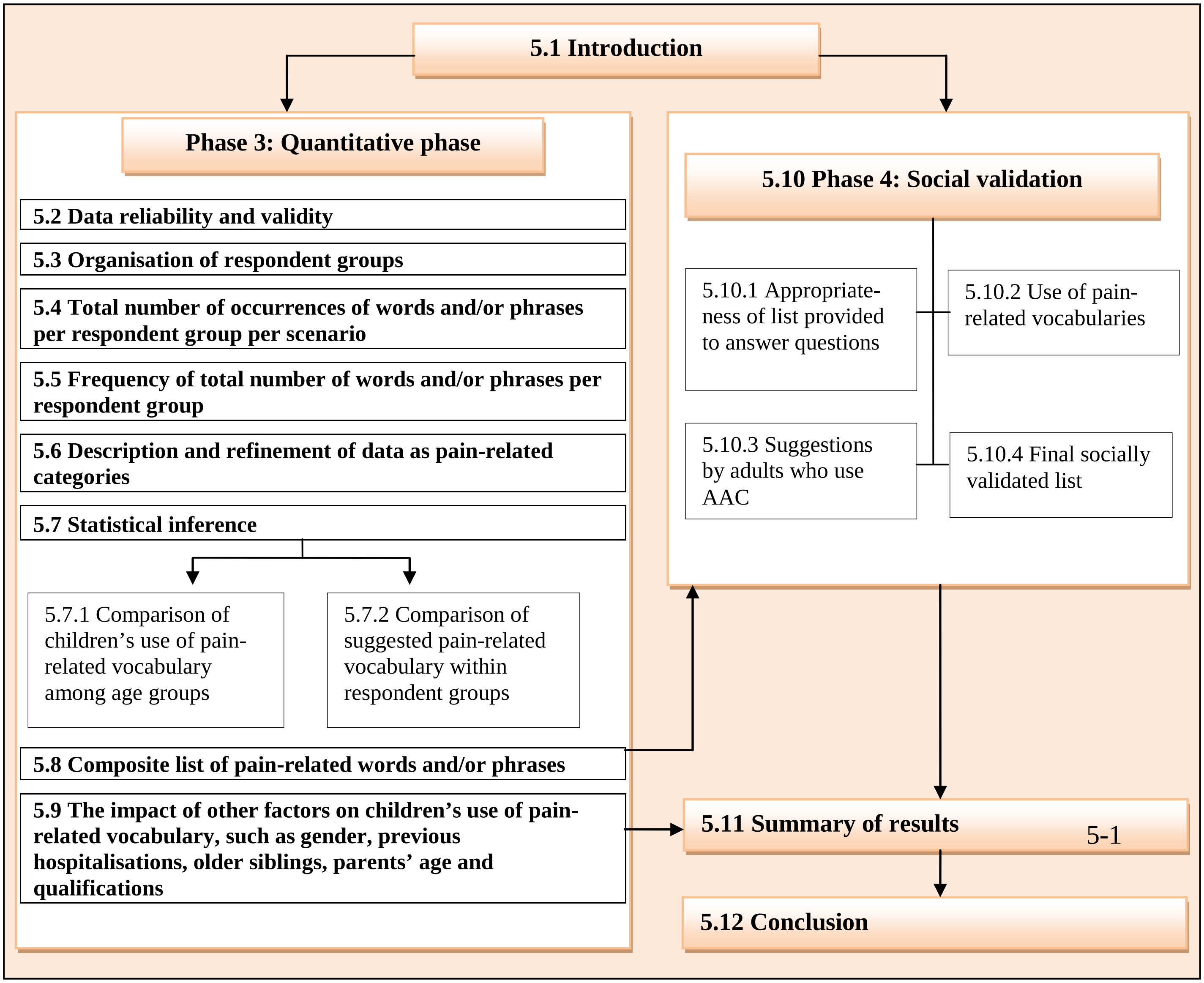


Figure 5.1. Schematic representation of the contents of Chapter 5.

5.2 Data reliability and validity

The percentage of adherence to the proposed procedures for the in-depth interview process was 94%, indicating good procedural integrity (see Section 4.2.7). The reliability of the transcriptions was ensured as the same transcription rules were followed (Appendix P) for all six respondent groups. Of the transcriptions, 30% were randomly selected and checked by an independent observer, and transcription reliability was calculated at 86%, indicating good reliability (see Section 4.2.7).

The validity of the coding process that was followed to categorise the pain-related words and phrases was enhanced by using a consensus approach between two coders. In addition, detailed descriptions for five of the categories were derived from a systematic literature search. Detailed descriptions were drawn up for the two newly identified categories which were added. Coders consistently compared data to the definitions of the categories to prevent any drift in meaning.

5.3 Organisation of respondent groups

In order to effectively compare results, the data is discussed within six respondent groups, namely (a) younger children (6;0 to 7;11) (*n*=39); (b) older children (8;0 to 9;11) (*n*=35); (c) parents of younger children (6;0–7;11) (*n*=29); (d) parents of older children (8;0–9;11) (*n*=32); (e) teachers of younger children (6;0–7;11) (*n*=30), and (f) teachers of older children (8;0–9;11) (*n*=26). These respondent group divisions are illustrated in Table 5.1.

Table 5.1

Six Respondent Groups

	Respondent groups		**Number of scenarios completed**	**Total number of participants**
Participants	Younger group (6;0–7;11)	Older group (8;0–9;11)		
Children	*n*=39	*n*=35	10	n=74
Parents	*n*=29	*n*=32	8	n=61
Teachers	*n*=30	*n*=26	5	n=56
Total	*N*=98	*N*=93		*N*=191

All six respondent groups suggested pain-related vocabulary that children would use in specific scenarios. However, the data sets were not equal in size as participant groups did not respond to an equal number of vignettes. Children responded to all 10 scenarios, while parents responded to either seven or eight scenarios (parents were requested to respond only to the scenario that dealt with operations [Scenario 5] if their child had had previous experiences of operations). Teachers only responded to five scenarios that were relevant to their experience and that could possibly occur at school, for example “falls” and “thorns”.

5.4 Total number of occurrences of pain-related words and/or phrases per respondent group per scenario

The total number of pain-related words and/or phrases that occurred per respondent group across the various scenarios was calculated. This implies that at this stage of the data analysis, the duplicates had not yet been removed. Although the number of scenarios varied, all six respondent groups were requested to respond to all five questions per scenario. A word count was done to determine the total number of pain-related words and/or phrases that were elicited throughout the scenarios. Each respondent group’s data is now described in more detail.

5.4.1 Children group

A total of 4576 pain-related words and/or phrases were elicited from all 74 children for the 10 scenarios they responded to. Of these, a total of 2194 occurrences of pain-related words and/or phrases were recorded for the younger children (*n*=39) and 2374 for the older children (*n*=35). Figure 5.2 provides a breakdown of the total number of pain-related words and/or phrases elicited by each scenario individually for the child respondent group as a whole.

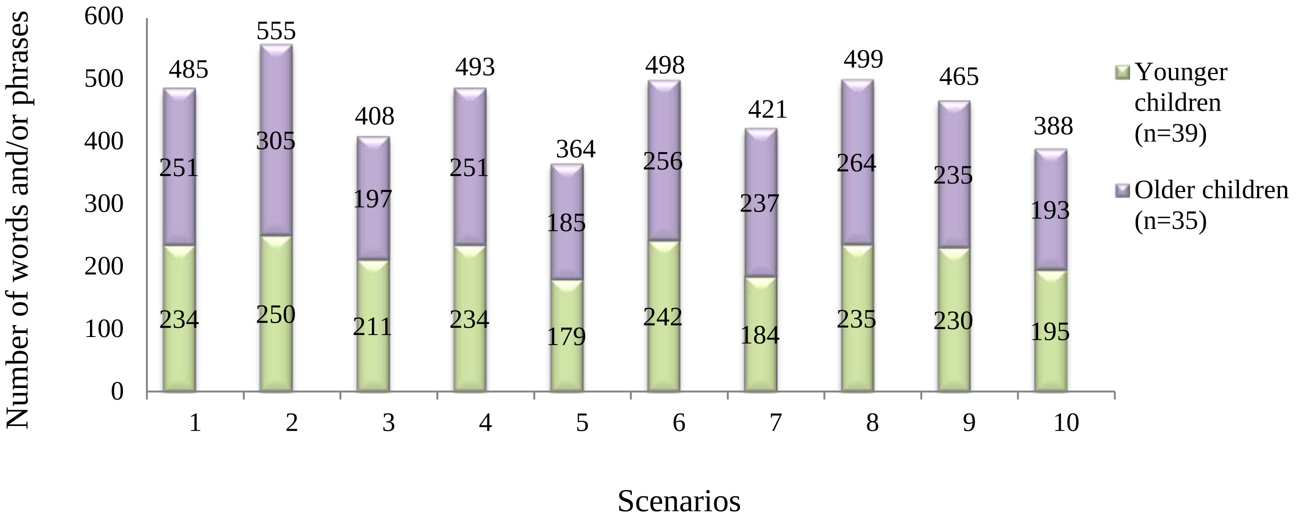


Figure 5.2. Total number of pain-related words and/or phrases used by the two child respondent groups per scenario (*N*=74).

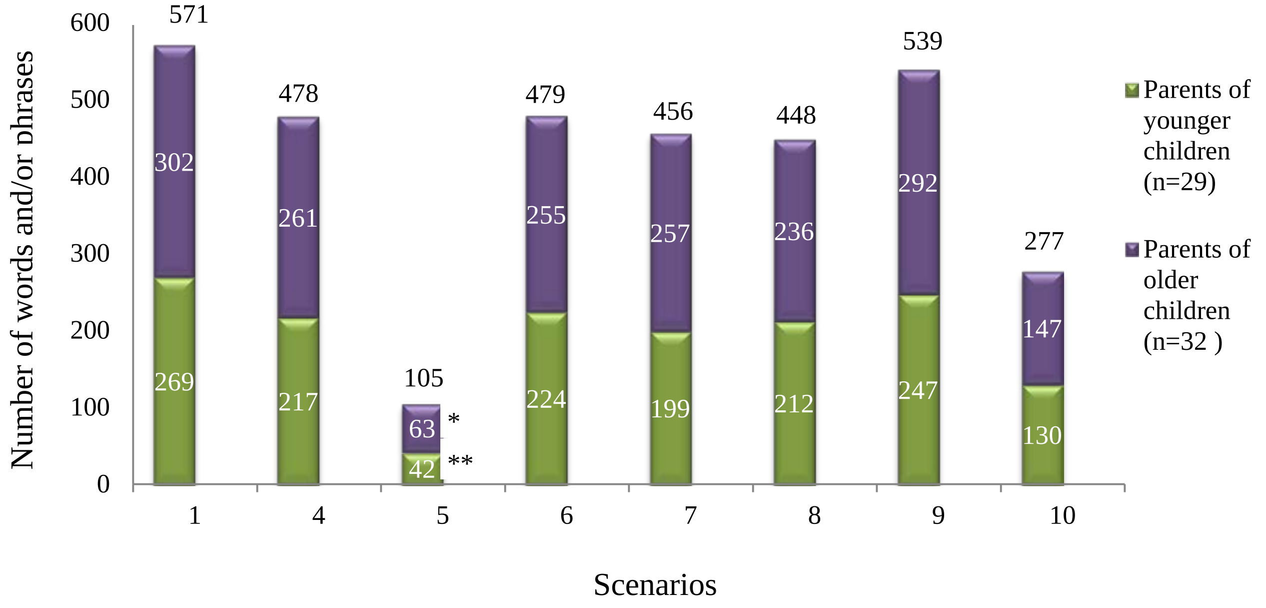
Based on the children's responses to the various scenarios, it is clear that the scenarios elicited a mean of 458 pain-related words and/or phrases with a range of 364 (Scenario 5) to 555 (Scenario 2) pain-related words and/or phrases. The overall mean number of pain-related words and/or phrases per child per scenario was six with a range of five to nine. The mean for younger children (6;0–7;11) was also six, although the range of pain-related words and/or phrases was narrower (5 to 6) than the range for all the participants combined. For the older children (8;0–7;11), the mean was higher (*M*=7) and the range larger (5 to 9).

As expected, the older children provided more pain-related words and/or phrases than the younger children in eight of the 10 scenarios. However, in Scenario 3, which focused on an accident, as well as in Scenario 10 (about the need for an IV in the hospital setting), younger children provided more pain-related words and/phrases than older children.

The two scenarios that elicited the lowest number of words and/or phrases were those that portray scenes in a hospital setting (i.e. Ziggi had an operation [Scenario 5] and Ziggi gets a drip [Scenario 10]).

5.4.2 Parents

All parents provided information for Scenarios 1, 4, 6, 7, 8, 9 and 10 and 17 parents also responded to Scenario 5 (meaning that their child had had an operation) as explained earlier. The 61 parents provided a total of 3353 pain-related words and/or phrases for eight scenarios – 1540 by parents of younger children (*n*=29) and 1813 by parents of older children (*n*=32). Figure 5.3 provides the total number of pain-related words and/or phrases that parents provided per scenario.



**n*=11; ***n*=6

Figure 5.3. Total number of pain-related words and/or phrases provided by the two parent respondent groups per scenario (*N*=61).

The mean number of pain-related words and/or phrases per parent was seven (range 2 to 9) per scenario across both groups. Parents of the younger children suggested a mean of seven pain-related words and/or phrases (range of 1 to 9) per scenario that their children may use, whilst parents of the older children also provided a mean of seven pain-related words and/or phrases, but with a slightly smaller range (range 2 to 9) per scenario. The scenarios elicited a mean of 419 pain-related words and/or phrases with a range of 105 (Scenario 5) to 571 (Scenario 1). Parents provided the highest number of pain-related words and/or phrases for Scenario 1 (fall) and Scenario 9 (bee sting) (571 and 539 respectively).

Similar to the children's responses, the two scenarios that dealt with pain associated with hospital settings (Scenarios 5 and 10) elicited the smallest number of pain-related words and/or phrases (105 and 277 respectively). It is, however, important to mention that only the parents, whose children had had operations, completed Scenario 5, in other words, six parents for the younger groups (21% of parents) and 11 parents for the older group (34% of parents).

5.4.3 *Teachers*

The 56 teachers provided 2272 pain-related words and/or phrases for five scenarios of which 1241 came from teachers of the younger age group (*n*=30) and 1031 from teachers of the older age group (*n*=26). Figure 5.4 depicts the total number of words and/or phrases suggested by teachers of 6;0 to 7;11-year-olds (typically Gr 1 teachers) and 8;0 to 9;11-year-olds (typically Gr 3 teachers). Data was collected for five scenarios (Scenarios 1, 4, 6, 7, 9) as only these scenarios were deemed relevant to teachers' experience.

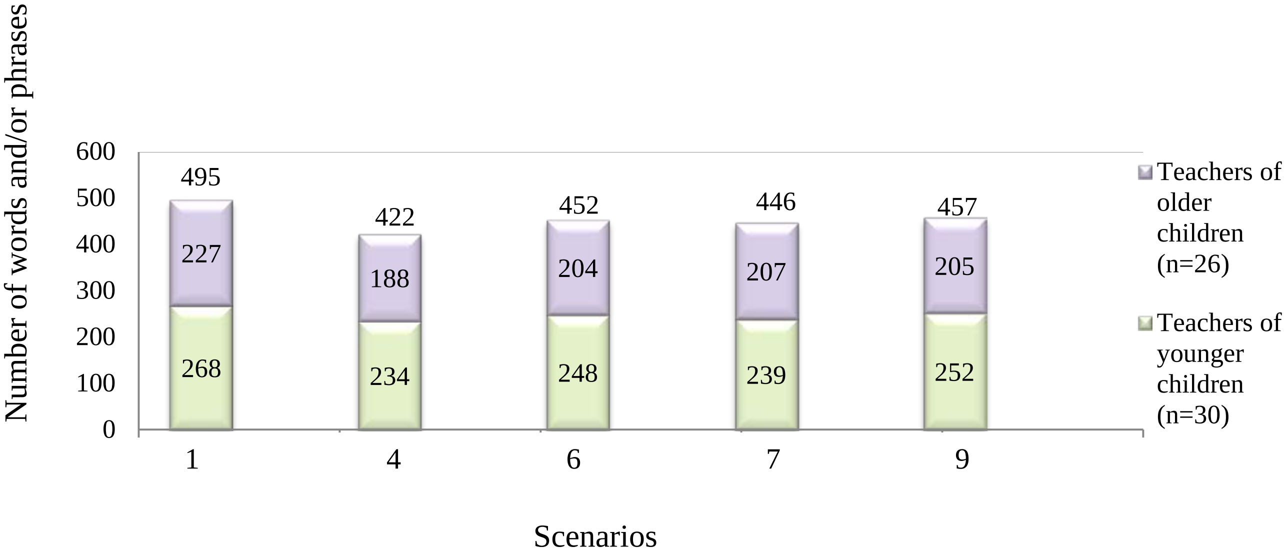


Figure 5.4. Total number of pain-related words and/or phrases provided by the two teacher respondent groups per scenario (*N*=56).

The mean number of pain-related words and/or phrases per teacher participant was eight (range of 8 to 9) per scenario across both groups. Grade 1 teachers (those who taught the younger children) gave a mean of 8 words and/or phrases (range of 8 to 9) per scenario, while

Grade 3 teachers (who taught the older children) also proposed a mean of eight words and/or phrases, but with a slightly broader range (range of 7 to 9) recorded per scenarios. The scenarios elicited a mean of 454 pain-related words and/or phrases per scenario ranging from 422 (Scenario 4) to 495 (Scenario 1). Unlike in the case of the responses by children and parents, the five scenarios elicited a relatively consistent number of pain-related words and/or phrases (range of 73) from the teachers.

5.4.4 Respondent group comparison for comparable scenarios

Figure 5.5 provides a summary of the total number of words and/or phrases proposed by all the participants in the six respondent groups for the five scenarios that were completed by all participants, namely scenarios 1, 4, 6, 7 and 9.

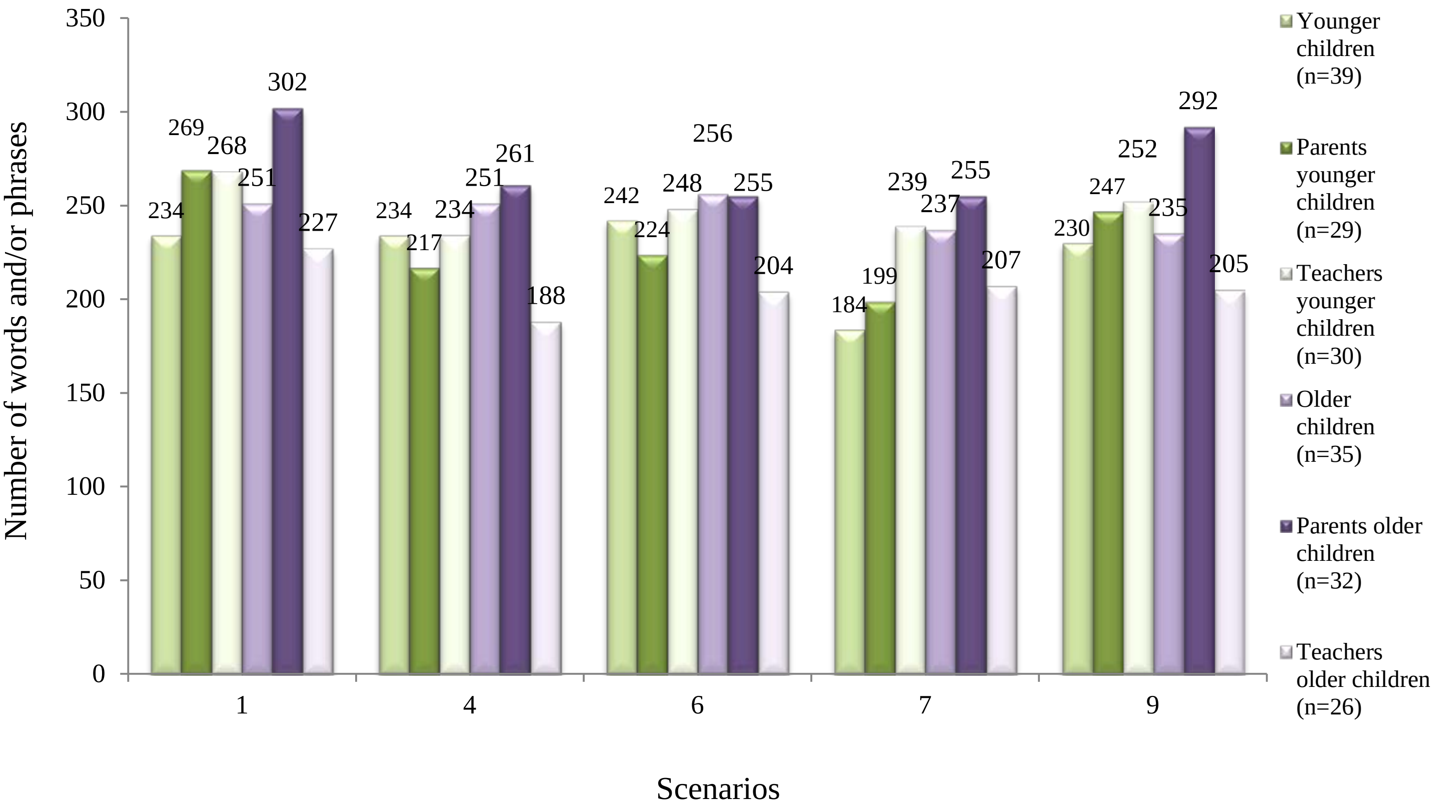


Figure 5.5. Total number of words and/or phrases provided by all six respondent groups.

In comparing the means of the five scenarios completed by all six respondent groups, the children in the younger group's mean responses were six (range of 5 to 7 words and/or phrases), while both the parents' and teachers' of the younger group gave a mean of eight words and/or phrases (range of 7 to 9 words and/or phrases). Children in the older group provided the lowest mean number (*M=7)* of words and/or phrases (range 6 to 7 words and/or phrases), while the parents of the older children provided the highest mean number (*M*=9) of words and/or phrases (range 8 to 9 words and/or phrases). Teachers of the older group of children gave a mean of eight words and/or phrases (range 7 to 9).

Table 5.2

Respondent Groups with Range of Words and/or Phrases and Number of Scenarios

	Respondent groups					
Participants	Younger group (6;0–7;11)	Mean for scenarios 1,4,6,7,9	Range of words and/or phrases per scenarios 1,4,6,7,9	Older group (8;0–9;11)	Mean for scenarios 1,4,6,7,9	Range of words and/or phrases per scenarios 1,4,6,7,9
Children	*n*=39	6	5–6	*n*=35	7	6–7
Parents	*n*=29	8	7–9	*n*=32	9	8–9
Teachers	*n*=30	8	8–9	*n*=26	8	7–9

Table 5.2 shows that, for the five scenarios completed by all six respondent groups, the mean of the responses given by the older children (*M*=7), their parents (*M*=9) and teachers (*M*=8) was higher than those of the younger children (*M*=6); their parents (*M*=8) and teachers (*M*=8).

5.5 Frequency of the total number of pain-related words and/phrases per respondent group

A total number of 11 201 pain-related words and/or phrases occurred in the complete sample of all six respondent groups. A total number of 4576 pain-related words and/or phrases were elicited from the children, 3353 from parents and 2272 from teachers. This declining number of total words and/or phrases was expected as these three respondent groups did not answer to the same number of scenarios. When all the duplicates were removed from the data sets of all six respondent groups, a total of 629 different pain-related words and/or phrases were identified. Pain-related words and/or phrases that occurred 10 times or more within the six respondent groups were identified and are displayed in Table 5.3, 5.4 and 5.5 for children, parents and teachers respectively. These words and/or phrases are presented in descending order of occurrence. In addition, the commonality across the six respondent groups was determined and is indicated in the tables. The commonality score assigned reflects the number of groups in which the words/phrases occurred 10 times or more.

Table 5.3

Pain-Related Words and/or Phrases Occurring 10 Times or More in Children's Responses

Younger children 6;0–7;11-year olds (*n*=39)	**Frequency**	**Commonality across groups**	**Older children 8;0–9;11-year olds (*n*=35)**	**Frequency**	**Commonality across groups**
it is sore	110	6	very sore/really sore/so sore	146	6
hurt (my body part)	93	6	it is sore	92	6
very sore/really sore/so sore	83	6	hurt (my body part)	65	6
put on plaster	77	5	put on plaster	65	5
it will feel better/will be better	71	5	I want to go home	58	2
ow	63	6	put on bandage	51	2
put on bandage	47	2	go to the doctor	47	2
ouch	46	6	it will feel better/will be better	46	5
take it/pull it (thorns/splinter) out	45	6	take it/pull it (thorns/splinter) out	45	6
please help	43	6	put on ice/ice pack	39	2
go to the hospital	41	2	ow	37	6
medicine/medication	39	4	please help	35	6
I fell	38	6	very, very sore/ extremely sore/really, really sore	34	2
go to the doctor	38	2	I fell	32	6
very painful/so painful	34	2	go to the hospital	32	2
I want to go home	33	2	put some cream/special cream (on)	31	3

Younger children **6;0–7;11-year olds** **(*n*=39)**	**Frequency**	**Commonality across groups**	**Older children** **8;0–9;11-year olds** **(*n*=35)**	**Frequency**	**Commonality across groups**
put on ice/ice pack	28	2	blood/bleeding (there is blood all over/the sore is bleeding)	28	4
very, very sore/ extremely sore/really, really sore	28	2	cry/cries/crying	28	6
hurts very bad/hurt a lot	22	2	call/tell (mommy/daddy/teacher)	27	6
make it better	21	4	the bee stung me	27	6
cry/cries/crying	21	6	it was painful	24	3
the bee stung me	21	6	very painful/so painful	24	2
I want to sleep/go to sleep (when in pain and to feel better afterwards)	20	1	I hit my.../ball hit me	23	6
I hit my.../ball hit me	20	6	lie in bed	22	2
it was painful	17	3	medicine/medication	22	4
it pains/paining	15	5	hurts very bad/hurt a lot	22	2
it is swollen	15	2	drink water/put water on the sore	21	1
pray to God/Allah* to make it better	15	1	put cold water on it	20	2
put on something	15	3	make it better	17	4
put some cream/special cream (on)	14	3	can't move (body part)	16	1
give me a/I need a hug	13	1	it pains/paining	15	5
let's play	13	1	it is swollen	15	2
blood/bleeding (there is blood all over/the sore is bleeding)	13	4	wait until it is better	15	1
call/tell (mommy/daddy/teacher)	12	6	I don't feel well	15	3
I want to vomit	12	2	I screamed	15	4
put cold water on it	11	2	ouch	13	6
really hurt	11	2	rest for a little bit	13	1
put on cast	10	1	clean it	13	1
lie in bed	10	2	I can't talk/speak (because it is sore)	13	1
they gave injection/inject	10	1	I have a headache	12	2
put on ointment	10	1	go to sickroom/office/principal	11	3
ouchie	10	1	it is not sore at all/wasn't that sore	11	1
			really hurt	11	2
			pain/sore feels really bad	11	1
			a dog ran across the street	11	1
			I have a blister	11	1
			I want to vomit	11	2

Younger children **6;0–7;11-year olds** **(*n*=39)**	**Frequency**	**Commonality across groups**	**Older children** **8;0–9;11-year olds** **(*n*=35)**	**Frequency**	**Commonality across groups**
			break (body part)	10	1
			be more careful	10	1
			doctor will help to make it better	10	1
			it feels not nice/ don't feel nice	10	1
			my skin has scratches	10	1
			stop hurting/poking me	10	1
			I've pulled the brakes too hard	10	1
			I touched the warm pot/kettle/iron	10	1

*Children used either "God" or "Allah"

From Table 5.3, it is interesting to note that the older children used a wider variety of pain-related words and/or phrases that occurred 10 times or more, when compared to the younger children. Eighty one percent (34/42) of the words and/or phrases used by younger children 10 times or more, occurred in at least two of the six respondent groups whereas 67% (37/55) words and/or phrases used by the older children occurred in at least two of the six groups.

Table 5.4

Pain-Related Words and/or Phrases That Occurred 10 Times or More as Reported by Parent Respondents

Parents of younger children **6;0–7;11-year olds** **(*n*=29)**	**Frequency**	**Commonality across groups**	**Parents of older children** **8;0–9;11-year olds** **(*n*=32)**	**Frequency**	**Commonality across groups**
it is sore	125	6	it is sore	165	6
cry/cries/crying	110	6	ow	118	6
eina	106	4	ouch	105	6

Parents of younger children 6;0–7;11-year olds (*n*=29)	**Frequency**	**Commonality across groups**	**Parents of older children 8;0–9;11-year olds (*n*=32)**	**Frequency**	**Commonality across groups**
ouch	82	6	hurt (my body part)	92	6
hurt (my body part)	71	6	cry/cries/crying	92	6
please help	67	6	please help	85	6
ow	56	6	eina	63	4
the bee stung me	35	6	very sore/really sore/so sore	56	6
take it/pull it (thorns/splinter) out	32	6	I am okay	46	4
very sore/really sore/so sore	30	6	the bee stung me	40	6
the sore sting(s)/is stinging	27	2	take it/pull it (thorns/splinter) out	35	6
the sore was burning	27	4	I hit my.../ball hit me	35	6
I screamed	27	4	medicine/medication	34	4
I hit my.../ball hit me	27	6	I rub it	23	2
owie	24	2	the sore was burning	23	4
I am okay	23	4	owie	23	2
I fell	22	6	the sore sting(s)/is stinging	22	2
put on plaster	21	5	call/tell (mommy/daddy/ teacher)	21	6
I rub it	21	2	I fell	18	6
do nothing/don't do anything (when in pain)	21	2	it will feel better/will be better	18	5
hold my hand	19	2	it was painful	18	3
it will feel better/will be better	18	5	I screamed	18	4
call/tell (mommy/daddy/ teacher)	18	6	hold my hand	17	2
put some cream/special cream (on)	17	3	I'm fine/ it is fine	17	2
medicine/medication	17	4	put on plaster	15	5
make it better	13	4	point at/show (the place of injury)	15	3
facial expressions/grimace (show they are in pain)	12	1	there is a splinter in my skin	15	2
point at/show (the place of injury)	11	3	moan	13	1
a thorn	11	1	it pains/paining	12	5
I hold (it)/hold on hurt	10	3	make it better	11	4
I feel sick	10	2	the sore aches/aching	11	1
hot	10	1	I don't feel well	10	3
			I have a headache	10	2

In general, the parents of both the younger and older children provided fewer pain-related words and/or phrases with a frequency of 10 or more than did the children themselves, which is possibly due to the fact that parents only responded to eight of the ten scenarios and there were fewer parents (*n*=61) than children (*n*=74). Of the words and/or phrases parents provided with a frequency of 10 times or more, parents of younger children provided 85% words and/or phrases (29/34) that occurred in at least two of the six respondent groups, where as parents of older children provided 94% words and/or phrases (31/33) that occurred in at least two of the six respondent groups.

Table 5.5

Pain-Related Words and/or Phrases That Occurred 10 Times or More as Reported by Teacher Respondents

Teachers of younger children 6;0–7;11-year olds (*n*=30)	**Frequency**	**Commonality across groups**	**Teachers of older children 8;0–9;11-year olds (*n*-26)**	**Frequency**	**Commonality across groups**
cry/cries/crying	116	6	ouch	96	6
hurt (my body part)	105	6	hurt (my body part)	90	6
it is sore	95	6	cry/cries/crying	68	6
ouch	82	6	it is sore	54	6
eina	65	4	please help	45	6
please help	48	6	the bee stung me	42	6
the bee stung me	29	6	eina	38	4
call/tell (mommy/daddy/teacher)	25	6	I am okay	38	4
do nothing/don't do anything (when in pain)	23	2	I fell	20	6
I fell	20	6	ow	19	6
I hold (it)/hold on hurt	20	3	call/tell (mommy/ daddy/teacher)	19	6
put on something	19	3	it pains/paining	17	5
ow	18	6	the sore was burning	17	4
lie down (when in pain)	18	2	put on something	16	3
I am okay	18	4	go to sickroom/office/principal	16	3
it was him (blame somebody else)	18	2	take it/pull it (thorns/splinter) out	16	6
take it/pull it (thorns/splinter) out	17	6	I hold (it)/hold on hurt	14	3

Teachers of younger children 6;0–7;11-year olds (*n*=30)	**Frequency**	**Commonality across groups**	**Teachers of older children 8;0–9;11-year olds (*n*-26)**	**Frequency**	**Commonality across groups**
I am sorry Mom (that I got hurt)	16	1	I don't feel well	12	3
the sore was burning	16	4	I hit my.../ball hit me	12	6
point at/show (the place of injury)	16	3	lie down (when in pain)	11	2
I screamed	16	4	very sore/really sore/so sore	11	2
it pains/paining	15	5	it was him (blame somebody else)	11	2
I hit my.../ball hit me	15	6	blood/bleeding (there is blood all over/the sore is bleeding)	10	4
very sore/really sore/so sore	13	6	I'm fine/ it is fine	10	2
put on plaster	12	5	there is a splinter in my skin	10	2
it will feel better/will be better	12	5			
there are thorns in my body part (head/skin/leg/hand	12	1			
I was hit by a ball	11	1			
ouwa	11	1			
go to sickroom/office/principal	10	3			
blood/bleeding (there is blood all over/the sore is bleeding)	10	4			
I feel sick	10	2			

The teachers of the younger children suggested 88% pain-related words and/or phrases (28/32) with a frequency of 10 or more that occurred twice or more in all six respondent groups, whereas 100% of the pain-related words and/or phrases (25/25) that occurred with a frequency of 10 or more provided by the teachers of older occurred in all six respondent groups.

5.6 Description and refinement of data as pain-related categories

The researcher and second coder worked together until consensus was reached to categorise the 629 words and/or phrases into one of the mutually agreed seven pain-related categories identified in literature. In cases where agreement was not obvious, the matter was discussed until consensus was reached. The seven categories were: (a) vocabulary to describe pain; (b) vocabulary to direct others' actions (c) vocabulary to describe pain location; (d) vocabulary to describe the causes of pain; (e) vocabulary to describe strategies to cope with pain; (f) vocabulary to reflect on how the pain could have been prevented, and (g) vocabulary to indicate the consequences of pain or injury and to influence activities and participation. (Refer to Table 4.4 for a clear description of the pain-related categories and the operational definitions used for each category.)

Next, the 629 pain-related words and/or phrases categorised within the seven pain-related categories (Categories A to G) were further categorised into 23 pain-related sub-categories within the pain-related categories. Under Category A (which contained 134 words and/or phrases to describe pain), there were seven sub-categories, namely 13 exclamations (e.g., ouch, 'eina', ouchie); 13 vocalisations and verbalisations (e.g., uuggghh/uuurgh; agh; cry, moan); 26 descriptor words (e.g., hurt; sore; painful; pokey); 10 sensory words (e.g., itchy, stingy; pinch); 31 intensifiers (e.g., intense; very, very sore; very painful); 21 comparisons (e.g., like a bee sting; like the skin pop; like there is fire on your hands), and 20 evaluative words (e.g., not nice; funny feeling; kind of sore).

Category B (vocabulary to direct other's actions in response to pain, which had 140 words and/or phrases) revealed three sub-categories, namely 72 actions (e.g., clean it; make it better; fix it); 15 places (e.g., go to doctor/hospital/sickroom/office; get me 'outa' here!; take me somewhere); and 53 remedies (e.g., put some cream/special cream; stitches; put on plaster). In the remedy sub-category, some children used brand names such as Allergex, Celestamine, Rescue tablet, BioOil, Burn shield, Dettol and Panado, whereas others were not as specific, and simply indicated: put on something; put stuff on sore, and put some (kind of) liquid on.

Category C (42 words and/or phrases to describe pain location and visible signs), revealed two sub-categories: seven sites of injury (e.g., just on one side; my whole body is crushed; in my mouth) and 35 visible signs of injury (e.g., blood; break; scrape). Vocabulary used to describe the causes of pain constituted Category D. The 75 words and/or phrases were divided into two sub-categories, namely 27 internal causes of pain (e.g., I fell; I tripped; I bumped into...) and 48 external causes of pain (e.g., I had an operation; I was hit by a car; I had a drip).

Four sub-categories were identified within Category E (101 words and/or phrases to describe strategies used to cope with pain), namely 44 self-talk words and/or phrases (e.g. it will be better; [it is a] small ‘eina’; I am okay); 33 actions to cope with pain (e.g., blow it; hold it; lie in bed); eight positive outcomes (e.g., pray to God/Allah to make it better; doctor will make it better; happy ending) and 16 distractions (e.g., forget about it; watch TV/movie; ignore it).

Category F (31 vocabulary items to reflect on strategies of how the pain could have been prevented) revealed two sub-categories, namely 18 that reflect on what happened (e.g., I did not see the [object]; I was too fast; I could not wait) and 13 that reflect on how to prevent pain (e.g., I should have ...; I will not do that again; I was not supposed to ...).

The last category, G (106 vocabulary items to indicate the consequences of pain or injury and its influence on activities and participation) had three sub-categories, namely 62 physical outcomes (e.g., I can’t concentrate on my work; I can’t walk); 34 showing secondary gain (e.g., ice cream helps for the pain; cuddle me; buy/bring me a present); and 10 emotional responses as a result of pain (e.g., angry at them; afraid/scared; ‘askies’ [sorry]).

All words and/or phrases were represented into one of the 23 sub-categories, although the number or words and/or phrases in each sub-category ranged from 31 items (Category F: Vocabulary to reflect on strategies of how the pain could have been prevented) to 140 items (Category B: Vocabulary to direct other's actions in response to the pain/injury/illness).

5.7 Statistical inference

5.7.1 Comparison of children’s use of pain-related vocabulary among age groups

In order to explore differences in the use of pain-related words and/phrases among age groups and also respondent groups, the percentage of respondents per group who offered words in the seven categories was determined. These were compared across (a) age groups and (b) respondent groups.

Table 5.6 summarises the percentage occurrence of the seven pain-related categories that was reported by the two child respondent groups, as well as the p-values, the test used to determine the p-values and the significance thereof.

In order to perform statistical inference, hypotheses were formulated for the data obtained. Regarding the data obtained from the child participants, a one-sided hypothesis was posed as the alternative hypothesis, as it was hypothesised that, per category, the percentage of children who used words/phrase falling in that category was higher in the older than the younger group:

H_0: Per category, the percentage of children using words and/or phrases falling in that category is the same across the younger and older groups.

H_1: Per category, the percentage of children using words and/or phrases falling in that category is higher in the older group (8;0–9;11) than in the younger group (6;0–7;11).

Pearson's Chi-Square Test was used to test for homogeneity of age groups across sub-categories for all six respondent groups. In some cases, Fisher's Exact Test (Field, 2013) was preferred over Pearson's Chi-Square Test (Field, 2013) as 50% of the cells had expected counts of less than five, rendering Pearson's Chi-Square Test not valid.

Table 5.6 shows the percentage of children who used words and/or phrases falling into the seven main pain-related categories. A distinction is made between the younger (6;0–7;11) and the older (8;0–9;11) age groups. Where no p-values are indicated, 100% of the children in both age groups used vocabulary falling in that specific category.

Table 5.6

Percentage of Younger and Older Child Respondents who Gave Words/Phrases That Fell in Each of the Seven Pain-related Categories

Pain-related main category	**% of participants offering words/phrases**		**Test used**	**p-value**
	Younger group (6;0–7;11) (*n*=39)	**Older group (8;0–9;11) (*n*=35)**		
A: Vocabulary to describe pain	100.0	100.0	-	-
B: Vocabulary to direct others' actions	100.0	100.0	-	-
C: Vocabulary to describe pain location	71.8	82.9	P	0.1294
D: Vocabulary to describe the causes of pain	97.4	97.1	F	0.5
E: Vocabulary to describe strategies used to cope with pain	92.3	100.0	P	0.047*
F: Vocabulary to reflect on strategies of how the pain could have been prevented	43.6	65.7	P	0.028*
G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	79.5	94.2	P	0.032*

Note. P = Pearson's Chi-Square Test; F = Fisher's Exact Test.
*p<0.05.

From Table 5.6, it is clear that only three categories in the children's data set were statistically significantly different on the 5% level of confidence ($p<0.05$), which means that older children suggested more words and/phrases in these categories than the younger children. The relevant categories were Category E (Vocabulary to describe strategies used to cope with pain), Category F (Vocabulary to reflect on strategies of how the pain could have been prevented) and Category G (Vocabulary to indicate the consequences of pain or injury and to influence activities and participation).

For Category A (Vocabulary to describe pain) and B (Vocabulary to direct others' actions), the same percentage of children (100%) used pain-related words and/phrases falling in these categories, whereas almost the same percentage of children (97.4% and 97.1%) used pain-related words and/phrases that fell in Category D (Vocabulary to describe the causes of pain). Although a slightly higher percentage of older children used words and/or phrases falling in Category C (Vocabulary to describe pain location and visible signs to the actual tissue damage a result of the physical injury), this difference was not statistically significant. Overall, the H_0 was therefore confirmed for four categories, and rejected for three.

A similar analysis was then made of the 23 sub-categories of pain-related words and/or phrases. The following one-sided hypothesis was formulated:

H_0: Per sub-category, the percentage of children using words and or/phrases falling in that sub-category is the same across the younger and older groups.

H_1: Per sub-category, the percentage of children using words and/or phrases falling in that sub-category, is higher in the older group than the younger group.

Table 5.7 lists those sub-categories where a greater percentage of older than younger children offered words and/phrases falling in that specific category.

Table 5.7

Percentage of Younger and Older Child Respondents who Offered Words/Phrases That Fell in Each of the 23 Pain-Related Sub-Categories

Pain-related sub-category	**% of participants offering words/phrases**		**Test used**	**p-value**
	Younger children (6;0–7;11) (*n*=39)	**Older children (8;0–9;11) (*n*=35)**		
A5: Intensifiers	90	100	P	0.0257*
E2: Actions to cope with pain	82	100	F	0.006*
G1: Physical outcome	66.7	91	F	0.0049*

Note. P = Pearson's Chi-Square Test; F = Fisher's Exact Test.
*<0.05.

From Table 5.7 it is clear that only three sub-categories A5 (Intensifiers), E2 (Actions to cope with pain) and G1 (Physical outcome) were statistically significantly different on the 5% level of significance with the p-values 0.0257; 0.006, and 0.0049 respectively. The H_0 therefore was rejected in favour of H_1 on a level of 5% significance for only three of the 23 sub-categories.

For the adult population (including both the parent and the teacher respondent groups), the following two-sided hypothesis was formulated:

H_0: Per category, the percentage of parent/teacher participants using words and/or phrases falling in that category is the same across the two age groups.

H_1: Per category, the percentage of parent/teacher participants using words and/or phrases falling in that category will be different between the two age groups.

The Pearson’s Chi Square Test was used to test for homogeneity of age groups across sub-categories for all six respondent groups. As for the children’s data, either Fisher’s Exact Test (Field, 2013) or Pearson’s Chi Square Test (Field, 2013) was used, depending on the data distribution.

Table 5.8 shows the percentage of parent respondents who gave words and/or phrases that fell in the seven main pain-related categories. A distinction was made between parents of the younger (6;0–7;11) and parents of the older (8;0–9;11) age groups.

Table 5.8

Percentage of Parent Respondents for Younger and Older Children Who Offered Words/Phrases That Fell in the Seven Pain-related Categories

Pain-related main category	**% of participants offering words/phrases**		**Test used**	**p-value**
	Younger group (6;0–7;11) (*n*=29)	**Older group (8;0–9;11) (*n*=32)**		
A: Vocabulary to describe pain	100.0	100.0	-	-
B: Vocabulary to direct others’ actions	100.0	100.0	-	-
C: Vocabulary to describe pain location	58.6	43.8	P	0.2460
D: Vocabulary to describe the causes of pain	96.6	93.8	P	0.613
E: Vocabulary to describe strategies used to cope with pain	100.0	90.6	P	0.239
F: Vocabulary to reflect on strategies of how the pain could have been prevented	34.5	28.1	P	0.5923

Pain-related main category	**% of participants offering words/phrases**		**Test used**	**p-value**
	Younger group (6;0–7;11) (*n*=29)	**Older group (8;0–9;11) (*n*=32)**		
G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	58.6	59.1	P	0.952

Note. P = Pearson's Chi-Square Test.
*p<0.05.

It is evident from Table 5.8 that only Pearson's Chi-Square Tests was used and that there were no statistically significant differences (p<0.05) in the percentage of participants who offered words and/or phrases per category for the five categories tested. Two categories, namely A and B were not tested, as the values showed that the same percentage of parents in each group offered words and/or phrases in these two categories (100%). As no statistical significant differences were reported for any of the categories, the sub-categories were not tested further.

Table 5.9 shows the percentage of teacher participants of younger and older children who gave words and/or phrases that fell in the seven main pain-related categories. A distinction was made between Gr 1 teachers who taught the younger (6;0–7;11) and Gr 3 teachers who taught the older (8;0–9;11) age groups.

Table 5.9

Percentage of Teacher Respondents for Younger and Older Children who Gave Words/Phrases That Fell in Each of the Seven Pain-Related Categories

Pain-related main category	**% of participants offering words/phrases**		**Test used**	**p-value**
	Younger group (6;0–7;11) (*n*=30)	**Older group (8;0–9;11) (*n*=26)**		
A: Vocabulary to describe pain	100.0	100.0	-	-
B: Vocabulary to direct others' actions	100.0	100.0	-	-
C: Vocabulary to describe pain location	33.3	30.8	P	0.838
D: Vocabulary to describe the causes of pain	100.0	100.0		-
E: Vocabulary to describe strategies used to cope with pain	93.3	88.5	P	0.524
F: Vocabulary to reflect on strategies of how the pain could have been prevented	16.7	11.5	F	0.711

Pain-related main category	**% of participants offering words/phrases**		**Test used**	**p-value**
	Younger group (6;0–7;11) (*n*=30)	**Older group (8;0–9;11) (*n*=26)**		
G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	56.7	50.0	P	0.618

Note. P = Pearson's Chi-Square Test; F = Fisher's Exact Test.
*p<0.05.

Table 5.9 shows that, similar to parents, there were no statistically significant differences ($p<0.05$), in the percentage of teacher participants who offered words and/or phrases per category for the four categories tested. In two categories (Category A and B), the teachers in both age groups used exactly the same vocabulary in these specific categories (100%). No further testing of sub-categories was thus undertaken.

5.7.2 Comparison of suggested pain-related vocabulary within respondent groups

In order to determine if there were any differences between the percentage of respondents who offered words and/or phrases in the different pain-related categories and sub-categories for the younger and older groups respectively as used by three respondent groups, three-way comparisons were made (Tables 5.10 and 5.14). The following two-sided hypothesis was formulated for the younger children:

H_0: The percentage of respondents who offered words and/or phrases relevant for the younger children in the pain-related categories and sub-categories is the same for children, parents and teachers.

H_1: The percentage of respondents (children, parents and teachers) who offered words and/or phrases relevant for the younger children in the pain-related categories and sub-categories differs across the three respondent groups.

Table 5.10

Three-way Comparisons of Vocabulary Across the Three Respondent Groups for the Younger Group

Pain-related main category with sub-categories	**Younger group (6;0–7;11) % of participants offering words/phrases**			**Test used**	**p-value**
	Children (*n*=39)	**Parents (*n*=29)**	**Teachers (*n*=30)**		
A: Vocabulary to describe pain	100.0	100.0	100.0	-	-
A1: Exclamation	66.7	100.0	93.0	F	0.0001*
A2: Vocalisations and verbalisations	46.1	86.2	86.7	P	0.0001*
A3: Descriptor words	100.0	100.0	96.7	F	0.602
A4: Sensory words	66.7	86.2	46.7	P	0.0057*
A5: Intensifiers	89.7	62.1	36.7	P	<0.0001*
A6: Comparisons	23.0	20.1	3.3	F	0.0032*
A7: Evaluative words	48.7	24.2	20.0	P	0.0211*
B: Vocabulary to direct others' actions	100.0	100.0	100.0	-	-
B1: Action	94.9	100.0	100.0	F	0.3328
B2: Where to go to when in pain	82.0	10.0	36.7	P	<0.0001*
B3: Remedy	97.4	79.3	70.0	F	0.0039*
C: Vocabulary to describe pain location	71.8	58.6	18.2	P	0.0058*
C1: Site of injury	18.0	3.5	23.3	P	0.08
C2: Visible signs of injury	66.7	58.6	16.7	P	<0.0001*
D: Vocabulary to describe causes of pain	100.0	100.0	100.0	-	-
D1: Internal causes	87.2	65.5	63.3	P	0.043
D2: External causes	92.3	96.6	96.7	P	0.638
E: Vocabulary to describe strategies used to cope with pain	100.0	100.0	100.0	-	-
E1:Self-talk	59.0	69.0	56.7	P	0.583
E2: Actions to cope with pain	82.1	79.3	80.0	P	0.9558
E3: Positive outcomes	79.5	34.5	26.7	P	<0.0001*
E4: Distractions	41.0	13.8	6.7	P	0.0013*
F: Vocabulary to reflect on strategies of how the pain could have been prevented	43.6	35.5	16.7	P	0.059*
F1: Reflect on what happened	3.3	20.7	16.7	P	0.238
F2: Reflect on future (how to prevent)	28.2	20.7	3.3	P	0.028*
G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	79.5	58.6	56.7	P	0.081
G1: Physical outcomes	66.7	51.7	53.3	P	0.379
G2: Secondary gain	82.4	11.8	5.9	P	0.0004*
G3: Emotional response as result of physical pain	15.4	10.3	10.0	P	0.742

Note. P = Pearson's Chi-Square Test; F = Fisher's Exact Test.
*p <0.05.

From Table 5.10, it is clear that only two of the three main categories tested (C and F) were statistically significantly different (p=0.058 and 0.059 respectively). Four main categories (A, B, D, and E) were not tested because 100% of the participants in all three respondent groups used words and/or phrases falling within these categories. Of the 23 sub-categories tested, 13 were statistically significantly different, namely A1 (p=0.0001), A2 (p=0.0001, A4 (p=0.0057), A5 (p<0.0001), A6 (p=0.0032), A7 (p=0.0211), B2 (p<.0001), B3 (p=0.0039), C2 (p<0.0001), E3 (p<0.0001), E4 (p=0.0013), F2 (p=0.028), and G2 (p=0.0004). This indicates that there was a difference in the percentage of respondents from the three groups who suggested vocabulary in these sub-categories.

In order to explore where the specific differences for these categories and sub-categories between the three respondent groups for the younger group occurred, pairwise comparisons were conducted for those main and sub-categories for which the H_0 was rejected during the three way comparison. The outcomes of these comparisons are represented in Table 5.11 to 5.13.

Table 5.11

Pairwise Comparison of the Percentage of Child and Parent Respondents for the Younger Group who Used Words and/or Phrases That Fell in the Pain-Related Categories and Sub-Categories

Pain-related main category with sub-categories	**Younger group (6;0–7;11) % of participants offering words/phrases**		**Test used**	**p-value**
	(Children: *n*=39)	**(Parents: *n*=29)**		
A: Vocabulary to describe pain	100	100	-	-
A1: Exclamations	66.7	100.0	P	0.0005*
A2: Vocalisations and verbalizations	46.2	86.2	P	0.0007*
A4: Sensory words	66.7	86.2	P	0.07
A5: Intensifiers	89.7	62.1	P	0.007*
A6: Comparisons/ Metaphors	23.1	20.7	P	0.81
A7: Evaluative words	48.7	24.1	P	0.04*
B: Vocabulary to direct others' actions	100	100	-	-
B2: Places	82.1	10.3	F	>0.00001*

Pain-related main category with sub-categories	**Younger group (6;0–7;11) % of participants offering words/phrases**		**Test used**	**p-value**
	(Children: *n*=39)	**(Parents: *n*=29)**		
B3: Remedy	97.4	79.3	F	0.037*
C: Vocabulary to describe pain location	71.8	58.6	P	0.256
C2: Visible signs of injury	66.7	58.6	P	0.496
D: Vocabulary to describe the causes of pain	100	100	-	-
D1: Internal causes of pain	87.2	65.5	P	0.033*
E: Vocabulary to describe strategies used to cope with pain	100	100	-	-
E3: Positive outcomes	79.5	34.5	P	0.0002*
E4: Distractions	41.0	13.8	P	0.015*
F: Vocabulary to reflect on strategies of how the pain could have been prevented	43.6	34.5	P	0.448
F2: Reflect on how to prevent pain	28.2	20.7	P	0.479
G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	79.5	58.6	-	-
G2: Secondary gain	35.9	6.9	P	0.005*

Note. P = Pearson's Chi-Square Test; F = Fisher's Exact Test.
*p<0.05.

Table 5.11 shows seven main categories and 14 sub-categories to illustrate the outcome of the pairwise comparisons between younger children and parents. Four main categories (A, B, D, and E) were not tested, because 100% of the participants in the three groups used vocabulary in these categories. Furthermore, Category G was not tested in the pairwise comparison, because no statistically significant difference was indicated in the three-way comparison of the three groups (Table 5.9). These five main categories were therefore only included in Tables 5.10 to 5.12 to clarify the sub-categories. For ten sub-categories (A1, A2, A5, A7, B2, B3, D1; E3; E4, G2), the H_0 was rejected in favour of H_1 ($p<0.05$), indicating statistically significant differences between the data of the younger children and those of the parents.

Table 5.12 indicates the pairwise comparisons between the younger children and Gr 1 teachers.

Table 5.12

Pairwise Comparison of the Percentage of Child and Teacher Respondents for the Younger Group who Used Words and/or Phrases That Fell in the Pain-Related Categories and Sub-Categories

Pain-related main category with sub-categories	**Younger group (6;0–7;11) % of participants offering words/phrases**		**Test used**	**p-value**
	Children(*n*=39)	**Teachers (*n*=30)**		
A: Vocabulary to describe pain	100.0	100.0	-	-
A1: Exclamations	66.7	93.3	P	0.008*
A2: Vocalisations and verbalisations	46.2	86.7	P	0.0005*
A4: Sensory words	66.7	46.7	P	0.096
A5: Intensifiers	89.7	36.7	P	<0.0001*
A6: Comparisons/ Metaphors	23.1	3.3	F	0.036*
A7: Evaluative words	48.7	20.0	P	0.014*
B: Vocabulary to direct others' actions	100.0	100.0	-	-
B2: Places	82.1	36.7	P	0.0001*
B3: Remedy	97.4	70.0	P	0.001*
C: Vocabulary to describe pain location	71.8	33.3	P	0.002*
C2: Visible signs of injury	66.7	16.7	P	<0.0001*
D: Vocabulary to describe the causes of pain	100.0	100.0	-	-
D1: Internal causes of pain	87.2	63.3	P	0.02*
E: Vocabulary to describe strategies used to cope with pain	100.0	100.0	-	-
E3: Positive outcomes	79.5	26.7	P	<0.0001*
E4: Distractions	41.0	6.7	P	0.001*
F: Vocabulary to reflect on strategies of how the pain could have been prevented	43.6	16.7	P	0.017*
F2: Reflect on how to prevent pain	28.2	3.3	P	0.007*
G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	79.5	56.7	-	-
G2: Secondary gain	35.9	3.3	P	0.001*

Note. P = Pearson's Chi-Square Test; F = Fisher's Exact Test.
*p<0.05.

Table 5.12 indicates that there was a statistically significant difference between the data of the younger children and their teachers in two main categories, namely Categories C (p=0.002) and F (p=0.017), as well as in 13 sub-categories (A1, A2, A5, A6, A7, B2, B3, C2, D1, E3, E4, F2, G2) as H_0 was rejected in favour of H_1 ($p<0.05$). In comparison, no main categories and only 10 sub-categories showed statistically significant differences between the percentage of child respondents and the percentage of parent respondents who suggested words and/or phrases within these categories (see Table 5.11).

Table 5.13 reflects the pairwise comparisons between the data of the younger children's parents and teachers. Similar to Table 5.11 and 5.12, four main categories (A, B, D and E) were not tested because 100% of the participants in all three respondent groups used vocabulary in the specific category. Category G was also not tested because H_0 was accepted in the three-way comparisons. The five main categories mentioned were thus only included in Table 5.13 to clarify the sub-categories.

Table 5.13

Pairwise Comparison of the Percentage of Parent and Teacher Respondents for the Younger Group who Used Words and/or Phrases That Fell in the Pain-Related Categories and Sub-Categories

Pain-related main category with sub-categories	**Younger group (6;0–7;11) % of participants offering words/phrases**		**Test used**	**p-value**
	Parents (*n*=29)	**Teachers (*n*=30)**		
A: Vocabulary to describe pain	100.0	100.0	-	-
A1: Exclamations	100.0	93.3	F	0.49
A2: Vocalisations and verbalisations	86.2	86.7	F	1.00
A4: Sensory words	86.2	46.7	P	0.001*
A5: Intensifiers	62.1	36.7	P	0.051
A6: Comparisons/ Metaphors	20.7	3.3	F	0.05*
A7: Evaluative words	24.1	20.0	P	0.701
B: Vocabulary to direct others' actions	100.0	100.0	-	-
B2: Places	10.3	36.7	P	0.018*
B3: Remedy	79.3	70.0	P	0.412
C: Vocabulary to describe pain location	58.6	33.3	P	0.051
C2: Visible signs of injury	58.6	16.7	P	0.0009*
D: Vocabulary to describe the causes of pain	100.5	100	-	-
D1: Internal causes of pain	65.5	63.3	P	0.861
E: Vocabulary to describe strategies used to cope with pain	100.0	100.0	-	-
E3: Positive outcomes	34.5	26.7	P	0.515
E4: Distractions	13.8	6.7	P	0.365
F: Vocabulary to reflect on strategies of how the pain could have been prevented	34.5	16.7	P	0.116
F2: Reflect on how to prevent pain	20.7	3.3	F	0.039*

Pain-related main category with sub-categories	**Younger group (6;0–7;11) % of participants offering words/phrases**		**Test used**	**p-value**
	Parents (*n*=29)	**Teachers (*n*=30)**		
G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	58.6	56.7	-	-
G2: Secondary gain	6.9	3.3	P	0.533

Note. P = Pearson's Chi-Square Test; F = Fisher's Exact Test.
*p<0.05.

Table 5.13 shows that, for most categories, similar percentages of the younger children's parents and teachers provided words and/or phrases falling in those specific categories. Statistically significant differences were observed for five sub-categories only: A4 (p=0.001), A6 (p=0.05), B2 (p=0.018), C2 (p=0.0009), and F2 (p=0.039) where hypothesis H_0 was rejected.

For the older children, the following two-sided hypothesis was formulated:

H_0: The percentage of respondents who offered words and/or phrases relevant for the older children in the pain-related categories and sub-categories is the same for children, parents and teachers.

H_1: The percentage of respondents who offered words and/or phrases relevant for the older children in the pain-related categories and sub-categories differs across the three respondent groups (children, parents and teachers).

Table 5.14

Three-way Comparisons of the Percentage of the Three Respondent Groups for the Older Group who Used Words and/or Phrases That Fell in the Pain-Related Categories and Sub-Categories

Pain-related main category with sub-categories	**Older group (8;0–9;11) % of participants offering words/phrases**			**Test used**	**p-value**
	Children (*n*=35)	**Parents (*n*=32)**	**Teachers (*n*=26)**		
A: Vocabulary to describe pain	100.0	100.0	100.0	-	-
A1: Exclamation	62.7	96.9	88.4	P	0.0009*
A2: Vocalisations and verbalisations	60.0	87.5	73.1	P	0.0401*
A3: Descriptor words	97.1	96.9	100.0	F	1.0
A4: Sensory words	77.1	75.0	53.8	P	0.108
A5: Intensifiers	100.0	78.1	42.3	P	<0.0001*
A6: Comparisons	17.1	15.6	7.7	F	0.607
A7: Evaluative words	62.9	40.6	30.8	P	0.0334*
B: Vocabulary to direct others' actions	100.0	100.0	100.0	-	-
B1: Action	100.0	96.9	88.5	F	0.0639
B2: Where to go to when in pain	94.2	6.3	23.1	P	<0.0001*
B3: Remedy	100.0	81.2	84.6	F	0.0168*
C: Vocabulary to describe pain location	82.9	43.8	30.8	P	<0.0001*
C1: Site of injury	20	0	15.4	F	0.0133*
C2: Visible signs of injury	77.1	43.8	19.2	P	<0.0001*
D: Vocabulary to describe the causes of pain	91.1	93.8	100.0	F	0.629
D1: Internal causes	94.3	56.3	61.5	P	0.0009*
D2: External causes	94.3	90.6	96.2	F	0.763
E: Vocabulary to describe strategies used to cope with pain	100.0	90.6	88.5	F	0.1039
E1:Self-talk	60.0	65.6	80.7	P	0.218
E2: Actions to cope with pain	100.0	68.8	53.9	P	<0.0001*
E3: Positive outcomes	68.6	40.6	23.1	P	0.0015*
E4: Distractions	42.9	28.1	11.6	P	0.028*
F: Vocabulary to reflect on strategies of how the pain could have been prevented	65.7	28.1	11.5	P	<0.0001*
F1: Reflect on what happened	42.9	21.9	11.5	P	0.018*
F2: Reflect on future (how to prevent)	40.0	6.3	0	P	<0.0001*
G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	94.3	59.4	50.0	P	0.0003*
G1: Physical outcomes	91.4	50.0	46.2	P	0.0001*
G2: Secondary gain	48.6	12.5	3.9	P	<0.0001*
G3: Emotional response as result of physical pain	22.9	3.1	11.5	F	0.585*

Note. P = Pearson's Chi-Square Test; F = Fisher's Exact Test.
*p<0.05.

For the older children, the H_0 was rejected for three of the five main categories tested, namely C (p<0.0001), F (p<0.0001 and G (p=0.0003). This indicated statistically significant differences between the data of the three respondent groups (children, parents, teachers). No calculations were made for two main categories (A and B) because 100% of the participants in the three data groups used vocabulary in these specific categories.

Of the 23 sub-categories that were tested, 17 sub-categories differed statistically significantly, namely A1, A2, A5, A7, B2, B3, C1, C2, D1, E2, E3, E4, F1, F2, G1, G2 and G3, which indicates that hypothesis H_0 is rejected in favour of H_1.

Tables 5.15 to 5.17 represent the outcomes of the pair wise comparisons between children, parents and teachers of the remaining categories. These comparisons were made to determine which respondent groups' (children, parents or teachers) data indicated statistically significant differences.

Two main categories (A and B) were not tested, because 100% of the respondents in the respondent groups used vocabulary that fell in these categories. However, these two categories, as well as, categories D and E, in which hypothesis H_0 was accepted in the three-way comparison with p=0.629 and p=0.1039 respectively, were included in Table 5.15 to assist with the interpretations of the sub-categories included in the table.

Table 5.15

Pairwise Comparison of the Percentage of Child and Parent Respondent Groups for the Older Group who Used Words/Phrases That Fell in the Pain-Related Categories and Sub-Categories

Pain-related main category with sub-categories	**Older group (8;0–9;11) % of participants offering words/phrases**		**Test used**	**p-value**
	Children (*n*=35)	**Parents (*n*=32)**		
A: Vocabulary to describe pain	100.0	100.0	-	-
A1: Exclamations	62.9	96.9	P	0.0006*
A2: Vocalisations and verbalisations	60.0	87.5	P	0.0112*
A5: Intensifiers	100.0	78.1	P	0.004*
A7: Evaluative words	62.9	40.6	P	0.069*
B: Vocabulary to direct others' actions	100.0	100.0	-	-
B2: Places	94.3	6.3	P	<0.0001*
B3: Remedy	100.0	81.3	P	0.007*
C: Vocabulary to describe pain location	82.9	43.8	P	0.0009*

Pain-related main category with sub-categories	**Older group (8;0–9;11) % of participants offering words/phrases**		**Test used**	**p-value**
	Children (*n*=35)	**Parents (*n*=32)**		
C1: Site of injury	20.0	0	P	0.008*
C2: Visible signs of injury	77.1	43.8	P	0.005*
D: Vocabulary to describe the causes of pain	91.1	93.8	-	-
D1: Internal causes of pain	94.3	56.3	P	0.0003*
E: Vocabulary to describe strategies used to cope with pain	100.0	90.6	-	-
E2: Actions to cope with pain	100.0	68.8	P	0.0003*
E3: Positive outcomes	68.6	40.6	P	0.022*
E4: Distractions	42.9	28.1	P	0.209
F: Vocabulary to reflect on strategies of how the pain could have been prevented	65.7	28.1	P	0.002*
F1: Reflect on what happened	42.9	21.9	P	0.07
F2: Reflect on how to prevent pain	40.0	6.3	F	0.001*
G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	94.3	59.4	P	0.0006*
G1: Physical outcome	91.4	50.0	P	0.0002*
G2: Secondary gain	48.6	12.5	P	0.002*
G3: Emotional response as a result of pain	22.9	3.13	P	0.018*

Note. P = Pearson’s Chi-Square Test; F = Fisher’s Exact Test.
*p<0.05.

As can be seen from the data presented in Table 5.15, for all 17 the sub-categories tested, with the exception of two, namely E4 (p=0.209) and F1 (p=0.07) the H_0 hypothesis was rejected in favour of H_1. This indicates that for the older group, the children’s data differ significantly from the parents’ data.

Table 5.16 presents the pairwise comparison between older children and Gr 3 teachers.

Table 5.16

Pairwise Comparison of the Percentage of Child and Teacher Respondent Groups for the Older Group who Used Words/Phrases That Fell in the Pain-Related Categories and Sub-Categories

Pain-related main category with sub-categories	**Older group (8;0—9;11) % of participants offering words/phrases**		**Test used**	**p-value**
	Children (*n*=35)	**Teachers (*n*=26)**		
A: Vocabulary to describe pain	100.0	100.0	-	-
A1: Exclamations	62.9	88.5	P	0.025*
A2: Vocalisations and verbalisations	60.0	73.1	P	0.288

Pain-related main category with sub-categories	**Older group (8;0—9;11) % of participants offering words/phrases**		**Test used**	**p-value**
	Children (*n*=35)	**Teachers (*n*=26)**		
A5: Intensifiers	100	42.3	P	<0.0001*
A7: Evaluative words	62.9	30.8	P	0.013*
B: Vocabulary to direct others' actions	100.0	100.0	-	-
B2: Places	100	23.1	P	<0.0001*
B3: Remedy	100	84.6	P	0.016*
C: Vocabulary to describe pain location	82.9	30.8	P	<0.0001*
C1: Site of injury	20	15.4	P	0.643
C2: Visible signs of injury	77.1	19.2	P	<0.0001
D: Vocabulary to describe the causes of pain	93.8	100.0	-	-
D1: Internal causes of pain	94.3	61.5	P	0.002*
E: Vocabulary to describe strategies used to cope with pain	100.0	88.5	-	-
E2: Actions to cope with pain	100	53.9	P	<0.0001*
E3: Positive outcomes	68.6	23.1	P	0.0004*
E4: Distractions	42.9	11.54	P	0.008*
F: Vocabulary to reflect on strategies of how the pain could have been prevented	65.7	11.5	P	<0.0001*
F1: Reflect on what happened	42.9	11.5	P	0.008*
F2: Reflect on how to prevent pain	40	0	P	0.0002*
G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	94.3	50.0	P	<0.0001*
G1: Physical outcome	91.4	46.2	P	<0.0001*
G2: Secondary gain	48.6	3.9	P	0.0002*
G3: Emotional response as a result of pain	22.9	11.5	P	0.256

Note. P = Pearson's Chi-Square Test.
*p<0.05.

Three main categories (A and B) were not calculated, because 100% of the respondents in the respondent groups used vocabulary within these categories. However, these three categories, as well as categories D and E, where hypothesis H_0 was accepted in the three-way comparison, were included in Table 5.16 to assist with the interpretations of the sub-categories included in the table.

Table 5.16 shows that for 13 of the 23 sub-categories, namely A1, A5, A7, B1, B2, D1, E1, E3, E4, F1, F2, G1 and G2 there is a statistically significant difference ($p<0.05$) between the data of the older children and that of the Gr 3 teachers.

Table 5.17 shows the data of the pairwise comparisons between the older children's parents and teachers.

Table 5.17

Pairwise Comparison of the Percentage of Parent and Teacher Respondent Groups in the Older Group who Used Words/Phrases That Fell in the Pain-Related Categories and Sub-Categories

Pain-related main category with sub-categories	**Older group (8;0–9;11) % of participants offering words/phrases**		**Test used**	**p-value**
	Parents (*n*=32)	**Teachers (*n*=26)**		
A: Vocabulary to describe pain	100.0	100.0	-	-
A1: Exclamations	96.9	88.5	F	0.21
A2: Vocalisations and verbalisations	87.5	73.1	F	0.163
A5: Intensifiers	78.1	42.3	P	0.052*
A7: Evaluative words	40.6	30.8	P	0.437
B: Vocabulary to direct others’ actions	100.0	100.0	-	-
B2: Places	6.3	23.1	P	0.06
B3: Remedy	81.3	84.6	P	0.736
C: Vocabulary to describe pain location	43.8	30.8	-	-
C1: Site of injury	0	15.4	P	0.022*
C2: Visible signs of injury	43.8	19.2	P	0.05*
D: Vocabulary to describe the causes of pain	93.8	100.0	F	0.629
D1: Internal causes of pain	56.3	61.5	P	0.684
E: Vocabulary to describe strategies used to cope with pain	90.6	88.5	-	-
E2: Actions to cope with pain	68.8	53.9	P	0.2447
E3: Positive outcomes	40.6	23.1	P	0.157
E4: Distractions	28.1	11.5	P	0.121
F: Vocabulary to reflect on strategies of how the pain could have been prevented	28.1	11.5	P	0.121
F1: Reflect on what happened	21.9	11.5	P	0.3
F2: Reflect on how to prevent pain	6.3	0	P	0.194
G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	59.4	50	P	0.48
G1: Physical outcome	50.0	46.2	P	0.77
G2: Secondary gain	12.5	3.9	P	0.243
G3: Emotional response as a result of pain	3.13	11.5	P	0.208

Note. P = Pearson’s Chi-Square Test; F = Fisher’s Exact Test.
*p<0.05.

Data from Table 5.17 indicates that, for most categories, similar percentages of parents and teachers suggested words and/or phrases falling into those categories. H_0 was rejected for sub-categories A5, C1 and C2, which indicated a statistically significant difference between the data of the parents and teachers of the older children.

Table 5.18 provides a summary of the number of main and sub-categories where the pairwise comparisons yielded statistically significant differences between respondent groups for the two age groups of children.

Table 5.18

Summary of Number of Main and Sub-Categories Where the Pairwise Comparisons Yielded Statistically Significant Differences Between Respondent Groups Within the two age Groups

Younger group (6;0–7;11)				**Older group (8;0–9;11)**			
Pairwise comparison		**Main**	**Sub-categories**	**Pairwise comparison**		**Main**	**Sub-categories**
Children *(n=39)*	Parents *(n=29)*	0	10	Children (*n*=35)	Parents (*n*=32)	3	15
Children *(n=39)*	Teachers (*n*=30)	2	13	Children (*n*=35)	Teachers (*n*=26)	3	13
Parents *(n=29)*	Teachers (*n*=30)	0	5	Parents (*n*=32)	Teachers (*n*=26)	0	3

In summary, Table 5.18 shows that, for the younger group, only two of the seven main categories were differed statistically significantly, namely for children and teachers, while no main categories differed significantly between children and parents or between teachers and parents. Of the 23 sub-categories, 10 showed differences between the data of children and parents; 13 between the data of children and parents, and only five between the data of parents and teachers.

For the older group, the differences between children and parents (five main categories and 15 sub-categories) and children and teachers (three main categories and 13 sub-categories) were larger when compared with the younger group. This indicates that the older the children are, the larger the differences become between children and parents or teachers, which highlights the importance of using older children as participants in the selection of vocabulary. Smaller differences were reported between parents and teachers (no main categories and only three sub-categories) in comparison with the younger group.

5.8 Composite list of pain-related words and/or phrases

Earlier in this chapter, the words and/or phrases that occurred 10 times or more in each respondent group was highlighted (Tables 5.3 to 5.5). In order to compile a composite list of pain-related words and/or phrases that could be included on the communication board for the social validation phase of this research, the commonality between groups was determined for these words and/or phrases. Table 5.19 represents the composite list of pain-related words and/or phrases in their respective pain-related sub-categories that occurred 10 times or more. The table also shows in which of the six respondent groups each word and/phrase occurred. A total score is furthermore added in the table to tally the number of respondent groups in which this word and/or phrase occurred – a higher number thus indicates that the specific words and/or phrases were provided or suggested in more respondent groups.

Table 5.19

Composite List of All Pain-Related Words and/or Phrases Across Respondent Groups

Main and sub pain-related categories	**Pain-relate words and/or phrases**	**Younger children**	**Older children**	**Parents of younger children**	**Parents of older children**	**Teachers of younger children**	**Teachers of older children**	**Total**
B1	call/tell (mommy/daddy/teacher)	1	1	1	1	1	1	6
A2	cry/cries/crying	1	1	1	1	1	1	6
A3	hurt (my body part)	1	1	1	1	1	1	6
D1	I fell	1	1	1	1	1	1	6
D2	ball hit me	1	1	1	1	1	1	6
A3	it is sore	1	1	1	1	1	1	6
A1	ouch	1	1	1	1	1	1	6
A1	ow	1	1	1	1	1	1	6
B1	please help	1	1	1	1	1	1	6
B1	take it (thorns/splinter) out	1	1	1	1	1	1	6
D2	the bee stung me	1	1	1	1	1	1	6
A5	very sore/really sore/so sore	1	1	1	1	1	1	6
A3	it pains/paining	1	1	1	0	1	1	5
E3	it will feel better/will be better	1	1	1	1	1	0	5
B3	put on plaster	1	1	1	1	1	0	5
A3	blood/bleeding (there is blood all	1	1	0	0	1	1	4

Main and sub pain-related categories	Pain-relate words and/or phrases	Younger children	Older children	Parents of younger children	Parents of older children	Teachers of younger children	Teachers of older children	Total
	over/the sore is bleeding)							
A1	eina	0	0	1	1	1	1	4
E1	I am okay	0	0	1	1	1	1	4
A2	I screamed	0	1	1	1	1	0	4
B1	make it better	1	1	1	1	0	0	4
B3	medicine/medication	1	1	1	1	0	0	4
A4	the sore was burning	0	0	1	1	1	1	4
B2	go to sickroom/office/principal	0	1	0	0	1	1	3
A7	I don't feel well	0	1	0	1	0	1	3
E2	I hold (it)/hold on hurt	0	0	1	0	1	1	3
A5	it was painful	1	1	0	1	0	0	3
G1	point at/show (the place of injury)	0	0	1	1	1	0	3
B3	put on something	1	0	0	0	1	1	3
B3	put some cream/special cream (on)	1	1	1	0	0	0	3
E2	do nothing/don't do anything (when in pain)	0	0	1	0	1	0	2
B2	go to the doctor	1	1	0	0	0	0	2
B2	go to the hospital	1	1	0	0	0	0	2
B1	hold my hand	0	0	1	1	0	0	2
A5	hurts very bad/hurt a lot	1	1	0	0	0	0	2
A3	I feel sick	0	0	1	0	1	0	2
D1	I have a headache	0	1	0	1	0	0	2
E2	I rub it	0	0	1	1	0	0	2
E2	I want to go home	1	1	0	0	0	0	2
G1	I want to vomit	1	1	0	0	0	0	2
E1	I'm fine/ it is fine	0	0	0	1	0	1	2
C2	it is swollen	1	1	0	0	0	0	2
D2	it was him (blame somebody else)	0	0	0	0	1	1	2
E2	lie down (when in pain)	0	0	0	1	1	0	2
E2	lie in bed	1	1	0	0	0	0	2
A1	owie	0	0	1	1	0	0	2
B3	put cold water on it	1	1	0	0	0	0	2
B3	put on bandage	1	1	0	0	0	0	2
B3	put on ice/ice pack	1	1	0	0	0	0	2
A5	really hurt	1	1	0	0	0	0	2
A4	the sore sting(s)/is stinging	0	0	1	1	0	0	2
D2	there is a splinter in my skin	0	0	0	1	0	1	2
A5	very painful/so painful	1	1	0	0	0	0	2
A5	very, very sore/ extremely sore/really, really sore	1	1	0	0	0	0	2
G1	facial expressions/grimace (show they are in pain)	0	0	1	0	0	1	2

Main and sub pain-related categories	**Pain-relate words and/or phrases**	**Younger children**	**Older children**	**Parents of younger children**	**Parents of older children**	**Teachers of younger children**	**Teachers of older children**	**Total**
D2	a dog ran across the street	0	1	0	0	0	0	1
F2	be more careful	0	1	0	0	0	0	1
C2	break (body part)	0	1	0	0	0	0	1
G1	can't move (body part)	0	1	0	0	0	0	1
B1	clean it	0	1	0	0	0	0	1
E3	doctor will help to make it better	0	1	0	0	0	0	1
B3	drink water/put water on the sore	0	1	0	0	0	0	1
B1	give me a/I need a hug	1	0	0	0	0	0	1
A4	hot	0	0	1	0	0	0	1
G3	I am sorry Mom (that I got hurt)	0	0	0	0	1	0	1
G1	I can't talk/speak (because it is sore)	0	1	0	0	0	0	1
C2	I have a blister	0	1	0	0	0	0	1
D2	I touched the warm pot/kettle/iron	0	1	0	0	0	0	1
E2	I want to sleep/go to sleep (when in pain to feel better afterwards)	1	0	0	0	0	0	1
D2	I was hit by a ball	0	0	0	0	1	0	1
A7	it feels not nice/ don't feel nice	0	1	0	0	0	0	1
E1	it is not sore at all/wasn't that sore	0	1	0	0	0	0	1
F1	I've pulled the brakes too hard	0	1	0	0	0	0	1
E4	let's play	1	0	0	0	0	0	1
A2	moan	0	0	0	1	0	0	1
C2	my skin has scratches	0	1	0	0	0	0	1
A1	ouchie	1	0	0	0	0	0	1
A1	ouwa	0	0	0	0	1	0	1
A5	pain/sore feels really bad	0	1	0	0	0	0	1
E3	pray to God/Allah* to make it better	1	0	0	0	0	0	1
B3	put on cast	1	0	0	0	0	0	1
B3	put on ointment	1	0	0	0	0	0	1
E2	rest for a little bit	0	1	0	0	0	0	1
B1	stop hurting/poking me	0	1	0	0	0	0	1
A3	the sore aches/aching	0	0	0	1	0	0	1
C1	there are thorns in my body part (head/skin/leg/hand	0	0	0	0	1	0	1
D2	they gave injection/inject	1	0	0	0	0	0	1
B1	wait until it is better	0	1	0	0	0	0	1

*Children used either “God” or “Allah”

The composite list comprised 87 pain-related words and/or phrases. All main categories and 21 of the 23 sub-categories were represented in this list. Only two sub-categories (A6: comparisons/metaphors) and (G2: secondary gain) were not represented.

5.9 The impact of other factors on children's use of pain-related vocabulary

Literature suggests that gender (Briggs, 2010; Fearon et al., 1996); the presence of older siblings (Franck et al., 2010); experiences of previous hospitalisations (Kortesluoma, Punämaki, et al., 2008); parental qualifications (Hoff, 2003; Lau et al., 1989; Rowe, 2008) and parental age (Turck et al., 1987) influence children's development and use of pain-related vocabulary. Therefore, hypotheses were set to determine the influence of said constructs on children's use of pain-related vocabulary.

5.9.1 The impact of gender on the pain vocabulary used by children

As literature suggests that boys and girls use different words to express their pain experiences (Beukelman & Mirenda, 2013; Fearon et al., 1996), the percentage of boys versus girls who used (a) individual words and/or phrases, and (b) words and/or phrases that fell into specific categories and subcategories was statistically compared for possible differences using either Pearson's Chi-Square Test or Fisher's Exact Test.

$H_{0:}$ Boys use the same pain-related words and/or phrases that fall in specific categories and sub-categories to describe pain-related experiences as do girls.

$H_{1:}$ The pain-related categories that boys use consist of different words and/or phrases that fall in specific categories and sub-categories than those that girls use to describe pain-related experiences.

No main categories differed statistically significantly, which indicated that H_0 was accepted. There was only one out of the possible 23 sub-categories (G2: Secondary gain) where H_0 was rejected in favour of H_1. Only four individual items differed statistically significantly. Of these, one is an example of an Intensifier (A5), namely "very, very sore/extremely sore/really, really sore". This was used more extensively by girls than boys (p-0.037). The secondary gain sub-category (G2) was also significant, with two examples of phrases used only by boys, namely, "I can go to the party" (p=0.10) and "I got some chips to eat." (p=0.027).

5.9.2 The impact of previous hospitalisations on the pain vocabulary used by children

To test for statistically significant differences in the data of children with previous hospitalisations versus those without, the following two-sided hypothesis was formulated:

H_0: Children with previous hospitalisations use the same words and/or phrases that fall in specific categories and sub-categories as do children with no previous hospitalisations.

H_1: Children with previous hospitalisations use different words and/or phrases that fall in specific categories and sub-categories than do children with no previous hospitalisations.

The population of children with previous hospitalisations (*n*=11) was tested against the population of children without experiences of previous hospitalisations (*n*=63). Only one of the seven main pain-related categories, namely D: Vocabulary to describe causes of pain (p=0.0006) and one of the 23 sub-categories, namely D1: Internal causes (p=0.03) showed a statistically significant difference on the 5% level of confidence. This implies that, for only one main and one sub-category the percentage of child participants with previous hospitalisations offered words and/or phrases which differed from the percentage of children without previous hospitalisations who suggested pain-related words and/or phrases.

5.9.3 *The impact of older siblings on the pain-related vocabulary used by children*

The following hypothesis was formulated to determine if the presence of an older sibling had any impact on the pain-related vocabulary elicited from the child participants. Again the data for the younger and older children were combined into one group, using the presence of an older sibling as the dividing construct. This resulted in two groups, namely those with an older sibling (*n*=38) and those without (*n*=36). The following two-sided hypothesis was formulated:

H_0: Children with older siblings use the same pain-related words and/or phrases that fall in specific categories and sub-categories than children without older siblings

H_1: Children with older siblings use different pain-related words and/or phrases that fall in specific categories and sub-categories than children without older siblings

The data set of the population of children with older siblings was tested for statistically significant difference against those without older siblings. The outcome indicated that only two of the 23 sub-categories, namely F2: Reflect on future (p=0.05) and G3: Emotional responses (p=0.05) differed statistically significant on the 5% level of confidence, indicating that there was a statistically significant difference between the data of children with and without older siblings in these two sub-categories.

5.9.4 *The impact of parents' age on the pain vocabulary used by children*

Parents' age influences their children's use of pain-related words and/or phrases (Turck et al., 1987). The data for the two groups of children were combined and re-organised according to those who have younger parents (*n*=41) and those who have older parents (*n*=33). Please note that this data was derived from the biographical data form of the children and thus refer to the children's own parents, and not to the parent participant respondent group. The following two-sided hypothesis was formulated:

H_0: Children with younger parents (≤40yr) use the same pain-related words and/or phrases that fall in specific categories and sub-categories as children with older parents (≥41yrs).

H_1: Children with younger parents (≤40yr) use different pain-related words and/or phrases that fall in specific categories and sub-categories than children with older parents (≥41yrs).

To test these hypotheses, Pearson's Chi-Square analyses were computed, comparing the words and/or phrases used by children with older parents' to those with younger parents.

However, no categories, sub-categories or words and/or phrases showed statistically significant difference on the 5% level of significance, which implies that children with older parents in this study's population did not use different words than those with younger parents.

5.9.5 The impact of parents' qualifications on the pain vocabulary used by children

Literature indicated that parents' qualifications influence their children's use of pain-related words (Hoff, 2003; Lau et al., 1989; Rowe, 2008). The younger and older children's data was combined into one group, in which parental qualification was used to make the new division. This resulted in two groups: children whose parents had lower qualifications (*n*=56) and children whose parents had higher qualifications (*n*=16). Two parents did not indicate their qualifications and their data were excluded and treated as missing data. The following two-sided hypothesis was formulated:

H_0: Children of parents with lower qualifications (≤3 years' post school) use the same pain-related words and/or phrases that fall in specific categories and sub-categories as children of parents with higher qualifications (≥4 years' post school).

H_1: Children of parents with lower qualifications (≤3 years' post school) use different pain-related words and/or phrases that fall in specific categories and sub-categories than children of parents with higher qualifications (≥4 years' post school).

H_0 was accepted for all seven main categories and 23 sub-categories. There was a significant difference in the use of 10 pain-related words and/or phrases within eight different sub-categories (A4: Sensory words; A5: Intensifiers; A7: Evaluative words; B1: Action; C2: Visible signs of injury; D1: Internal causes of pain; D2: External causes of pain; E3: Positive outcomes) by children whose parents had higher qualifications than whose parents had lower qualifications ($p < 0.05$). Individual words and/phrases that differed statistically significantly between children of parents with lower qualifications (≤ 3 years' post school) compared to those with parents with higher qualifications (≥ 4 years post school) were : "The sore was burning" (A4) (p=0.007); "very, very painful" (A5) (p=0.0049); "I can't feel" (A7) (p=0.039); "I have a blister" (C2) (p=0.009); "I fell" (D1) (p=0.036); "I touched the warm pot" (D2))p-0.46); "They draw blood" (D2) (p=0.009), and "It will feel better" (E3) (p=0.0081).

Table 5.20 summarises the other factors that were previously shown to have an impact on vocabulary development and use, such as gender, previous hospitalisations; presence of older siblings, parental age, and parental qualifications.

Table 5.20

Summary of Other Factors That Influence Children's use of Pain-Related Vocabulary

Factor	Main category	Sub-categories	Pain-related items
Gender	0/7	1/23	3/549
Previous hospitalisations	1/7	1/23	0/549
Presence of older siblings	0/7	2/23	0/549
Parents' age	0/7	0/23	0/549
Parents' qualifications	0/7	2/23	8/549

From Table 5.20, it is clear that although some differences were found for all factors tested, most categories, subcategories and individual words and phrases did not differ.

5.10 Phase 4: Social validation

In Phase 4, the composite list of physical pain-related words was socially validated by three literate adults who use AAC. Input from the adults was received (a) to determine how appropriate the compiled list was to answer questions based on three hypothetical scenarios; (b) to determine to what extent words and/or phrases from the different pain-related categories were used by the adults when communicating about three hypothetical pain scenarios; and (c) to obtain their suggestions on how to improve the list for use by children who could benefit from AAC. This input was used to amend the composite word list determined in Phase 3 and arrive at a list of socially validated pain-related vocabulary (words and/or phrases) as proposed in the main aim of the study.

5.10.1 Appropriateness of the list provided to answer three hypothetical physical pain scenarios

Table 5.23 presents the results of each participant's answers to the questions as per scenario. The words and/or phrases as well as the sub-category (in brackets) are indicated per answer.

Table 5.23

Results of the Social Validation of the Pain-Related Vocabulary by Adults who use AAC

Scenario and question	**Participant 1 Pain-related word(s) and/phrase(s), sub-category**	**Participant 2 Pain-related word(s) and/phrase(s), sub-category**	**Participant 3 Pain-related word(s) and/phrase(s), sub-category**
Scenario 5 (Ziggi had an operation)			
Question 1	*it pains* **(A3)**	*owie* **(A1)**	*ouch* **(A1)**
Question 2	*make it better* **(B1)**	*very painful/so painful*	(Participant typed out on

Scenario and question	Participant 1 Pain-related word(s) and/phrase(s), sub-category	Participant 2 Pain-related word(s) and/phrase(s), sub-category	Participant 3 Pain-related word(s) and/phrase(s), sub-category
		(A5)	Lightwriter: *It's the doctor's fault)* Selected on board: *it will feel better* **(E3)** *give me a hug* **(B1)**
Question 3	*medicine/medication* **(B3)**	*I want to go home* **(E2)**	*Wait until it is better* **(B1)**
Scenario 7 (Ziggi has a headache)			
Question 1	*I have a headache* **(D1)**	*it was painful* **(A5)**	*I have a headache* **(D1)**
Question 2	*I want to vomit* **(G1)**	*pray to God/Allah to make it better* **(E3)**	*put on something* **(B3)**
Question 3	*go to the doctor* **(B2)**	*go to the doctor* **(B2)**	*go to the doctor* **(B2)**
Scenario 10 (Ziggi gets a drip)			
Question 1	*ouch* **(A1)**	*ouch* **(A1)**	(Participant typed out on Lightwriter: *dammit)* Selected on board: *very sore/really sore/so sore* **(A5)**
Question 2	*very sore/really sore/so sore* **(A5)**	*cry* **(A2)**	*it feels not nice* **(A7)**
Question 3	*I want to go home* **(E2)**	*be more careful* **(F2)**	*put on ice/ice pack* **(B3)**

From Table 5.23 it is clear that all three participants used various pain-related words/and or phrases displayed on the communication board from different sub-categories to answer the different questions per scenario. The three participants mostly used different categories and sub-categories for the same question in the same scenario. For example, in Scenario 5 (Ziggi had an operation), three main categories (A, B and E) were used. In Question 1, the three participants used two different sub-categories (A1 and A3); in Question 2, they each used a different sub-category (B1, A5, and E3), as was also the case in Question 3 (B3, E2, and B1).

In Scenario 7 (Ziggi has a headache), four main categories (A, B, E and G) were used. Two different sub-categories (A5 and D1) were used by the three participants in Question 1; three different sub-categories (G1, E3 and B3) in Question 2, but the same sub-category and phrase ("go to the doctor" [B2]) was used by all three participants to answer Question 3.

In Scenario 10 (Ziggi gets a drip), four main categories (A, B, E and F) were used. Two sub-categories were used for Question 1 (A1 and A5) as two of the adults answered "ouch"

(A1) for this question; three sub-categories were used for Question 2 (A5, A2 and A7) and three sub-categories for Question 3 (E2, F2 and B3).

Participant 3 opted twice to use his communication device to provide answers. He used a swear word "dammit", as his first reaction to the scenario where the nurse struggles to find Ziggi's vein, highlighting the fact that swear words should be considered in a list of pain-related vocabulary. The fact that this particular participant had undergone the specific procedure (getting an IV) just hours before completing the HPPS-S, could also have contributed to this response, as the scenario reflected a recent lived experience, eliciting a more emotional reaction.

5.10.2 The use of pain-related categories and sub-categories

Table 5.23 shows that the participants used a variety of categories and sub-categories to answer the questions for the different scenarios. Table 5.24 summarises the categories and sub-categories that were used by the different participants.

Table 5.24

Selection of Sub-Categories per Participant

Main and sub-category	Participant 1	Participant 2	Participant 3	Total
A: Vocabulary to describe pain				
A1	1	2	1	4
A2	0	1	0	1
A3	1	0	0	1
A4	0	0	0	0
A5	1	2	1	4
A6	0	0	0	0
A7	0	0	1	1
B: Vocabulary to direct other's actions				
B1	1	0	2	3
B2	1	1	1	3
B3	1	0	2	3
C: Vocabulary to describe pain location				
D: Vocabulary to describe causes of pain				
D1	1	0	1	2
D2	0	0	0	0

Main and sub-category	Participant 1	Participant 2	Participant 3	Total
E: Vocabulary to describe strategies used to cope with pain				
E1	0	0	0	0
E2	1	1	0	2
E3	0	1	1	2
E4	0	0	0	0
F: Vocabulary to reflect on strategies of how the pain could have been prevented				
F1	0	0	0	0
F2	0	1	0	1
G: Vocabulary to indicate the consequences of pain or injury				
G1	1	0	0	1
G2	0	0	0	0
G3	0	0	0	0

Although only three questions were posed about the three scenarios (nine in total) to each of the participants, which could limit the options for the use of various categories, six of the seven categories were used. Only Category C (Vocabulary used to describe pain location and visible signs to the actual tissue damage as a result of the physical injury) was not used by any of the participants, possibly due to the fact that the scenarios in the HPPS-S did not elicit words within this category. Furthermore, it can be seen from Table 5.24 that 13 of the 23 sub-categories were used at least once. In Category A, sub-categories A1 (Exclamation) and A5 (Intensifiers) were used most often (four times each) while the sub-categories in Category B were all equally used (three times). In Categories F and G one sub-category each was used, namely F2 (Reflection on how to prevent pain) and G1 (Physical outcome). Both of these sub-categories were used only once. Participant 1 used nine different sub-categories (none were used twice); Participant 2 used seven sub-categories (and used two sub-categories twice), while Participant 3 used eight different sub-categories (and used two twice).

5.10.3 Suggestions made by adults who use AAC

Participant 3 suggested that the words “cream”, “band aid” and “pain pill” should be added to the list. However, “cream” was included in the composite list (B3 sub-category), but due to the fact that it formed part of a phrase, it was not easily retrievable. All the participants suggested that single words and not sentences or phrases should rather be included in a list of pain-related vocabulary for use by children; for example, they suggested to use a core word like “put” and to add to it different options like “cast”, “cream”, “ice”, etc. for the child to choose from. Participant 3 further suggested arranging the words alphabetically, possibly in columns for easier retrieval:

> “*Make messages short and effective, as a person like me does not want to struggle to find the word, because it takes so much effort*.” (Participant 3)

He further suggested adding a body figure for the child to indicate where the pain is located on the body. This may be more useful than the words and/or phrases suggested in Category C (describe pain location) and may be linked to the fact that words and/or phrases from this category were never used. Participant 3 also emphasised the inclusion of descriptive words, such as those mentioned in Category A (Vocabulary to describe pain) of the composite list.

As described in Chapter 4, the different categories were randomly colour-coded on the communication board in an attempt to assist the users to retrieve the groupings of words and/or phrases in the same categories faster (Wilkinson, et al., 2008). All three participants agreed that the colour coding helped them to retrieve the words and/or phrases they needed to answer the questions. However, due to their individual physical challenges, the three participants obtained mixed results with regard to how quickly they found their desired response: Participant 1, who functions on Level 1 of the GMFCS (Palisano et al., 1997) and on Level II of the BFMF (Beckung & Hagberg, 2002) could indicate all her answers within one or two seconds. Participant 2 (on Level V in both the GMFCS and BFMF), however, took an average of 25 seconds (a range of 9 to 61 seconds) to indicate his answers. Participant 3 (on Levels V and IV of the GMFCS and BFMF respectively) obtained his answers within a mean of 17 seconds (ranging from 7 seconds to 30 seconds).

5.10.4 Socially validated list of pain-related vocabulary (words and/or phrases)

Participants stipulated that they thought that single words would be more applicable for children to communicate their pain on a communication board. Therefore, the researcher determined the single words that occurred in the composite list by means of Atlas-ti word cruncher. These words are shown in Figure 5.6 as a word cloud.

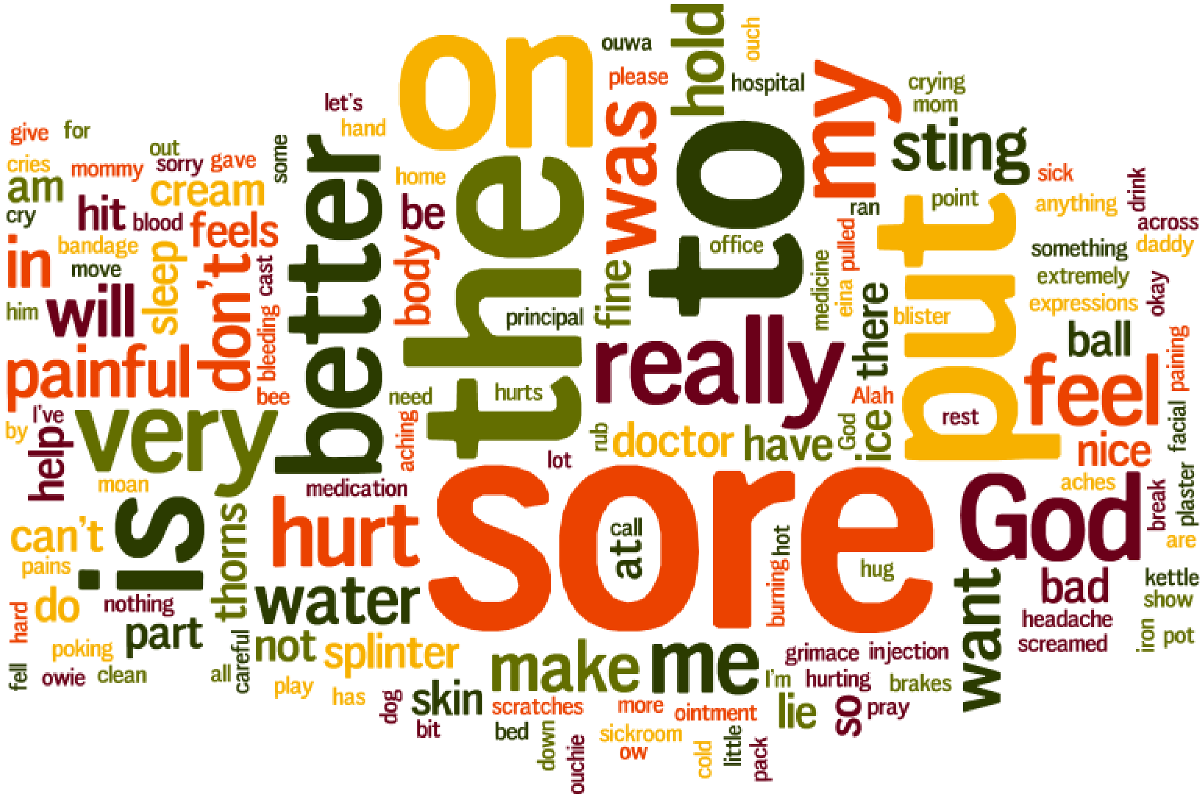


Figure 5.6. Word cloud of the words in the socially valid composite list.

Next, the researcher and second coder mutually agreed about which words were core words, based on the core word lists of Banajee et al. (2003); Marvin et al. (1994) and Trembath et al. (2007) and which words were fringe words (pain-related or other). Altogether, 78 different core words (45%) were reflected in the composite list, as well as 98 (55%) different fringe words of which 41 were classified as pain-related words (23%) and 57 as other words (32%).

Table 5.25 shows the updated version of the composite list comprising of words and/or phrases according to the sub-categories, core and fringe (pain-related and other). In Table 5.25 the words and/or phrases of the composite list, are divided into core words, pain-related fringe words and pain-related other words, therefore the multiple headings indicating “core”, “fringe – pain” and “fringe – other”.

Table 5.25

Composite List of Pain-Related Vocabulary According to Sub-Categories; Words and/or Phrases; Core Words, Fringe (Pain-Related) and Fringe (Other)

Sub-category	Words and/or phrases	Core	Core	Core	Core	Core	Fringe –pain	Fringe - pain	Fringe - other	Fringe - other	Fringe - other
A1	ouch						ouch				
A1	ow						ow				
A1	eina						eina				
A1	owie						ouwie				
A1	ouchie						ouchie				
A1	ouwa						ouwa				
A2	cry/cries/crying						cry/cries	crying			
A2	I screamed	I					scream				
A2	moan						moan				
A3	hurt (my body part)						hurt				
A3	it is sore	it	is				sore				
A3	it pains/paining	it					pains	paining			
A3	blood/bleeding						blood	bleeding			
A3	I feel sick	I					sick		feel		
A3	the sore aches/aching	the					sore	aches/aching			
A4	the sore was burning	the	was				sore	burning			
A4	the sore sting(s)/is stinging	the	is				sore	stings/stinging			

Sub-category	Words and/or phrases	Core	Core	Core	Core	Core	Fringe –pain	Fringe - pain	Fringe - other	Fringe - other	Fringe - other
A4	hot	hot									
A5	very sore/really sore/so sore	very	really				sore				
A5	it was painful	it	was				painful				
A5	hurts very bad/hurt a lot	very	bad	a	lot		hurts				
A5	really hurt	really					hurt				
A5	very painful/so painful	very	so				painful				
A5	very, very sore/ extremely sore/really, really sore	very	really				sore		extremely		
A5	pain/sore feels really bad	really	bad				pain	sore			
A7	I don't feel well	I	don’t	well					feel		
A7	it feels not nice/ don't feel nice	it	don’t						feels		
B1	call/tell (mommy/daddy/teacher)	call	tell	mommy					teacher	daddy	
B1	please help	please	help								
B1	take it (thorns/splinter) out	take	it	out							
B1	make it better	make	it	better							
B1	hold my hand	hold	my	hand							
B1	clean it	it							clean		
B1	give me a/I need a hug	give	me	a	I	need			hug		
B1	stop hurting/poking me	stop	me				hurting	poking			
B1	wait until it is better	wait	it	is	better				until		
B2	go to sickroom/office/principal	go	to						sickroom	office	principal
B2	go to the doctor	go	to	the	doctor						

Sub-category	Words and/or phrases	Core	Core	Core	Core	Core	Fringe –pain	Fringe - pain	Fringe - other	Fringe - other	Fringe - other
B2	go to the hospital	go	to	the			hospital				
B3	put on plaster	put	on				plaster				
B3	medicine/medication						medicine	medication			
B3	put on something	put	on	something							
B3	put some cream/special cream (on)	put	some						cream	special	
B3	put cold water on it	put	water	on	it				cold		
B3	put on bandage	put	on				bandage				
B3	put on ice/ice pack	put	on						ice	pack	
B3	drink water/put water on the sore	drink	water	put	on	the	sore				
B3	put on cast	put	on				cast				
B3	put on ointment	put	on				ointment				
C1	there are thorns in my body part (head/skin/leg/hand	there	are	in	my				thorns		
C2	it is swollen	it	is				swollen				
C2	break (body part)									break	
C2	I have a blister	I	have	a			blister				
C2	my skin has scratches	my	has				scratches			skin	
D1	I fell	I	fell								
D1	I have a headache	I	have	a			headache				
D2	ball hit me	ball	me						hit		
D2	the bee stung me	the		me			stung		bee		
D2	it was him (blame somebody	it	was	him							

Sub-category	Words and/or phrases	Core	Core	Core	Core	Core	Fringe –pain	Fringe - pain	Fringe - other	Fringe - other	Fringe - other
	else)										
D2	there is a splinter in my skin	there	is	a	in	my			splinter	skin	
D2	a dog ran across the street	a	dog	the					ran	across	street
D2	I touched the warm pot/kettle/iron	I	the						touched	warm	pot kettle iron
D2	I was hit by a ball	I	was		a				hit	ball	by
D2	they gave injection/inject	they	me	an			injection	inject	gave		
E1	I am okay	I	am	okay							
E1	I'm fine/ it is fine	I'm	it	is					fine		
E1	it is not sore at all/wasn't that sore	it	is	not	at	all	sore				
E2	I hold (it)/hold on hurt	I	hold	on			hurt				
E2	do nothing/don't do anything (when in pain)	do	don’t						nothing	anything	
E2	I rub it	I	it						rub		
E2	I want to go home	I	wany	to	go	home					
E2	lie down (when in pain)	down							lie		
E2	lie in bed	in	bed						lie		
E2	I want to sleep/go to sleep (when in pain to feel better afterwards)	i	want	to	go				sleep		
E2	rest for a little bit	for	a	little	bit				rest		
E3	it will feel better/will be better	it	will	better	better				feel		
E3	doctor will help to make it better	doctor	will	help	to	make; it; better					

Sub-category	Words and/or phrases	Core	Core	Core	Core	Core	Fringe –pain	Fringe - pain	Fringe - other	Fringe - other	Fringe - other
E3	pray to God/Allah to make it better	to	make	it	better				pray	God	Allah
E4	let's play	let's	play								
F1	I've pulled the brakes too hard	I've	too						pulled	brake	hard
F2	be more careful	be	more						careful		
G1	point at/show (the place of injury)	at	show						point		
G1	I want to vomit	I	want	to			vomit				
G1	facial expressions/grimace (show they are in pain)								facial	expressions	grimace
G1	can't move (body part)	can't	move								
G1	I can't talk/speak (because it is sore)	I	can't						talk	speak	
G3	I am sorry Mom (that I got hurt)	I	am	sorry							

5.11 Summary of results

The results of Chapter 5 confirmed that older children, when compared to younger children, suggested more words and/or phrases in three main categories (E: Vocabulary to describe strategies used to cope with pain [p=0.047]; F: Vocabulary to reflect on strategies of how the pain could have been prevented [p=0.028] and G: Vocabulary to indicate the consequences of pain or injury and influence activities and participation [p=0.032]). There were no statistically significant differences ($p<0.05$), in the number of words reported per category by parents or teachers of the younger and older children.

For both the younger and older groups, there were statistically significant differences between the data of the three respondent groups (children, parents and teachers). Two main categories (C: Vocabulary to describe pain location and visible signs to the actual tissue damage a result of the physical injury [p=0.0058] and F: Vocabulary to reflect on how the pain could have been prevented [p=0.059]) differed statistically significantly for the younger group, and three main categories (C: Vocabulary to describe pain location and visible signs to the actual tissue damage a result of the physical injury [p<.0001]; F: Vocabulary to reflect on how the pain could have been prevented [p<.0001], and G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation [p=0.0003]) differed for the older group.

A composite list of all pain-related words and/or phrases was compiled, which comprised 87 pain-related words and/or phrases that included all identified main and sub-categories, with the exception of sub-categories A6: Comparisons/metaphors and G2: Secondary gain.

Of the other factors that influenced children's use of pain-related vocabulary, children's previous hospitalisations differed statistically differently in one main category (D: Vocabulary to describe causes of pain [p=0.0006]) and one sub-category (D1: Internal causes (p=0.02]) to children without previous hospitalisations. The presence of older siblings tested statistically significant difference against those without older siblings in two sub-categories (F2: Reflect on future [0.05] and G3: Emotional responses [0.05]).

The social validation process during which three adults who use AAC socially validated the composite list of pain-related vocabulary resulted in an updated socially validated composite list based on the recommendations made by these adults.

5.12 Conclusion

The quantitative results of this study were presented in Chapter 5. Chapter 5 commenced with a discussion of steps adhered to in order to ensure reliability of the data. Next, the organisation of the respondent groups was discussed, followed by the identification of total number of pain-related words and/or phrases per respondent group per scenario and the occurrence frequency of these words and/or phrases elicited across respondent groups. The description and refinement of the data as pain-related categories; sub-categories and words and/or phrases were addressed. Thereafter, three-way and pairwise comparisons were used to identify specific differences between the six respondent groups. Statistical inference was employed to generalise the results to the population and to investigate the influence of age, gender, siblings, previous hospitalisations, parents’ age and parents’ qualifications on children’s development and use of pain-related words. The chapter concluded with the contribution made by literate adults who use AAC and who socially validated the composite list of pain-related vocabulary as part of a stakeholder review. These adults suggested an updated version of the socially validated composite list of pain-related vocabulary, which included core and fringe words (pain-related and other).

CHAPTER 6

DISCUSSION

6.1 Introduction

This chapter discusses the results of the Quantitative phase (Phase 3) and the Social Validation phase (Phase 4). It shows how the use of hypothetical scenarios and targeted questions elicited appropriate responses from participants. The inclusion of different respondent groups allowed for rich data and the incorporation of multiple perspectives in drawing up a composite list of pain-related vocabulary. The involvement of stakeholders to socially validate the composite list of physical pain vocabulary was discussed next, and finally, a model for vocabulary selection when determining vocabulary for sensitive topics is proposed based on the findings of this study.

6.2 Methods for vocabulary selection

Children with significant communication difficulties need to communicate about their pain experiences for a number of reasons, including receiving appropriate pain-relieving treatment, and coping with pain. However, they struggle to do so. Apart from their communication difficulties, they may not display pain in traditional ways (such as expected facial expressions or crying), which may result in them not receiving the necessary pain treatment they require (Beyer et al., 1990). Therefore, it is imperative that children with significant communication difficulties should be provided with the necessary pain-related vocabulary on their AAC systems to enable them to communicate their pain.

Apart from crying and other unaided communication means such as facial expressions, typically developing children use words when pain occurs, whereas children with significant communication difficulties need pre-selected pain messages stored on their AAC systems to communicate about pain. Thus, a broad list of relevant vocabulary applicable to describe pain is necessary from which the specific words needed by the individual can be selected to be stored on his/her personal AAC system. The challenge is to compile a list of relevant pain-related vocabulary as pain is a sensitive topic to study.

Many research studies in the AAC field suggest that typical language development should be used as a point of reference and that the words most frequently used by typically developing children should be used to propose possible core vocabulary lists (Da Fonte et al., 2010). However, as discussed in Section 2.3.3.1.4, existing core vocabulary lists (Banajee et al., 2003; Marvin et al., 1994; Trembath et al., 2007) do not contain words that would enable a person to formulate pain-related messages. These lists were based on recordings of activities that are unlikely to result in painful experiences, and /or pain-related words and phrases may be uttered with a frequency that designates them as fringe rather than as core words. Activity-based approaches (as discussed in Section 2.3.3.1.3) have been used to compile vocabulary lists relevant to specific activities. Such approaches have resulted in published resources focussing primarily on activities of daily living (e.g. eating, dressing) and fun activities (e.g. book reading or play) due to their motivational value (Banajee et al., 2003; Da Fonte et al., 2010; Goossens et al., 1994; Trembath et al., 2007). More sensitive and “unpleasant” topics, such as pain were often not considered.

A third method that has been used to determine vocabulary is the use of observations and the recording of actual spoken communication during specific events (Banajee et al., 2003). Such methodologies have also been employed in other studies focusing on children’s pain vocabulary, and include video recordings of children receiving injections (Stanford, Chambers, Craig, et al., 2005) as well as observing paediatric patients after surgery (Wennström & Bergh, 2008). However, making video or audio recordings of children’s interactions during pain experiences and thereby adding additional stress to situations that were already stressful and sensitive, could be seen as violating the ethical principles of non-maleficence (the obligation to do no harm) and respect for human dignity and privacy (Herr, et al., 2011). Furthermore, since the presence of the researcher might well hamper the work of the medical staff, these methodologies were not deemed appropriated for the current study (Wennström & Bergh, 2008). The methods employed in this study to arrive at a relevant list of pain-related vocabulary included the use of hypothetical scenarios (which were developed based on an analysis of children's reports on actual pain-related situations experienced by them) in combination with specific questions posed to multiple informants, including children themselves (Phase 3). A stakeholder review was used to validate the vocabulary list obtained and make further amendments (Phase 4). These methods and the results obtained from them will now be discussed in an attempt to evaluate the success with which these methods were used.

6.2.1 Hypothetical physical pain scenarios

In order to determine hypothetical pain scenarios that children experience, children were asked in Phase 1 to draw pictures of when they got hurt. Children typically like to draw and through their pictures they could effectively reveal distressing issues, such as painful experiences (Kortesluoma, Punämaki, et al., 2008). Drawings help children to think about their real-life experiences and plan what they want to share in their narrative, thus helping them to visualise and talk about the scenarios that caused physical pain (Bornman, 2006; Punch, 2002). Providing children with an opportunity to draw pictures as part of an interview strategy can be a helpful and inexpensive technique to enhance interaction between the researcher and child. Drawing during the interview helps the child to talk about painful memories which he/she would not have mentioned otherwise (Dolidze, Smith, & Tchanturia, 2013; Stafstrom, Rostasy, & Minster, 2002). From the child's perspective, the use of drawings involves him/her as an active participant in the research process, which enables the researcher to better understand the child's views and perspectives and not just "assume" what they may be (Holliday, Harrison, & McLeod, 2009).

In a study that focused specifically on children's pain vocabulary (Jerrett & Evans, 1986), children were asked to draw pictures and talk about their pain. These authors report that the content validity of the children's drawings was enhanced by their verbal reports on their pain experiences. A similar method was used during Phase 1 of this study, namely to encourage children to talk about their pain experiences to enable the researcher to determine (by using deductive thematic analysis) specific themes of South African children's painful experiences. To ensure a depth of pain-related vocabulary, participants from various perspectives were included in Phase 3.

Previously, hypothetical pain scenarios with illustrations (CPPP and PPI respectively) were used to determine children's pain perception (Belter et al., 1988; Lollar et al., 1982). Since no published information on the development of these scenarios could be found, the original researchers were contacted to request more information. Both researchers were keen to assist and indicated that regrettably no rigorous scientific processes were followed in the development of their scenarios (R.W. Belter, personal communication, May 2011; D. J. Lollar, personal communication, June 2013). Hypothetical pain scenarios to elicit pain words from children speaking a second language were employed by Azize et al. (2013) who used some of the scenarios from the PPI (Lollar et al., 1982). Although these scenarios were successfully used in a first world country (United Kingdom), Azize acknowledged the possible influence of culture on the experience of pain or the use of pain-related words, as does the socio-communication model of pain. Due to the multi-cultural South African context, an instrument (HPPS) with themes suggested by South African children and relevant to the current South African context was thus developed to ensure that local children, parents and teachers could relate to it. Using the HPPS allowed the researcher to present stimuli in a standardised and controlled way, which added to the study's internal validity (Stanford, Chambers, & Craig, 2006) and allowed a comparison of vocabulary suggested by different informant groups. Furthermore, due to the multi-cultural South African context, the researcher aimed to ensure that the cartoon character Ziggi, featured in the vignettes, was gender and culturally blind, thereby allowing children from all cultures and both genders to identify with it.

Results indicated that the implementation of the HPPS succeeded in eliciting pain-related vocabulary in different categories, seeing that a total of 10 201 responses were provided by the six respondent groups who were representative of different cultural groups (African, Caucasian, Indian and Coloured).

Five specific questions, based on the suggested categories derived from literature (Franck et al., 2010; Johnson et al., 2015) were asked after each scenario to elicit vocabulary in these five categories. The categories were: A: Vocabulary to describe pain (Azize et al., 2013; Ely, 1992;

Jerret & Evans, 1986; Johnson et al., submitted); B: Vocabulary to request help or assistance (Ely, 1992) or manage pain (Azize et al., 2013); C: Exclamations to indicate pain; D: Pain locations, referred to by Ely (1992) as “Inside hurt” and “Outside hurt”; and E: Words to describe the causes of the pain. The current study

- adapted and expanded the list (see Appendix T: Exclamations [previously Category C] were included within Category A [vocabulary to describe pain]);
- changed the previous name of Category B to “vocabulary to direct other's actions in response to the pain/injury/illness”;
- changed the previous Category D to Category C: Vocabulary to describe pain location and visible signs to the actual tissue damage a result of the physical injury and the previous Category E to Category D: Vocabulary to describe the causes of pain); and
- added three new categories, namely Category E: Vocabulary to describe strategies to cope with pain; Category F: Vocabulary to reflect on strategies of how the pain could have been prevented and Category G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation.

Results indicated that the pain-related words and or phrases in the composite list could be divided into seven categories and 23 sub-categories (Table 5.19). Results also showed that pain vocabulary does not only consist of descriptions of the location and intensity of pain, but that it is more extensive. The importance of including all the pain-related categories in a composite list of pain-related vocabulary for inclusion in an AAC system was therefore emphasised. The adults who use AAC also confirmed the use of different categories when answering the various questions of the vignettes, when they used six of the seven categories. Category C: Vocabulary used to describe pain location and visible signs to the actual tissue damage a result of the physical injury, was not used by the adults during social validation, possibly because the scenarios and vignettes selected for the social validation activitiy did not provide an opportunity for the adult to choose vocabulary from this specific category.

Furthermore, the children found the illustrations of the vignettes based on the HPPS displayed on the iPad tablet fascinating, which motivated them to participate in the in-depth interviews. The breadth of vocabulary relating to pain that was elicited in this study may not have been obtained if informants had been asked to suggest vocabulary that they thought children would need in a specific context, without providing them with hypothetical scenarios illustrated in the vignettes (Fallon, Light, & Page, 2001).

The current study has demonstrated how the use of hypothetical scenarios based on themes taken from children's discussions of their drawings of their painful experiences succeeded in eliciting appropriate vocabulary on a sensitive topic such as pain. It is proposed that the same method could possibly be appropriate for other sensitive topics, such as physical, sexual or emotional abuse. The participants found the custom-designed hypothetical scenarios (relevant to the specific topic) less invasive and stressful to talk about than actual experiences and therefore a large pool of potentially appropriate vocabulary items was elicited. This method also did not result in secondary stress due to the participants having to relive the painful event .

6.3 Different perspectives

During the process of selecting vocabulary for children, SLPs would typically consult multiple informants to compile the best possible list of either core or fringe words to be placed on an AAC communication system (Beukelman & Mirenda, 2013). As part of evidence-based practice (Roulstone, 2015), most often, the informants are adults (such as parents, teachers and/or therapists). These adults were asked to suggest the typical vocabulary children would need for a specific activity, such as eating or playing, based on their experience and expertise (Beyer & Wells, 1989; Roulstone, 2015). However, it is hypothesised that children may perhaps use different words and/or phrases than those suggested by adults (Beukelman & Mirenda, 2013), which highlights the importance of including child informants as well as adult informants when selecting vocabulary for children's AAC systems (Roulstone, 2015).

Therefore, the input from the six groups of respondents (i.e. typically developing children aged 6;0 to 7;11 and 8;0 to 9;11 respectively, as well as the parents and teachers of the two said age groups of children respectively) who all have different perspectives contributed to the rich data that was obtained.

6.3.1 Perspectives of children, parents and teachers

Results from all six respondent groups were combined to compile a composite list of 87 pain-related words and/or phrases that occurred 10 times or more per respondent group in order to establish the truest possible reflection of children's pain-related vocabulary. A mere 13% (12/87) of the pain-related words and/or phrases in the composite list appeared in the data of all six respondent groups – emphasising the importance of including more than one respondent group in a study like this. However, 80% (70/87) of the pain-related words and/or phrases in the composite list occurred in two or more groups with only 20% (17/87) occurring in only one respondent group.

The statement that children use different words and/or phrases when compared to adults (Beukelman & Mirenda, 2013) was confirmed in the present study, as statistically significant differences were found when the responses from the children were compared to those of the adults. The teachers were included in the study due to their experiences of children's minor bumps and bruises during minor injuries at school and were requested to complete five scenarios (Scenarios 1, 4, 6, 7, 9) that are relevant to their experience. Parents, on the other hand, could comment on the pain their children experience due to minor as well as severe injuries, such as needle procedures and surgeries. Although paediatric nurses were involved in Phase 2 of the current study, due to their daily experiences of children's pain, they were not included in Phase 3, as nurses are exposed to children of different ages (i.e. younger than 6;00 and older than 9;11) who are admitted to paediatric wards. Therefore, it would not have been possible to match them with the children's ages and assign them to either the younger or the older group of children.

In the three-way comparison of the responses of children in the younger group with the responses of parents and teachers of this age group, 14 out of 23 sub-categories differed statistically significantly ($p<0.05$) (see Table 5.10). For the older group, 16 out of 23 sub-categories for the three respondent groups differed statistically significantly ($p<0.05$) (see Table

5.14), which suggests that as children become older, the difference between child and adult informants becomes even greater. There were statistically significant differences in the pairwise comparisons between the responses of the children and those of the parents (Table 5.11 and Table 5.15) and of the teachers (Table 5.12 and Table 5.16) for both age groups, which indicates that children provided different words and/or phrases than the two adult respondent groups. For the younger group, 10 sub-categories differed statistically significantly between children and parents, while in the older group, two main categories and 15 sub-categories differed statistically significantly between the children and parents. When the children and teachers in the younger group were compared, two main and 13 sub-categories differed statistically significantly, but when comparing children and teachers in the older group, three main and 13 sub-categories showed statistically significant differences. Thus it was clear that children provided different vocabulary items than their parents or teachers. This finding supports the importance of including the children's viewpoint that was obtained from the children themselves, the so called "child's perspective" as opposed to simply employing a "child perspective" which refer to adults' reflections on children (Nilsson et al., 2013). In order to gain understanding of the use of child language to express pain, SLPs should thus never rely only on the input from adults (Ely, 1992). Obtaining a child's perspective by talking directly to children about their pain could thus reveal the rich and descriptive language children use to express their pain experiences (Ely, 1992; Nilsson et al., 2013; Snodgrass, Stoner, & Angell, 2013).

6.3.2 Age

Previous research indicated that the development of children's pain-related vocabulary is similar to their natural language development and hinges on their chronological age and cognitive development (Franck et al., 2010; Stanford, Chambers, & Craig, 2005). For that reason, the present study included two different age cohorts. Results indicated that the children in the older group (8;0 to 9;l1) used different categories of words and/or phrases to describe their pain-experiences compared to the children in the younger group (6;0 to 7;11); thus reflecting their natural vocabulary growth based on their age and cognitive development.

Although literature has indicated that older children tend to be more economic in their use of pain-related words compared to younger children (Harman et al., 2005), the older group has a bigger vocabulary from which to choose pain messages than younger children. Older children can therefore use fewer but more specific words from their bigger vocabulary to describe their pain; this is in contrast with younger children who would rather use more, but non-specific words from a smaller vocabulary (Dubois et al., 2008; Harman et al., 2005). Older children also focused more on how to cope with their pain (Category E) or on what they could have done to prevent their pain (Category F) than did younger children.

The older children's vocabulary of words and/or phrases that occurred 10 times or more comprised of 55 words, compared to younger children's list of 42 words and/or phrases that occurred 10 times or more. Furthermore, 2374 words and/or phrases per vignette were recorded for the older children, compared to the 2194 for the younger children.

The responses of parents of the younger group did not differ from those of parents of the older group in any of the seven main categories. Similar results were found for teachers of the two groups. The difference between age groups was therefore only visible in the children's data, but not in the data reported by the other two informant groups. This finding once again underlines the importance of including children themselves as informants. The inclusion of children from two distinctive age groups (6;0–7;11 and 8;0–9;11) ensured that the development of the children's pain-related vocabulary across chronological age was considered during the development of a composite list of pain-related vocabulary for children. However, the impact of other factors such as gender, previous hospitalisations, presence of older siblings and parents' qualifications is also acknowledged and should be taken into account when selecting pain-related vocabulary for children.

6.3.3 Gender

Research has shown that gender affects the use of vocabulary (Beukelman & Mirenda, 2013). In a similar way, boys and girls use pain vocabulary differently (Franck et al., 2010). Previous research indicates that girls received more attention from their adult caregivers than boys when in pain, because girls employed more intense vocal response styles to get attention from their caregivers (Fearon et al., 1996). In contrast, boys would typically be told to “stop crying” and be brave (Briggs, 2010). The result is that girls received more attention when in pain, that caregivers spoke more to them about their pain, and taught them exclamations, words and later sentences, and therefore the girls acquired a more extensive pain-related vocabulary during the process (Craig, 2006; Franck et al., 2010). On the other hand, boys learned to be “brave” by not showing their pain because their caregivers’ reactions encouraged them to use pain for secondary gains, such as receiving “rewards” after an operation for being “brave” (Harbeck & Peterson, 1992). In the current study, however, no statistically significant differences between boys and girls were reported in any of the seven categories. Only one of the 23 sub-categories (G2: Secondary gain) reported a statistically significant difference. This may be because the hypothetical scenarios did not indisputably create the opportunity to indicate gender differences as would have been in the case in naturalistic observations in typical environments.

6.3.4 Impact of previous hospitalisations

Although previous research (Franck et al., 2010) has shown that previous hospitalisations influence children’s development and use of pain-related vocabulary, only one of the 23 sub-categories (D1 – Internal causes) in the current study showed a statistically significant difference (p=0.03) between children with and without previous hospitalisations. This implied that children with previous hospitalisations in this study’s population used the same words as those without previous hospitalisations, except for the specific sub-category. In the current study, the two scenarios that elicited the lowest number of pain-related words and/or phrases were those set in a hospital setting, namely Scenario 5 (Ziggi had an operation) and Scenario 10 (Ziggi gets a drip). These two scenarios elicited 364 and 388 words and/or phrases respectively, compared to 458 on average for other scenarios. This confirmed the fact that the majority of children in the school-settings had not had earlier experiences of hospitalisations and could therefore not contribute to the discussions to the same extent as with scenarios where they had more experience. If the impact of this variable were to be further explored, children with previous hospitalisations would need to be purposefully selected to ensure a larger group size. The group of children with previous hospitalisations was small compared to those without (n=11 and n=63 respectively) and the small group size might well have masked the impact of this variable in the current study.

6.3.5 Impact of the presence of older siblings

From the perspective of the family systems theory, the illness of one family member influences the rest of the family (Carandang et al., 1979) as family members learn by observing one another (Bandura, 1977; Jaaniste et al., 2013). The current study revealed that there was a difference between the pain-related vocabulary the children with older siblings used, compared to those with no siblings – but only for two sub-categories, namely F2: Reflecting on future (p=0.05) as well as G3: Emotional responses (p=0.05). The influence of older siblings on the younger siblings' use of pain-related vocabulary may be supported from a family systems theory perspective, as younger siblings observe how their older siblings communicate pain, and see how their older siblings reflect on the future (Bandura, 1977; Koopman et al., 2004). Thus, the younger children in this study could have learned from their older siblings' responses to pain-related experiences how to react to pain.

6.3.6 Impact of parents' educational level

Results from this study do not support previous research that children of parents with higher educational qualifications (≥4 years post school) use more pain-related vocabulary than children of parents with lower qualifications (≤3 years post school), as the H_0 hypothesis was accepted in all the main and sub-categories. The group of parents with higher educational levels (≥4yrs post school) was very small (n=16) compared to parents with lower educational levels (≤3yrs post school) (n=58), which could have masked the impact of this variable in the current study. However, children of parents with higher educational levels (≥4years post school) used a wider variety of pain-related words and/or phrases from more of the main and sub-categories than did the children of the parents with lower qualifications. It is suggested that this variable be explored in greater depth in a next study by ensuring equal group size to allow for such comparison.

6.4 Stakeholder review

To ensure that the pain-related vocabulary list is appropriate for use by persons who use AAC, literate adults who use AAC were asked to socially validate the pain-related vocabulary list by means of a stakeholder review (Schlosser, 1999). This procedure entailed requesting the opinions of persons with lived experiences (such as those who use AAC), to assess the suitability and functionality of selected vocabulary (Balandin & Iacono, 1998a; Beukelman et al., 1991; Bornman & Bryen, 2013; Schlosser & Raghavendra, 2004) because these unique experiences may provide guidelines on how to improve the quality of the vocabulary list (Kildea et al., 2011; Schlosser, 1999). Stakeholders' perspectives should be regarded as important, because they are the ones who will need to live with the outcomes of the decisions made by the researchers (Schlosser & Raghavendra, 2004). This stakeholder review by literate adults who use AAC made heard the voices of potential vulnerable groups such as children who use AAC and who are in pain, which could result in improved identification and management of their pain (Kildea et al., 2011).

Schlosser (1999) proposed various options to conduct social validation assessments such as interviews, direct observations, questionnaires, Likert-type scales and experiments in an attempt to gain relevant information. In the current study, the researcher conducted an interview with three literate adults who use AAC. Results confirmed that the content of the 87 pain-related words and/or phrases on the composite list could successfully be used on AAC systems. The participants were able to answer all nine questions posed in the three scenarios from the HPPS-S by using the pain-related communication board that displays the words and/or phrases from the composite list. Six of the seven main categories and 13 of the 23 sub-categories were used by the participants. This implied that the coverage of the pain-related vocabulary was appropriate to enable the participants to communicate different messages across the various categories. The individuality of the participants was highlighted in their choices of different answers to the same questions and scenarios, which emphasised the importance of acknowledging the individual differences when selecting vocabulary for each specific individual (Beukelman & Mirenda, 2013).

The use of swear words was highlighted by a response offered by Participant 3, who immediately responded with the word “dammit” to indicate what Ziggi’s reaction would be if a nurse struggles to insert the IV into his arm (as in response to Scenario 10: Ziggi gets a drip). As it happened, this participant had had the same experience (getting an IV) on the morning of the interview. This response not only indicated that he could fully relate to the hypothetical scenario, but also showed that the painful experience was still fresh in his mind. This may well indicate that different vocabulary would have been obtained from participants if direct observations took the place of the participant in real-life contexts (Schechter, Bernstein, Beck, Hart, & Scherzer, 1991). The child respondents, who were children in the beginning phase of primary school, could relate to the scenarios that would result in pain, including the experience of receiving an IV or injection, yet none of them provided a swear word – possibly because they were interviewed by an adult researcher and because it would be considered socially inappropriate for them to use swear words, given their age and the context in which the interviews were conducted (school). The issue of including swear words in AAC displays for adults and adolescents has been addressed before, as researchers reasoned that people without disabilities used swear words in different contexts, such as when they got hurt or when they were upset, whereas people with disabilities did not have access to swear words on their AAC systems (Brewster, 2013; Smith, 2005). Swear words are usually uttered in anger – therefore the availability of these words on AAC systems for persons who use AAC could empower them to show that they are in control of their emotions and feelings as they managed to get the attention of their listeners when using swear words (Brewster, 2013). Although adults may well respond to their anger and pain by swearing, children tend to rather cry in these situations to indicate their anger or pain (Stanford, Chambers, Craig, et al., 2005). For this reason, the inclusion of swear words in pain-related vocabulary lists for children may not be necessary.

Based on the results of the pilot study, it was recommended to include both words and/or phrases in the composite pain-related vocabulary list, because it was difficult to categorise the single words in the different main categories when these words were void of context. However, the participants in the social validation phase suggested that only single words should be used on a communication board as they found it difficult to retrieve messages that involved longer phrases – even though they had been familiarised with the board. Phrases are usually also included on communication boards to enhance the speed of interaction (Wilkinson & Hennig, 2007), but in the current study, it actually slowed the process down. Furthermore, the adults were of opinion that single words could assist the children to generate more messages, including novel messages, compared to phrases. Table 5.25 shows that many of the phrases had been compiled by combining core words with single separate pain-related words. For example "put on something", "put on cream" and "put on bandage" can be divided into "put" + "on" + "something" / "cream" / "bandage". The implementation of core words as part of the display on the AAC system, could help the child to communicate messages for multiple purposes and not only pain-related messages (Davoudi et al., 2008). Individual pain words, on the other hand, could be selected to address the specific needs of the individuals relating to pain. In the current study, the words and/or phrases represented in the final socially valid composite pain-related vocabulary list, were split into core words, pain-related fringe words and other fringe words (see Table 5.25).

6.5 Proposed model for selecting vocabulary for sensitive topics

The current study investigated the complex process of selecting vocabulary for children about a sensitive topic namely pain. Results from this study therefore suggest a methodology to be employed for the selection of vocabulary for sensitive topics such as pain. Figure 6.1 shows a model of the proposed methodology.

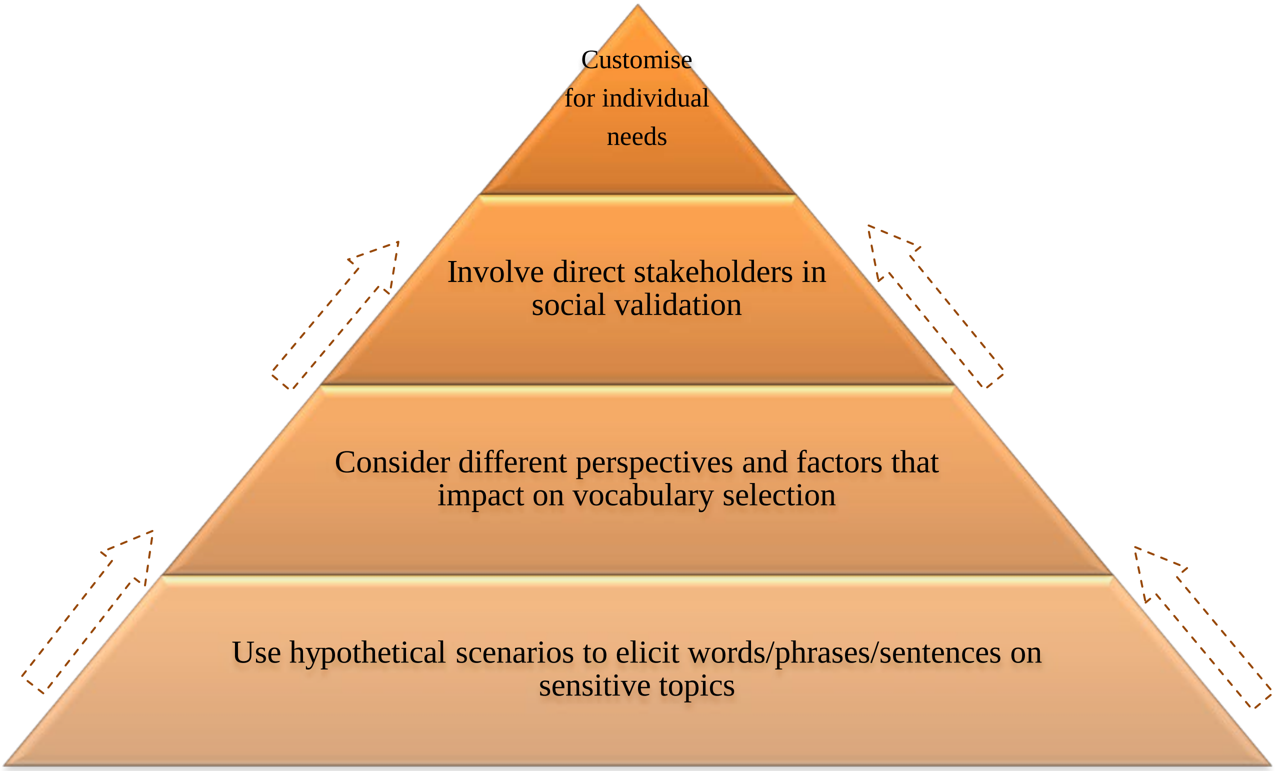


Figure 6.1. Model for vocabulary selection when determining vocabulary for sensitive topics.

The process suggested for vocabulary selecting for sensitive topics entails four distinct phases.

First it is suggested that hypothetical scenarios with semi-structured follow-up questions be developed, which can be used during interviews in focus groups or by means of questionnaires. The hypothetical scenarios can be presented either as vignettes in the form of text or used with illustrations as in the present study, or with puppets, or as video clips where the vignettes have been played out. The use of hypothetical scenarios to elicit vocabulary is less threatening than being asked directly about real-life experiences (Braun & Clarke, 2013) and children (and adults) can easily relate to such scenarios (Belter et al., 1988). The vignettes should provide sufficient background and information for participants to understand the scenario that is portrayed, but they should also be vague enough to enable participants to respond to the open-ended questions about the story or fill in the missing detail. Open-ended questions should aim at eliciting sentences that tap different categories of messages that have been shown to form part of a topic. In the current study, the use of a story grammar format (Montague et al., 1990) proved to be successful for younger children (aged 6;0 to 9;11), as it guided the researcher to develop vignettes by using a formal set of rules to join events in the stories together in a specific and predictable way (Hayward & Schneider, 2000; Whaley, 1981). Using repetitive story grammar also increases the predictability of the text, an element that has been reported as increasing children's enjoyment of stories (Montague et al., 1990). The story grammar structure used for the vignettes ensured that the children were able to relate to the vignettes and thus elicited pain-related vocabulary, probably because the content of the vignettes had originally been provided by children themselves (in Phase 1) and therefore were familiar experiences for children. The same story grammar format could be used for people with learning disabilities as it ensures short sentences and avoids information overload (Hughes & Huby, 2002).

Written vignettes of short stories that simulate real-life experiences (Schoenberg & Ravdal, 2000) had also been used in research into sensitive topics with adults, such as abuse of the elderly (Rahman, 1996), drug-related issues (Jenkins, Bloor, Fischer, Berney, & Neale, 2010) and HIV/Aids (Chan, Yang, Zhang, & Reidpath, 2007). Distancing themselves from a sensitive topic, for example by using a vignette the participants are helped to share their ideas without feeling personally embarrassed or exposed during the interview (Schoenberg & Ravdal, 2000). Participants may for example be asked how they think the character should ideally act or how they think the character should respond or react in the specific circumstance.

Second, the inclusion of a variety of respondents with different perspectives should be investigated. In the current study it was clear that the fact that more than one respondent group was included, added to the comprehensiveness of the vocabulary list – the one group informed and added to the responses of the other groups, and vice versa. However, it was also found that the inclusion of more than two groups who share similar features (such as parents and adults) could result in similar data. This indicated that one of these groups may perhaps have been redundant. The selection of suitable respondents should therefore be carefully considered to suit the specific topic and the different groups should be deliberately selected to be as diverse as possible, e.g. children and adults. Other factors that influenced the perspectives of specific respondents in the current study were the age and gender of the participants.

Third, the results obtained from the different respondent groups should be validated by means of a stakeholder review in order to gather information from the consumers (for example persons who use AAC). The social validation process ensures that the appropriateness of the vocabulary and the quality of the list are confirmed by the group who will make use of it. Social validation assessments could be done by means of various strategies such as interviews, direct observations, Likert-type scales or questionnaires (Schlosser, 1999).

Steps 1 to 3 were executed in the current study and resulted in a composite list of children’s pain-related vocabulary. When this word list is applied to a specific individual, however, a fourth step is necessary, namely customisation. Each individual’s experience is unique and each will have different pain experiences due to his/her unique circumstances. Therefore, the list of pain-related words can be used as a basis to identify and customise a vocabulary that would suit the specific needs of an individual in order to communicate his/her pain.

6.6 Conclusion

Chapter 6 dealt with the results of the last two phases, the Quantitative (Phase 3) and Social Validation phases (Phase 4) respectively. Pain expression by children with significant communication difficulties was addressed and the study highlighted their struggle to communicate pain due to various reasons. Various methods for vocabulary selection were investigated as possible methods to pre-select vocabulary to express pain. Due to the sensitive nature of the topic, the use of both hypothetical physical pain scenarios and informants with different perspectives was discussed. Next, a social validation process was implemented by means of a stakeholder review to highlight how this process validated the composite pain-related vocabulary list for children. The chapter concluded with a proposed model for the selection of vocabulary when determining vocabulary for sensitive topics, such as pain or abuse. The chapter also emphasised the need for the customisation of vocabulary to suit the needs of each unique individual.

CHAPTER 7

CONCLUSION AND RECOMMENDATIONS

7.1 Introduction

The main aim of this study was to develop a socially valid composite list of pain-related words for use by children with significant communication difficulties who use or could benefit from AAC. Chapter 7 provides a summary of the results and the conclusions reached regarding the pain-related vocabulary that children with typical development use to express their pain, as a first step in compiling a list of pain-related vocabulary. Furthermore, this chapter explores the clinical implications of the study and undertake a critical evaluation to discuss the strengths and limitations of the study. The chapter concludes with recommendations for future research.

7.2 Summary of results and the contributions of the study

The purpose of this study was to compile a list of children’s pain-related vocabulary to be used by children with significant communication difficulties when expressing their pain. A sequential exploratory mixed methods approach was used to identify the common pain-related words and/or phrases that typically developing children use to express their pain. During the four phases of the study, a vocabulary selection process model has been proposed that can guide the process of determining vocabulary for sensitive topics, such as pain, abuse and neglect.

In Phase 1, typically developing children shared their experiences of when they had been hurt. These results were used in Phase 2 to compile a set of hypothetical physical pain scenarios that were used in Phase 3 to conduct in-depth interviews with children (HPPS-C), as well to administer questionnaires for parents (HPPS-P) and teachers (HPPS-T) so as to elicit potential vocabulary items. The success with which the different versions of the HPPS elicited pain-related vocabulary suggests that hypothetical scenarios could also be used for other sensitive topics such as physical or sexual abuse. The words and/or phrases suggested by the six respondent groups (younger children aged 6;0 to 7;11; older children aged 8;0 to 9;11; parents of younger children aged 6;0 to 7;11; parents of older children aged 8;0 to 9;11; teachers of younger children aged 6;0 to 7;11 and teachers of older children aged 8;0 to 9;11) were categorised into seven main pain-related categories and 23 sub-categories. All the words and/or phrases that occurred 10 times or more from the suggestions by the six respondent groups were subsequently extrapolated to determine a composite list of children's pain-related words and/or phrases. In order to confirm the usefulness of the composite list of children's pain-related vocabulary, stakeholders (literate adults who use AAC) socially validated the list in Phase 4. They suggested that the pain-related phrases should be divided into individual words. This recommendation resulted in a list of individual words that were categorised as core and fringe (pain-related and other) words.

7.3 Clinical implications of this study

The composite list of children's pain-related vocabulary could be used by SLPs to help children to expand their pain-related vocabulary and also to develop language skills relating to pain concepts in children with significant communication difficulties.

Furthermore, the updated, socially validated composite list could assist SLPs, healthcare professionals and parents to provide core and fringe words that represent the different identified categories of words and/or phrases forming part of pain communication to children with significant communication difficulties who use AAC or who could benefit from AAC. It is suggested that (if possible) all the core words presented in the list should be included on the individual's AAC system. For each specific sensitive topic, the fringe words will have to be categorised to "fringe words related to the topic" and "those not related to the topic" (e.g. fringe – pain and fringe – other).

The pain-related vocabulary list could be displayed on any type of AAC system, such as a low-tech communication board to be used by children with significant communication difficulties who experience a temporary inability to speak (e.g. children in intensive care units), as well as by those with disabilities and complex communication needs. Likewise, the list of children’s pain-related vocabulary could be included on high-technology AAC devices – dedicated (i.e. Tobii Eyegaze) and/or non-dedicated (i.e. iPad with AAC software) – to enable children with significant communication difficulties to communicate effectively about their pain.

The resulting pain-related vocabulary list could be used in multi-lingual contexts such as in South Africa to ensure effective communication between the child and healthcare staff. It often happens that healthcare staff and parents do not speak the same language and then it is difficult for the two parties to communicate about the child’s pain. Thus the healthcare staff could now use the list of pain-related vocabulary to discuss the child’s pain with the parents. Furthermore, seeing that some hospitals in South Africa are the medical hub for patients from Sub-Saharan countries who need to undergo surgery or receive medical treatments that cannot be done in their home countries, patients often do not understand or they have a limited knowledge of the language spoken by healthcare staff at these hospitals. In some instances, for example, paediatric patients do not have their parents with them when they are in the hospital for long periods. The proposed composite and socially valid pain-related vocabulary list could be used to enhance receptive and expressive communication of these patients, regardless of whether they are typically developing children or children with significant communication difficulties.

Self-report is regarded as the golden standard for pain assessment (Herr et al., 2011), because it ensures more effective pain management and treatment than proxy reports from parents, observations or physiological assessments. The list of pain-related words could be used by various healthcare staff to ask children with significant communication difficulties to self-report their pain.

Children become anxious and experience stress before surgery, especially when they know that they will not be able to communicate verbally after the operation, should they be intubated (Patak et al., 2006). As a result, nurses could also use the pain-related words on an AAC system to prepare children before medical procedures. Providing the children also with a means to communicate their pain after the surgery will also lower the children’s stress levels.

There is a paucity of published research on the gold standard that should be followed for the process of vocabulary selection. The model that is proposed in this study to be used for the vocabulary selection process when determining vocabulary for sensitive topics is novel, and it could potentially be implemented successfully to determine lists of vocabulary on sensitive topics such as abuse.

The illustrations of the two hospital-related scenarios (“Ziggi had an operation” and “Ziggi gets a drip”) which formed part of the HPPS-C, could be used by healthcare staff as a projection technique to discuss the procedures with the children, as it was clear in the responses of the children that they could relate to the vignettes and illustrations.

7.4 Critical evaluation of the research

The strengths and limitations of the study are represented in Table 7.1.

Table 7.1

Critical Evaluation of the Study

Discussion area	Strengths of this study	Limitations of this study
Design		
Sequential, mixed method exploratory design	- This study made an important contribution to methodology that could be employed in the process of selecting vocabulary for sensitive topics. The type of design is aimed at developing an instrument and therefore suited this study well (Creswell & Plano Clark, 2011). - The sequential steps followed in this design in each phase enabled the researcher to focus on only one type of data, before proceeding to the next phase. This allowed the researcher to reflect clearly on the outcome of each phase, before continuing with the next phase. - A similar method is proposed as a model for vocabulary selection of sensitive topics, such as abuse or neglect.	- It was time consuming to develop the set of hypothetical pain-related scenarios which included the vignettes as well as the measuring instrument.
Participants		
Six respondent groups were used: (a) children aged 6;0 to 7;11; (b) children aged 8;0 to 9;11; (c) parents of children aged 6;0 to 7;11; (d) parents of children aged 8;0 to 9;11; (e) teachers of children aged 6;0 to 7;11 (Gr 1 children); (f) teachers of children aged 8;0 to 9;11 (Gr 3 children) Finally, the results of the study were socially	- The inclusion of these six respondent groups ensured that the data of each group was validated by the different stakeholders, namely children themselves, parents, teachers and literate adults who use AAC. - Results of this study showed that there were differences between the responses of child and adult respondents. This implied that the perspective of children should be obtained when selecting vocabulary for them. One (or more) adult groups could also be included in the process of selecting vocabulary for children. - All the respondents (children in the school and hospital settings, as well as the adults from all the adult respondent groups) were from the same geographical area (Tshwane South).	- Practical challenges (such as changing the appointment times of the children with cancer at the hospital without notifying the researcher; or not informing the researcher that children were admitted to the hospital who may be possible study participants) resulted in the minimum target of children in hospital settings (30) not being met. More children in hospital settings (cancer or burn patients) should have been interviewed to determine the effect of these experiences on their pain language. - The ideal would have been to have the same parents of the children who participated in the study in the two different sub-groups. However, some parents were only willing to consent that their children may participate in the study, whereas others were only willing to participate themselves in the study and did not allow their children to be included in the study. The result was that the children could not be matched with their parents and instead a comparison between the two groups had to be done. - A non-random sample of only-English literate parents participated. Although access to the Internet was not a prerequisite for inclusion in the study, it was essential as an electronic survey questionnaire

Discussion area	**Strengths of this study**	**Limitations of this study**
validated by literate adults who use AAC		was used in the data collection with the parents. The results may therefore not be representative of the general population with regard to socio-economic status or literacy skills, even though the sample was representative of the cultural diversity in South Africa. • Children, parents and teachers who participated in this study were generally from middle to higher socio-economic backgrounds. The degree to which these results may be generalised to children from other socio-economic backgrounds is not clear.
Phase 1 (Qualitative phase)		
Child's perspective	• A child's perspective was obtained from their painful experiences (Nilsson et al., 2013).	• Due to the fact that the children were seen in their age groups and drew their pictures and discussed their pain experiences in focus groups, it is possible that they were influenced by their peers' drawings and discussions. The repetition of painful experiences may have had a different outcome if the children had been interviewed individually.
Thematic analysis	• A rigorous process was followed by the researcher and second coder to determine themes and codes	
Phase 2 (Development of instrument; pilot study)		
Set of hypothetical pain-related scenarios	• The set of hypothetical physical pain scenarios is based on the South African context and included themes that children in South Africa could relate to. Children from different cultures (African, Caucasian, Indian and Coloured) were involved in the study in the first three phases (drawing pictures and discussing pain experiences; character development; participating in in-depth interviews of HPPS-C), highlighting cultural validity. Furthermore, the aim was to develop a character for the vignettes that was gender and culturally unbiased so that children from all cultures and both genders would be able to relate to it. The fact that the children were involved in choosing both the drawing of the character and its name (Ziggi), ensured that children from all cultures and both genders were able to relate to it. • From the results, it is clear that the implementation of the cartoon-type vignettes was successful as all the vignettes elicited a large number of responses. These results are similar to other studies where vignettes were implemented, either to investigate how children use self-report scales (Chambers & Craig, 1998; Lollar et al., 1982; Von Baeyer, 2006; Von Baeyer et al., 1998) or to elicit pain-related words (Azize, 2012). The advantage of using vignettes may be that the set of	• The high internal validity provided by the use of the hypothetical vignettes may potentially be counterbalanced by relatively lower levels of external validity (i.e. the children had to relate to the pain experience while not actually experiencing it). The set of hypothetical pain scenarios required children to translate pain depicted in a cartoonlike illustration into how they would feel in that situation. For each vignette, children had to picture themselves in the hypothetical pain situation, guess the amount of pain they would have in the situation, and share their answers with the researcher. Although this method may permit controlled evaluation and manipulation of subjective experiences, the children's real-life expressions while in pain in clinical settings are not known (Stanford et al., 2006). Furthermore, having a child suggest words to an adult researcher created a power imbalance and hence they may have censored or adjusted their vocabulary. However, given the age of the children, this factor might have had a small effect. • In Phase 4, one of the participants received a drip on the morning of the social validation interview and he could therefore identify strongly with the Scenario: "Ziggi gets a drip", resulting in an

Discussion area	Strengths of this study	Limitations of this study
	common pain-related experiences could be presented in a consistent and standardised format and the children could relate to the story-telling approach.	emotional response and also providing a swear word. This could imply that direct observations might have yielded other words hence the inclusion of this intrusive procedure could be in future studies be part of the social validation process.
Expert panel	• The views from the expert panel, which added to the depth of the study, were also validated by literature on children's painful experiences depicted in hypothetical pain scenarios (Belter et al., 1988; Lollar et al., 1982).	
Phase 3 (Quantitative phase)		
Data collection	• The same set of hypothetical pain-related scenarios that emerged from Phase 1was used during the data collection with children (HPPS-C), parents (HPPS-P) and teachers (HPPS-T). Using the same set of hypothetical pain-related scenarios for all six respondent groups ensured comparability of results. • The children found the illustrations of the vignettes on the iPad fascinating and it motivated them to participate in the in-depth interviews. • Although the same scenarios were used, the procedure allowed flexibility. Teachers without Internet could be accommodated by completing a hard copy version of the HPPS-T. • A percentage (30%) of transcriptions was checked by an independent second person (a teacher with a postgraduate qualification in AAC). • Categories and sub-categories as found from published literature were first identified deductively by mutual agreement between the researcher and a second coder. The words and/or phrases that were categorised in the "other" category were subcategorised using an inductive thematic analysis. Two new main categories (Category F: Vocabulary to reflect on strategies of how the pain could have been prevented and Category G: Vocabulary to indicate the consequences of pain or injury and to influence activities and participation) were reported.	• The six respondent groups did not all complete all ten scenarios. Children completed ten, parents completed only eight and teachers completed only five. • When the child respondent groups were combined and redistributed in order to calculate inferential statistics to determine the influence of other factors such as gender, previous hospitalisations, presence of siblings, parents' age and qualifications, it resulted in unequal groups that were in some cases very small (e.g. n=16 for parents with a ≥4 years' post-school qualifications).
Phase 4 (Social validation)		
Stakeholder review	• Literate adults who use AAC were asked to socially validate the list of pain-related vocabulary as depicted on the communication board by means of a stakeholder review. Three of the same vignettes of the	• Due to the fact that only three scenarios were selected for the social validation process, adults did not have the option to select from category F (Vocabulary used to describe pain location, visible signs

Discussion area	Strengths of this study	Limitations of this study
Finalise list of children's pain-related vocabulary	HPPS-C (Scenarios 5, 7 and 10) were used in the HPPS-S during this social validation process. The process confirmed that children may be able to use the selected vocabulary to express their pain. • The literate adults who use AAC gave practical suggestions on how to implement the proposed vocabulary list for children, such as by the use of individual words (core plus fringe pain-related words) that could be represented as graphic symbols. • The final list of pain-related vocabulary was based on the outcomes of the social validation process indicating single words divided into core and fringe vocabulary.	to the actual tissue damage and/or body structures and functions affected as a result of the physical injury), and hence this category was not socially validated. • Exploring the symbol representation of the single words could have expanded the depth of the study; however, the visual presentation of these words should be explored in a follow-up study.

7.5 Recommendations for future research

Recommendations for future research are as follows:

- Determine the most effective way to represent and organise the vocabulary on boards intended for use with communication vulnerable paediatric patients in hospital/healthcare settings.

- Determine the effective way to incorporate, represent and organise vocabulary into existing AAC systems of children with complex communication needs.

- Compare the effectiveness of the use of different ways of presenting these pain words on an AAC system, e.g. single words versus phrases. The present core word lists for children (Banajee et al., 2003; Beukelman et al., 1991; Trembath et al., 2007) have no pain-related core words, therefore, fringe topic-based pain-related words should be introduced.

- Validate the vocabulary for use in medical settings by incorporating the perspective of paediatric nurses (by means of a focus group discussion).

- Determine the impact of previous hospitalisations on the use and development of pain-related vocabulary by including equal numbers of children with and without previous hospitalisations compared.

- Determine whether the pain-related vignettes are appropriate for children whose demographic profiles differ from those of the children included in this study, such as other language groups and children from other socio-economic backgrounds.

- Determine the extent to which the responses of between children and adults change with increasing age of the children, as the current study found that there were more marked differences between the responses of older children and adults than between those of younger children and adults.

7.6 Conclusion

This chapter presented the important findings and contributions of the study, as well as the clinical implications of having a proposed model for selecting vocabulary for children with significant communication difficulties who need AAC when investigating sensitive topics. The study was next evaluated in terms of its strengths and limitations, and finally, recommendations for future research were made.

REFERENCES

Abu-Saad, H. (1984). Assessing children's responses to pain. *Pain*, *19*(2), 163-171.

Adesman, A. R., & Walco, G. A. (1992). Validation of the Charleston Pediatric Pain Pictures in school-age children. *Journal of Clinical Child and Adolescent Psychology, 21*(1), 10-13.

Alant, E., Kolatsis, A., & Lilienfeld, M. (2010). The effect of sequential exposure of color conditions on time and accuracy of graphic symbol location. *Augmentative and Alternative Communication, 26*(1), 41-47.

Ambuel, B., Hamlett, K. W., Marx, C. M., & Blumer, J. L. (1992). Assessing distress in pediatric intensive care environments: the COMFORT scale. *Journal of Pediatric Psychology, 17*(1), 95-109.

Anand, K. J. S., & Craig, K. D. (1996). Editorial: New perspectives in the definition of pain. *Pain*, *67*, 3-6.

Azize, P. M. (2012). *The impact of language on the expression and assessment of pain in children aged 4-7 years: A mixed methods study.* (Doctor of Philosophy), University of Plymouth, Plymouth.

Azize, P. M., Endacott, R., Cattani, A., & Humphreys, A. (2013). Cultural responses to pain in UK children of primary school age: A mixed-methods study. *Nursing and Health Sciences*.

Azize, P. M., Humphreys, A., & Cattani, A. (2011). The impact of language on the expression and assessment of pain in children. *Intensive and Critical Care Nursing, 27*(5), 235-243.

Baker, B., Hill, K., & Devylder, R. (2000). *Core vocabulary is the same across environments.* Paper presented at the California State University at Northridge Conference.

Balandin, S., & Iacono, T. (1998a). A few well-chosen words. *Augmentative and Alternative Communication, 14*(3), 147-161.

Balandin, S., & Iacono, T. (1998b). Topics of meal-break conversations. *Augmentative and Alternative Communication, 14*(3), 131-146.

Banajee, M., Dicarlo, C., & Buras Stricklin, S. (2003). Core vocabulary determination for toddlers. *Augmentative and Alternative Communication, 19*(2), 67-73.

Bandstra, N. F., Johnson, S. A., Filliter, J. H., & Chambers, C. T. (2012). Self-reported and Parent-reported Pain for Common Painful Events in High-functioning Children and Adolescents With Autism Spectrum Disorder. *Clinical Journal of Pain, 28*(8), 715-721. doi: 10.1097/AJP.0b013e318243ecf6

Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191.

Banerjee, R., Bennett, M., & Luke, N. (2012). Children's reasoning about self-presentation following rule violations: The role of self-focused attention. *Child Development, 83*(5), 1805-1821. doi: 10.1111/j.1467-8624.2012.01813.x

Baruch, Y., & Holtom, B. C. (2008). Survey response rate levels and trends in organizational research. *Human Relations, 61*(8), 1139-1160.

Beacroft, M., & Dodd, K. (2011). ‘I Feel Pain’–audit of communication skills and understanding of pain and health needs with people with learning disabilities. *British Journal of Learning Disabilities, 39*(2), 139-147.

Beckung, E., & Hagberg, G. (2002). Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Developmental Medicine and Child Neurology, 44*(5), 309-316.

Belter, R. W., McIntosh, J. A., Finch Jr, A. J., & Saylor, C. F. (1988). Preschoolers' ability to differentiate levels of pain: relative efficacy of three self-report measures. *Journal of Clinical Child Psychology, 17*(4), 329-335.

Beringer, A., Tönsing, K. M., & Bornman, J. (2013). The self-determined and partner-predicted topic preferences of adults with aphasia. *Aphasiology, 27*(2).

Beukelman, D. R., Jones, R., & Rowan, M. (1989). Frequency of word usage by nondisabled peers in integrated preschool classrooms. *Augmentative and Alternative Communication, 5*(4), 243-248.

Beukelman, D. R., McGinnis, J., & Morrow, D. (1991). Vocabulary selection in augmentative and alternative communication. *Augmentative and Alternative Communication, 7*(3), 171-185.

Beukelman, D. R., & Mirenda, P. (2013). *Augmentative and Alternative Communication. Supporting Children and Adults with Complex Communication Needs* (4 ed.).

Beukelman, D. R., & Ray, P. (2010). Communication supports in pediatric rehabilitation. *Journal of Pediatric Rehabilitation Medicine, 3*(4), 279-288.

Beyer, J. E., McGrath, P. J., & Berde, C. B. (1990). Discordance between self-report and behavioral pain measures in children aged 3-7 years after surgery. *Journal of Pain and Symptom Management, 5*(6), 350-356.

Beyer, J. E., & Wells, N. (1989). The assessment of pain in children. *Pediatric Clinics of North America, 36*(4), 837-854.

Bieri, D., Reeve, R., Champion, G., Addicoat, L., & Ziegler, J. (1990). The Faces Pain Scale for the self-assessment of the severity of pain experienced by children: development, initial validation and preliminary investigation for ratio scale properties. . *Pain, 41*(1), 139-150.

Blackstone, S. W. (1988). Vocabulary selection: Current practices and a glimpse at the future. *Augmentative Communication News, 1*(5), 1-5.

Blackstone, S. W., Ruschke, K., Wilson-Stronks, A., & Lee, C. (2011). Converging communication vulnerabilities in health care: An emerging role for speech-language pathologists and audiologists. *SIG 14 Perspectives on Communication Disorders and Sciences in Culturally and Linguistically Diverse (CLD) Populations, 18*(1), 3-11.

Boenisch, J., & Soto, G. (2015). The Oral Core Vocabulary of Typically Developing English-Speaking School-Aged Children: Implications for AAC Practice. *Augmentative and Alternative Communication, 31*(1), 77-84.

Bornman, J. (2006). Using a narrative and drawing approach to investigate Grade 1 children's depictions of disability. *The Social Work Practitioner - Researcher*, *18*(2), 144-165.

Bornman, J., & Bryen, D. N. (2013). Social validation of vocabulary selection: Ensuring stakeholder relevance. *Augmentative and Alternative Communication, 29*(2), 174-181.

Bottos, S., & Chambers, C. T. (2006). The epidemiology of pain in developmental disabilities. In T. M. Orlander & F. J. Symons (Eds.), *Pain in children and adults with developmental disabilities* (pp. 67-87). Baltimore, Maryland: Paul Brookes Publishing Company.

Boyce, C., & Neale, P. (2006). *Conducting in-depth interviews: A guide for designing and conducting in-depth interviews for evaluation input*: Pathfinder International Watertown, MA.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2). doi: 10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners* London: SAGE.

Breau, L. M. (2003). Non-communicating children's pain checklist: better pain assessment for severely disabled children. *Expert Review of Pharmacoeconomics and Outcomes Research, 3*(3), 327-339.

Breau, L. M., & Burkitt, C. (2009). Assessing pain in children with intellectual disabilities. *Pain Research & Management: The Journal of the Canadian Pain Society, 14*(2), 116.

Breau, L. M., Camfield, C. S., McGrath, P. J., & Finley, G. A. (2003). The Incidence of Pain in Children With Severe Cognitive Impairments. *Archives of Pediatrics and Adolescent Medicine, 157*(12), 1219-1226.

Breau, L. M., Finley, G. A., McGrath, P. J., & Camfield, C. S. (2002). Validation of the Non-communicating Children's Pain Checklist-Postoperative Version [corrected] [published erratum appears in ANESTHESIOLOGY 2002 Sep;97(3):769]. *Anesthesiology, 96*(3), 528-535.

Breau, L. M., McGrath, P. J., Camfield, C. S., & Finley, G. A. (2002). Psychometric properties of the non-communicating children's pain checklist-revised. *Pain, 99*(1–2), 349-357. doi: http://dx.doi.org/10.1016/S0304-3959(02)00179-3

Brewster, S. (2013). Saying the ‘F word… in the nicest possible way’: augmentative communication and discourses of disability. *Disability & Society*, *28*(1), 125-128.

Briggs, E. (2010). Assessment and expression of pain. *Nursing Standard, 25*(2), 35-38.

Cameron, L., & Murphy, J. (2002). Enabling young people with a learning disability to make choices at a time of transition. *British Journal of Learning Disabilities, 30*(3), 105-112.

Cano, A., Leong, L., Heller, J. B., & Lutz, J. R. (2009). Perceived entitlement to pain-related support and pain catastrophizing: Associations with perceived and observed support. *Pain, 147*(1-3), 249-254.

Carandang, M. L. A., Folkins, C. H., Hines, P. A., & Steward, M. S. (1979). The role of cognitive level and sibling illness in children's conceptualizations of illness. *American Journal of Orthopsychiatry, 49*(3), 474.

Carney, R. N., & Levin, J. R. (2002). Pictorial illustrations still improve students' learning from text. *Educational psychology review, 14*(1), 5-26.

Carr, E. G., Levin, L., McConnachie, G., Carlson, J. I., Kemp, D. C., & Smith, C. E. (1994). *Communication-based intervention for problem behavior*. Baltimore: Paul H Brookes Publishing Company.

Castarlenas, E., Miró, J., & Sánchez-Rodríguez, E. (2013). Is the Verbal Numerical Rating Scale a Valid Tool for Assessing Pain Intensity in Children Below 8 Years of Age? *Journal of Pain, 14*(3), 297-304.

Chambers, C. T., & Craig, K. D. (1998). An intrusive impact of anchors in children's faces pain scales. *Pain, 78*(1), 27-37.

Chambers, C. T., Finley, G. A., McGrath, P. J., & Walsh, T. M. (2003). The parents' postoperative pain measure: replication and extension to 2-6-year-old children. *Pain, 103*(3), 437-443.

Chambers, C. T., Reid, G. J., Craig, K. D., McGrath, P. J., & Finley, G. A. (1998). Agreement between child and parent reports of pain. *The Clinical journal of pain*, *14*, 336-342.

Chan, K. Y., Yang, Y., Zhang, K., & Reidpath, D. D. (2007). Disentangling the stigma of HIV/AIDS from the stigmas of drugs use, commercial sex and commercial blood donation–a factorial survey of medical students in China. *BMC Public Health*, *7*(1), 280.

Clarke, Z. J., Thompson, A. R., Buchan, L., & Combes, H. (2008). Parents' experiences of pain and discomfort in people with learning disabilities. *British Journal of Learning Disabilities, 36*(2), 84-90.

Cohen, W. I. (2003). Health care guidelines for individuals with Down syndrome—1999 revision. *Down syndrome*, 237.

Coleman-Martin, M. B., Heller, K. W., Cihak, D. F., & Irvine, K. L. (2005). Using computer-assisted instruction and the nonverbal reading approach to teach word identification. *Focus on Autism and Other Developmental Disabilities*, *20*(2), 80-90.

Connelly, M. A., & Neville, K. (2010). Comparative prospective evaluation of the responsiveness of single-item pediatric pain-intensity self-report scales and their uniqueness from negative effect in a hospital setting. *The Journal of Pain, 11*(12), 1451-1460.

Costello, J. (2000). AAC intervention in the intensive care unit: The Children's Hospital Boston model. *Augmentative and Alternative Communication, 16*(3), 137-153.

Coyne, I. (2005). Consultation with children in hospital: children, parents' and nurses' perspectives. *Journal of Clinical Nursing, 15,* 61-71.

Craig, K. D. (2004). Social communication of pain enhances protective functions: a comment on Deyo, Prkachin and Mercer (2004). *Pain, 107*(1–2), 5-6. doi: http://dx.doi.org/10.1016/S0304-3959(03)00264-1

Craig, K. D. (2006). The construct and definition of pain in developmental disability. In T. F. Oberlander & F. J. Symons (Eds.), *Pain in children and adults with developmental disabilities by . Paul Brookes Publishing Company: Baltimore, Maryland. pp 7-18.* (pp. 7-18). Baltimore, Maryland: Paul Brookes Publishing Company.

Craig, K. D. (2009). The social communication model of pain. *Canadian Psychology/Psychologie canadienne, 50*(1), 22-32. doi: 10.1037/a0014772

Craig, K. D., & Korol, C. T. (2008). Developmental issues in understanding, assessing, and managing pediatric pain *Pain in Children* (pp. 9-20): Springer.

Craig, K. D., Lilley, C. M., & Gilbert, C. A. (1996). Social barriers to optimal pain management in infants and children. *Clinical Journal of Pain, 12*, 232-242.

Craig, K. D., Stanford, E. A., Fairbairn, N. S., & Chambers, C. T. (2006). Emergent pain language communication competence in infants and children. *Enfance, 1*, 52-71.

Crawford, K. (1996). Vygotskian approaches in human development in the information era. *Educational Studies in Mathematics, 31*(1-2), 43-62.

Creswell, J. W. (2014). *Research design: qualitative, quantitative and mixed method approaches.* (4 ed.). London: SAGE.

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research*. London: SAGE.

Creswell, J. W., & Zhang, W. (2009). The application of mixed methods designs to trauma research. *Journal of Traumatic Stress, 22*(6), 612-621.

Cui, W., Wu, Y., Liu, S., Wei, F., Zhou, M. X., & Qu, H. (2010). *Context preserving dynamic word cloud visualization.* Paper presented at the Pacific Visualization Symposium (PacificVis), 2010 IEEE.

Da Fonte, M. A., Pufpaff, L. A., & Taber-Doughty, T. (2010). Vocabulary use during storybook reading: Implications for children with augmentative and alternative communication needs. *Psychology in the Schools, 47*(5), 514-524.

Dada, S., Huguet, A., & Bornman, J. (2013). The Iconicity of Picture Communication Symbols for Children with English Additional Language and Mild Intellectual Disability. *Augmentative and Alternative Communication, 29*(4), 360-373.

Dark, L., & Balandin, S. (2007). Prediction and selection of vocabulary for two leisure activities 1. *Augmentative and Alternative Communication, 23*(4), 288-299.

Davoudi, N., Afsharzadeh, P., Mohammadalizadeh, S., & Haghdoost, A. A. (2008). A comparison of patients' and nurses' assessments of pain intensity in patients with coronary artery disease. *International Journal of Nursing Practice, 14*(5), 347-356.

Dodd, J. L., & Gorey, M. (2013). AAC Intervention as an Immersion Model. *Communication Disorders Quarterly*, 1525740113504242.

Dolidze, K., Smith, E. L., & Tchanturia, K. (2013). A Clinical Tool for Evaluating Emotional Well-Being: Self-Drawings of Hospitalized Children. *Journal of Pediatric Nursing, 28*(5), 470–478.

Dubois, A., Bringuier, S., Capdevila, X., & Pry, R. (2008). Vocal and verbal expression of postoperative pain in preschoolers. *Pain Management Nursing, 9*(4), 160-165. doi: 10.1016/j.pmn.2007.10.003

Dubois, A., Capdevila, X., Bringuier, S., & Pry, R. (2010). Pain expression in children with an intellectual disability. *European Journal of Pain, 14*(6), 654-660. doi: 10.1016/j.ejpain.2009.10.013

Dunn, L. M., & Dunn, D. M. (2007). *Peabody Picture Vocabulary Test: PPVT-4B*: NCS Pearson.

Ely, J. (1992). The experience of pain for school-age children: Blood, band-aids, and feelings. *Children's Health Care, 21*(4), 168-175.

Engel, J. M., & Kartin, D. (2006). Pain in individuals with Cerebral Palsy. In T. F. Oberlander & F. J. Symons (Eds.), *Pain in children and adults with developmental disabilities* (pp. 109-119). Baltimore, Maryland: Paul Brookes Publishing Company.

Esteve, R., & Marquina-Aponte, V. (2011). Children's pain perspectives. *Child: Care, Health and Development, 38*(4), 441-452.

Fager, S., & Spellman, C. (2010). Augmentative and alternative communication intervention in children with traumatic brain injury and spinal cord injury. *Journal of Pediatric Rehabilitation Medicine, 3*(4), 269-277.

Fallon, K. A., Light, J., & Page, T. K. (2001). Enhancing Vocabulary Selection for Preschoolers Who Require Augmentative and Alternative Communication (AAC). *American Journal of Speech-Language Pathology and Immunopathology Research, 10*(81-94).

Fang, Z. (1996). Illustrations, text, and the child reader: what are pictures in children's storybooks for? *Reading Horizons, 37*(2), 3.

Fearon, I., McGrath, P. J., & Achat, H. (1996). 'Booboos': the study of everyday pain among young children. *Pain, 68*(1), 55-62.

Field, A. (2013). *Discovering statistics using IBM SPSS statistics* (4 ed.). London: SAGE.

Finley, G. A., Kristjánsdóttir, O., & Forgeron, P. A. (2009). Cultural influences on the assessment of children's pain. *Pain Research and Management*, *14*(1), 33–37.

Franck, L., Noble, G., & Liossi, C. (2010). From tears to words: the development of language to express pain in young children with everyday minor illnesses and injuries. *Child: Care, Health and Development, 36*(4), 524-533. doi: http://dx.doi.org/10.1111/j.1365-2214.2010.01084.x

Gaffney, A., & Dunne, E. A. (1986). Developmental aspects of children's definitions of pain. *Pain, 26*(1), 105-117. doi: http://dx.doi.org/10.1016/0304-3959(86)90177-6

Garrett, K. L., Costello, J., & Fried-Oken, M. (2007). AAC in the ICU. *Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions*.

Gaynard, L., Wolfer, J., Goldberger, J., Thompson, R., Redburn, L., & Laidley, L. (1990). *Psychosocial care of children in hospital: A clinical practice manual from the ACCH child life research project*. Bethesda, MD: Association for the Care of Children's Health.

Gilbert-MacLeod, C. A., Craig, K. D., Rocha, E. M., & Mathias, M. D. (2000). Everyday pain responses in children with and without developmental delays. *Journal of Pediatric Psychology, 25*(5), 301-308.

Godzicki, L., Godzicki, N., Krofel, M., & Michaels, R. (2013). Increasing Motivation and Engagement in Elementary and Middle School Students through Technology-Supported Learning Environments. *Online Submission*.

Goossens, C., Crain, S., & Elder, P. S. (1994). *Communication displays for engineered preschool environments*. Solana Beach, CA: Mayer-Johnson Company.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), 105-112.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of qualitative research, 2*, 163-194.

Hadjistavropoulos, T., Breau, L. M., & Craig, K. D. (2011). Assessment of pain in adults and children with limited ability to communicate. In D. C. Turck & R. Melzack (Eds.), *Handbook of pain assessment* (3 ed., pp. 260-280). New York: The Guilford Press.

Hadjistavropoulos, T., & Craig, K. D. (2002). A theoretical framework for understanding self-report and observational measures of pain: a communications model. *Behaviour Research and Therapy*, *40*(5), 551-570. doi: http://dx.doi.org/10.1016/S0005-7967(01)00072-9

Hadjistavropoulos, T., & Craig, K. D. (2004). *Pain* T. Hadjistavropoulos & K. D. Craig (Eds.), *Psychological Perspectives*

Haley, W. E. (1985). Social skills deficits and self-evaluation among depressed and nondepressed psychiatric inpatients. *Journal of Clinical Psychology*.

Hamers, J. P. H., Abu-Saad, H. H., Halfens, R. J. G., & Schumacher, J. N. M. (1994). Factors influencing nurses' pain assessment and interventions in children. *Journal of Advanced Nursing, 20*(5), 853-860.

Harbeck, C., & Peterson, L. (1992). Elephants dancing in my head: A developmental approach to children's concepts of specific pains. *Child Development, 63*(1), 138-149.

Harman, K., Lindsay, S., Adewami, A., & Smith, P. (2005). An investigation of language used by children to describe discomfort expected and experienced during dental treatment. *International journal of paediatric dentistry / the British Paedodontic Society [and] the International Association of Dentistry for Children, 15*(5), 319-326.

Harris, D. B. (1963). *Children's drawings as measures of intellectual maturity: A revision and extension of the Goodenough Draw-a-Man Test*: Harcourt, Brace & World New York.

Hay, I., Oates, J., Giannini, A., Berkowitz, R., & Rotenberg, B. (2009). Pain perception of children undergoing nasendoscopy for investigation of voice and resonance disorders. . *Journal of Voice, 23*, 380-388. doi: 10.1016/j.voice.2007.10.008

Hayward, D., & Schneider, P. (2000). Effectiveness of teaching story grammar knowledge to pre-school children with language impairment. An exploratory study. *Child Language Teaching and Therapy, 16*(3), 255-284.

Heilmann, J., Miller, J. F., Iglesias, A., Fabiano-Smith, L., Nockerts, A., & Andriacchi, K. D. (2008). Narrative transcription accuracy and reliability in two languages. *Topics in Language Disorders, 28*(2), 178-188.

Herr, K., Coyne, P. J., Key, T., Manworren, R., McCaffery, M., Merkel, S. I., . . . Wild, L. (2006). Pain assessment in the nonverbal patient: position statement with clinical practice recommendations. *Pain Management Nursing, 7*(2), 44-52.

Herr, K., Coyne, P. J., McCaffery, M., Manworren, R., & Merkel, S. I. (2011). Pain assessment in the patient unable to self-report: position statement with clinical practice recommendations. *Pain Management Nursing, 12*(4), 230-250.

Hicks, C. L., Von Baeyer, C. L., Spafford, P. A., Van Korlaar, I., & Goodenough, B. (2001). The Faces Pain Scale - Revised: Toward a common metric in pediatric pain measurement. *Pain, 93*(2), 173-183.

Hill, K. (2004). Augmentative and alternative communication and language: Evidence-based practice and language activity monitoring. *Topics in Language Disorders, 24*(1), 18-30.

Himmelmann, K., Beckung, E., Hagberg, G., & Uvebrant, P. (2006). Gross and fine motor function and accompanying impairments in cerebral palsy. *Developmental Medicine and Child Neurology, 48*(6), 417-423.

Hoff, E. (2003). The specificity of environmental influence: Socioeconomic status affects early vocabulary development via maternal speech. *Child Development, 74*(5), 1368-1378.

Holliday, E. L., Harrison, L. J., & McLeod, S. (2009). Listening to children with communication impairment talking through their drawings. *Journal of Early Childhood Research, 7*(3), 244-263.

HPCSA. (2013). Registration criteria.

Hughes, R., & Huby, M. (2002). The application of vignettes in social and nursing research. *Journal of Advanced Nursing, 37*(4), 382-386. doi: 10.1046/j.1365-2648.2002.02100.x

Huguet, A., Miró, J., & Nieto, R. (2008). The inventory of parent/caregiver responses to the children's pain experience (IRPEDNA): development and preliminary validation. *Pain, 134*(1), 128-139.

Huguet, A., Stinson, J. N., & McGrath, P. J. (2010). Measurement of self-reported pain intensity in children and adolescents. *Journal of Psychosomatic Research, 68*(4), 329-336. doi: 10.1016/j.jpsychores.2009.06.003

Hunt, A., Goldman, A., Seers, K., Crichton, N., Moffat, V., & Oulton, K. (2004). Clinical validation of the paediatric pain profile. *Developmental Medicine and Child Neurology, 46*(1), 9-18.

IASP. (1979). Pain terms: A list with definitions and notes on usage. *Pain, 6,* 249-252.

IASP. (2011). IASP Taxonomy. http://www.iasp-pain.org/AM/Template.cfm?Section=Pain _Defi...isplay.cfm& ContentID=1728#Pain

Jaaniste, T., Phipps, E., Lang, T., & Champion, G. D. (2013). Impact of pediatric chronic pain on siblings: Evidence and theory. *Pediatric Pain Letter, 15*(3), 34-37.

Jenkins, N., Bloor, M., Fischer, J., Berney, L., & Neale, J. (2010). Putting it in context: the use of vignettes in qualitative interviewing. *Qualitative research, 10*(2), 175-198.

Jensen, M. P., Turner, J. A., & Romano, J. M. (1994). What is the maximum number of levels needed in pain intensity measurement? *Pain, 58*(3), 387-392. doi: http://dx.doi.org/10.1016/0304-3959(94)90133-3

Jerrett, M., & Evans, K. (1986). Children's pain vocabulary. *Journal of Advanced Nursing, 11*(4), 403-408.

Johnson, E., Boshoff, K., & Bornman, J. (2015). Systematic review of children’s pain vocabulary.

Jonsen, A. R. (1978). Research involving children: recommendations of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *Pediatrics*, *62*(2), 131-136.

Jordan, A. (2005). The impact of pediatric chronic pain on the family. *Pediatric Pain Letter*, *7*(1), 5-8.

Kildea, S., Wright, J., & Davies, J. (2011). Making sense of ADHD in practice: A stakeholder review. *Clinical child psychology and psychiatry*, *16*(4), 599-619.

Koopman, H. M., Baars, R. M., Chaplin, J., & Zwinderman, K. H. (2004). Illness through the eyes of the child: the development of children's understanding of the causes of illness. *Patient Education and Counseling*, *55*(3), 363-370.

Kortesluoma, R., & Nikkonen, M. (2004). I had a horrible pain: The sources and causes of pain experiences in four to eleven year old hospitalized children. *Journal of Child Health Care*, *8*(3), 210-231. doi: 10.1177/136749354045822

Kortesluoma, R., & Nikkonen, M. (2006). ‘The most disgusting ever’: Children’s pain descriptions and views of the purpose of pain. *Journal of Child Health Care*, *10*(3), 213-227. doi: 10.1177/1367493506066482

Kortesluoma, R., Nikkonen, M., & Serlo, W. (2008). "You Just Have to Make the Pain Go Away"-Children's Experiences of Pain Management. *Pain Management Nursing*, *9*(4), 143-149.e145.

Kortesluoma, R., Punämaki, R., & Nikkonen, M. (2008). Hospitalized children drawing their pain: The contents and cognitive and emotional characteristics of pain drawings. *Journal of Child Health Care, 12*(4), 284-300.

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy, 45*(3), 214-222.

Lau, R. R., Bernard, T. M., & Hartman, K. A. (1989). Further explorations of common-sense representations of common illnesses. *Health Psychology, 8*(2), 195.

Leedy, P. D., & Ormrod, J. E. (2010). *Practical Research-Planning and Design* (9 ed.). Upper Saddle River, New Jersey: Merrill Prentice Hall

Lietz, C. A., & Zayas, L. E. (2010). Evaluating qualitative research for social work practitioners. *Advances in Social Work, 11*(2), 188-202.

Light, J. (1997). “Let's go star fishing”: Reflections on the contexts of language learning for children who use aided AAC. *Augmentative and Alternative Communication, 13*(3), 158-171.

Light, J., & Drager, K. (2007). AAC technologies for young children with complex communication needs: State of the science and future research directions. *Augmentative and Alternative Communication, 23*(3), 204-216.

Lloyd, L. L., Fuller, D. R., & Arvidson, H. H. (1997). Augmentative and alternative communication: A handbook of principles and practices.

Logan, D. E., Coakley, R. M., & Scharff, L. (2007). Teachers’ perceptions of and responses to adolescents with chronic pain syndromes. *Journal of Pediatric Psychology, 32*(2), 139-149.

Lollar, D. J., Smits, S. J., & Patterson, D. L. (1982). Assessment of pediatric pain: an empirical perspective. *Journal of Pediatric Psychology, 7*(3), 267-277.

Malviya, S., Voepel-Lewis, T., Burke, C., Merkel, S. I., & Tait, A. R. (2006). The revised FLACC observational pain tool: improved reliability and validity for pain assessment in children with cognitive impairment. *Paediatric Anaesthesia, 16*(3), 258-265.

Marteau, T. M., & Bekker, H. (1992). The development of a six-item short-form of the state scale of the Spielberger State-Trait Anxiety Inventory (STAI). *British Journal of Clinical Psychology*(31), 301-306.

Marvin, C., Beukelman, D. R., & Bilyeu, D. (1994). Vocabulary-use patterns in preschool children: Effects of context and time sampling. *Augmentative and Alternative Communication, 10*(4), 224-236.

Mauthner, M. (1997). Methodological aspects of collecting data from children: Lessons from three research projects. *Children & Society, 11*(1), 16-28.

McCaffery, M. (1968). *Nursing practice theories related to cognition, bodily pain, and man-environment interactions* Los Angeles: University of California, Los Angeles

McCaffery, M., & Ferrell, B. R. (1997). Nurses' knowledge of pain assessment and management: How much progress have we made? *Journal of Pain and Symptom Management, 14*(3), 175-188.

McGrath, P. A., Seifert, C. E., Speechley, K. N., Booth, J. C., Stitt, L., & Gibson, M. C. (1996). A new analogue scale for assessing children's pain: an initial validation study. *Pain, 64*(3), 435-443.

McGrath, P. J., Johnson, G., Goodman, J. T., Schillinger, J., Dunn, J., & Chapman, J. (1985). CHEOPS: a behavioral scale for rating postoperative pain in children. *Adv Pain Res Ther, 9*, 395-402.

McMillan, J. H., & Schumacher, S. (2001). Research in education. Evidence based inquiry. *Research in education. Evidence based inquiry*. (6 ed.). Boston: Pearson.

McMurtry, C. M., Noel, M., Chambers, C. T., & McGrath, P. J. (2011). Children's Fear During Procedural Pain: Preliminary Investigation of the Children's Fear Scale. *Health Psychology, 30*(6), 780-788. doi: 10.1037/a0024817

Merkel, S. I., Voepel-Lewis, T., Shayevitz, J. R., & Malviya, S. (1997). The FLACC: a behavioral scale for scoring postoperative pain in young children. *Pediatric Nursing, 23*(3), 293-297.

Merskey, H., & Bogduk, N. (1994). IASP Pain Terminology. In H. Merskey & N. Bogduk (Eds.), *Classification of chronic pain. Descriptions of chronic pain syndromes and definitions of pain terms* (2 ed., pp. 209-214). Seattle: IASP Press.

Miró, J., & Huguet, A. (2004). Evaluation of reliability, validity, and preference for a pediatric pain intensity scale: the Catalan version of the faces pain scale – revised. *Pain, 111*, 59-64. doi: 10.1016/j.pain.2004.05.023

Montague, M., Maddux, C. D., & Dereshiwsky, M. I. (1990). Story grammar and comprehension and production of narrative prose by students with learning disabilities. *Journal of Learning Disabilities, 23*(3), 190-197.

Moodley, V. (2007). Codeswitching in the multilingual English first language classroom. *International Journal of Bilingual Education and Bilingualism, 10*(6), 707-722.

Murphy, J., Tester, S., Hubbard, G., Downs, M., & MacDonald, C. (2005). Enabling frail older people with a communication difficulty to express their views: the use of Talking Mats™ as an interview tool. *Health and Social Care in the Community, 13*(2), 95-107.

Nadar, R., Oberlander, T. F., Chambers, C. T., & Craig, K. D. (2004). The expression of pain in children with autism. *Clinical Journal of Pain, 20*, 88-97.

National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research. (1979). The Belmont Report.

Nilsson, S., Björkman, B., Almqvist, A., Almqvist, L., Björk-Willén, P., Donohue, D. K., . . . Hvit, S. (2013). Children's voices - differentiating a child perspective from a child's perspective. *Developmental neurorehabilitation*(0), 1-7.

Nilsson, S., Buccholz, M., & Thunberg, G. (2012). Assessing children's anxiety using the Modified Short State-Trait Anxiety Inventory and Talking Mats: A pilot study. *Nursing Research and Practice, 2012*(2012), 1-7. doi: 10.1155/2012/932570

Nilsson, S., Finnström, B., & Kokinsky, E. (2008). The FLACC behavioral scale for procedural pain assessment in children aged 5–16 years. *Pediatric anesthesia, 18*(8), 767-774.

Nortjé, N., & Albertyn, R. (2015). The cultural language of pain: a South African study. *South African Family Practice, 57*(1), 24-27.

O'Rourke, D. (2004). The measurement of pain in infants, children, and adolescents: from policy to practice. *Physical Therapy, 84*(6), 560-570.

Oberlander, T. F., Gilbert, C. A., Chambers, C. T., O'Donnell, M. E., & Craig, K. D. (1999). Biobehavioral responses to acute pain in adolescents with a significant neurologic impairment. *The Clinical journal of pain, 15*(3), 201-209.

Palermo, T. M., Valrie, C. R., & Karlson, C. W. (2014). Family and Parent Influences on Pediatric Chronic Pain. *American Psychologist, 69*(2), 142-152. doi: 10.1037/a0035216

Palisano, R. J., Rosenbaum, P., Walter, S., Russell, D. J., Wood, E., & Galuppi, B. E. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology, 39*(4), 214-223.

Parkinson, K. N., Dickinson, H. O., Arnaud, C., Lyons, A., Colver, A. F., Beckung, E., . . . Marcelli, M. (2013). Pain in young people aged 13 to 17 years with cerebral palsy: cross-sectional, multicentre European study. *Archives of Disease in Childhood, 98*(6), 434-440.

Penno, J. F., Wilkinson, I. A. G., & Moore, D. W. (2002). Vocabulary acquisition from teacher explanation and repeated listening to stories: Do they overcome the Matthew effect? *Journal of Educational Psychology, 94*(1), 23.

Percy, A. K., & Lane, J. B. (2005). Rett syndrome: model of neurodevelopmental disorders. *Journal of Child Neurology, 20*(9), 718-721.

Piaget, J. (2003). Part 1. Cognitive development in children: Piaget. Development and learning. . *Journal of Research in Science Teaching, 40*(supplement), S8-S18.

Pistorius, M. (2011). *Ghost boy*. London: Simon and Schuster.

Poland, B. D. (1995). Transcription quality as an aspect of rigor in qualitative research. *Qualitative inquiry, 1*(3), 290-310.

Punch, S. (2002). Research with children: The same or different from research with adults? *Childhood, 9*(3), 321-341.

Rahman, N. (1996). Caregivers' sensitivity to conflict: The use of the vignette methodology. *Journal of Elder Abuse & Neglect, 8*(1), 35-47.

Ramstad, K., Jahnsen, R., Skjeldal, O. H., & Diseth, T. H. (2011). Characteristics of recurrent musculoskeletal pain in children with cerebral palsy aged 8 to 18 years. *Developmental Medicine and Child Neurology, 53*(11), 1013-1018. doi: 10.1111/j.1469-8749.2011.04070.x

Reid, G. J., Gilbert, C. A., & McGrath, P. J. (1998). The pain coping questionnaire: preliminary validation. *Pain, 76*(1), 83-96.

Rossi, W. C., Reynolds, W., & Nelson, R. M. (2003). Child assent and parental permission in pediatric research. *Theoretical Medicine and Bioethics, 24*(2), 131-148.

Roulstone, S. (2015). Exploring the relationship between client perspectives, clinical expertise and research evidence. *International Journal of Speech-language Pathology*(0), 1-11.

Rowe, M. L. (2008). Child-directed speech: relation to socioeconomic status, knowledge of child development and child vocabulary skill. *Journal of Child Language, 35*(01), 185-205.

SACE. (2011). Registration 2011, from http://www.sace.org.za/Registration/jit_default_14.Registration.html

Sánchez-Rodríguez, E., Miró, J., & Castarlenas, E. (2012). A comparison of four self-report scales of pain intensity in 6- to 8-year-old children. *Pain, 153*(8), 1715-1719. doi: 10.1016/j.pain.2012.05.007

SAS. (2011). *SAS/IML 9.3 User's Guide*. Cary, NC: SAS Institute Inc.

Savedra, M., Gibbons, P., Tesler, M., Ward, J., & Wegner, C. (1982). How Do Children Describe Pain? A Tentative Assessment. *Pain, 14,* 95-104.

Schechter, N. L., Bernstein, B. A., Beck, A., Hart, L., & Scherzer, L. (1991). Individual differences in children's response to pain: role of temperament and parental characteristics. *Pediatrics, 87*(2), 171-177.

Schiavenato, M., & Craig, K. D. (2010). Pain assessment as a social transaction: beyond the "gold standard". *The Clinical journal of pain, 26*(8), 667-676.

Schieffelin, B. B., & Ochs, E. (1986). Language socialization. *Annual review of anthropology,* 163-191.

Schlosser, R. W. (1999). Social validation of interventions in augmentative and alternative communication. *Augmentative and Alternative Communication, 15*(4), 234-247.

Schlosser, R. W., & Raghavendra, P. (2004). Evidence-based practice in augmentative and alternative communication. *Augmentative and Alternative Communication, 20*(1), 1-21.

Schoenberg, N. E., & Ravdal, H. (2000). Using vignettes in awareness and attitudinal research. *International Journal of Social Research Methodology, 3*(1), 63-74.

Shapiro, J. (1983). Family reactions and coping strategies in response to the physically ill or handicapped child: A review. *Social Science and Medicine, 17*(14), 913-931.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information, 22*(2), 63-75.

Shoham, Y. (1986). *Chronological ignorance.* Paper presented at the Proceedings of the Fifth National Conference on Artificial Intelligence.

Shott, S. R. (2006). *Down syndrome: Common otolaryngologic manifestations.* Paper presented at the American Journal of Medical Genetics Part C: Seminars in Medical Genetics.

Smith, J., & Firth, J. (2011). Qualitative data analysis: the framework approach. *Nurse researcher, 18*(2), 52-62.

Smith, M. M. (2005). The dual challenges of aided communication and adolescence. *Augmentative and Alternative Communication, 21*(1), 67-79.

Snodgrass, M. R., Stoner, J. B., & Angell, M. E. (2013). Teaching Conceptually Referenced Core Vocabulary for Initial Augmentative and Alternative Communication. *Augmentative and Alternative Communication, 29*(4), 322-333.

Spielberger, C. D. (1973). *Manual for the State-Trait Anxiety Inventory for Children*. Palo Alto, CA: Consulting Psychologists Press.

Stafstrom, C. E., Rostasy, K., & Minster, A. (2002). The usefulness of children’s drawings in the diagnosis of headache. *Pediatrics, 109*(3), 460-472.

Stähle-Öberg, L., & Fjellman-Wiklund, A. (2009). Parent’s experiences of pain in children with cerebral palsy and multiple disabilities - an interview study. *Advances in Physiotherapy, 11*, 137-144. doi: 10.1080/14038190902906318

Stallard, P., Williams, L., Lenton, S., & Velleman, R. (2001). Pain in cognitively impaired, non-communicating children. *Archives of Disease in Childhood, 85*(6), 460-462.

Stallard, P., Williams, L., Velleman, R., Lenton, S., McGrath, P. J., & Taylor, G. (2002). The development and evaluation of the pain indicator for communicatively impaired children (PICIC). *Pain, 98*, 145-149.

Stanford, E. A., Chambers, C. T., & Craig, K. D. (2005). A normative analysis of the development of pain-related vocabulary in children. *Pain, 114*(1-2), 278-284.

Stanford, E. A., Chambers, C. T., & Craig, K. D. (2006). The role of developmental factors in predicting young children's use of a self-report scale for pain. *Pain, 120*(1-2), 16-23.

Stanford, E. A., Chambers, C. T., Craig, K. D., McGrath, P. J., & Cassidy, K. L. (2005). "Ow!": Spontaneous verbal pain expression among young children during immunization. *Clinical Journal of Pain, 21*(6), 499-502.

Stuart, S., Beukelman, D. R., & King, J. (1997). Vocabulary use during extended conversations by two cohorts of older adults. *Augmentative and Alternative Communication, 13*(1), 40-47.

Suraseranivongse, S., Santawat, U., Kraiprasit, K., Petcharatana, S., Prakkamodom, S., & Muntraporn, N. (2001). Cross-validation of a composite pain scale for preschool children within 24 hours of surgery. *BJA: British Journal of Anaesthesia, 87*(3), 400-405.

SurveyMonkey. (2014). Survey Monkey. https://www.surveymonkey.com/

Terstegen, C., Koot, H. M., De Boer, J. B., & Tibboel, D. (2003). Measuring pain in children with cognitive impairment: pain response to surgical procedures. *Pain, 103*(1), 187-198.

The, J. C. (2010). Advancing Effective Communication, Cultural Competence, and Patient and Family Centered Care: A Roadmap for Hospitals. In T. J. Commission (Ed.).

Thistle, J. J., & Wilkinson, K. M. (2009). The effects of color cues on typically developing preschoolers' speed of locating a target line drawing: Implications for augmentative and alternative communication display design. *American Journal of Speech-Language Pathology, 18*(3), 231-240.

Tomlinson, D., Von Baeyer, C. L., Stinson, J. N., & Sung, L. (2010). A systematic review of faces scales for the self-report of pain intensity in children. *Pediatrics, 126*(5), e1168-e1198.

Tönsing, K. M., & Alant, E. (2004). Topics of social conversation in the work place: A South African perspective. *Augmentative and Alternative Communication, 20*(2), 89-102.

Tönsing, K. M., Dada, S., & Alant, E. (2014). Teaching Graphic Symbol Combinations to Children with Limited Speech During Shared Story Reading. *Augmentative and Alternative Communication, 30*(4), 279-297.

Trembath, D., Balandin, S., & Togher, L. (2007). Vocabulary selection for Australian children who use augmentative and alternative communication. *Journal of Intellectual and Developmental Disability, 32*(4), 291-301.

Turck, D. C., Flor, H., & Rudy, T. E. (1987). Pain and families. I.: Ethiology, maintenance and psycosocial impact. *Pain, 30*, 3-27.

Versloot, J., & Craig, K. (2009). The communication of pain in Paediatric Dentistry. *European Archives of Paediatric Dentistry, 10*(2), 61-66.

Versloot, J., Veerkamp, J. S. J., & Hoogstraten, J. (2008). Children's self-reported pain at the dentist. *Pain, 137*(2), 389-394.

Von Baeyer, C. L. (2006). Children's self-reports of pain intensity: scale selection, limitations and interpretation. *Pain Research & Management: The Journal of the Canadian Pain Society, 11*(3), 157.

Von Baeyer, C. L., Baskerville, S., & McGrath, P. J. (1998). Everyday pain in three-to five-year-old children in day care. *Pain Research and Management, 3*(2), 111-116.

Von Baeyer, C. L., Marche, T. A., Rocha, E. M., & Salmon, K. (2004). Children's memory of pain: Overview and implications for practice. *The Journal of Pain, 5*(5), 241-249. doi: 10.1016/j.pain.2004.05.001

Von Baeyer, C. L., & Spagrud, L. J. (2007). Systematic review of observational (behavioral) measures of pain for children and adolescents aged 3 to 18 years. *Pain, 127*(1-2), 140-150. doi: 10.1016/j.pain.2006.08.014

Von Baeyer, C. L., Spagrud, L. J., McCormick, J. C., Choo, E., Neville, K., & Connelly, M. A. (2009). Three new datasets supporting use of the Numerical Rating Scale (NRS-11) for children's self-reports of pain intensity. *Pain, 143*(3), 223-227.

Vygotsky, L. S. (1978). *Mind and society: The development of higher mental processes*: Cambridge, MA: Harvard University Press.

Wennström, B., & Bergh, I. (2008). Bodily and Verbal Expressions of Postoperative Symptoms in 3- to 6-Year-Old Boys. *Journal of Pediatric Nursing, 23*(1), 65-76.

Whaley, J. F. (1981). Story Grammars and Reading Instruction. *The Reading Teacher, 34*(7), 762-771.

Wilkie, D. J., Holzemer, W. L., Tesler, M. D., Ward, J. A., Paul, S. M., & Savedra, M. C. (1990). Measuring pain quality: validity and reliability of children's and adolescents' pain language. *Pain, 41*(2), 151-159.

Wilkinson, K. M., Carlin, M., & Jagaroo, V. (2006). Preschoolers' speed of locating a target symbol under different color conditions. *Augmentative and Alternative Communication, 22*(2), 123-133.

Wilkinson, K. M., & Hennig, S. (2007). The state of research and practice in augmentative and alternative communication for children with developmental/intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(1), 58-69.

Willis, M. H. W., Merkel, S. I., Voepel-Lewis, T., & Malviya, S. (2003). FLACC Behavioral Pain Assessment Scale: A Comparison with the Child's Self-Report. *Pediatric Nursing, 29*(3), 195.

Wong, D. L., & Baker, C. M. (1988). Pain in children: comparison of assessment scales. *Pediatric Nursing*, *14*(1), 9-17.

Yorkston, K., Dowden, P., Honsinger, M., Marriner, N., & Smith, K. (1988). A comparison of standard and user vocabulary lists. *Augmentative and Alternative Communication, 4*(4), 189-210.

Yung, A., Haagsma, J. A., & Polinder, S. (2014). A systematic review on the influence of pre-existing disability on sustaining injury. *Accident Analysis and Prevention, 62,* 199-208.

Zhou, H., Roberts, P., & Horgan, L. (2008). Association between self-report pain ratings of child and parent, child and nurse and parent and nurse dyads: meta-analysis. *Journal of Advanced Nursing*, *63*(4), 334-342.

APPENDICES

APPENDIX A: Behavioural Observational Measurement Tests

Table 1.

Behavioural Observational Measurement Tools Used by Healthcare Professionals, Parents and Caregivers to Assess Pain

Name of measurement tool with acronym in brackets	**Intended age group**	**Description**	**Administered by**	**Purpose**	**Evaluation**
a) Procedural pain					
Children's Hospital of Eastern Ontario Pain Scale (CHEOPS) (McGrath et al., 1985)	1;0–7;11	Incorporates six behavioural categories (cry, facial, verbal, torso, touch, and legs) that are each scored individually using the ranges 0 to 1 (child not crying); 2 (child is complaining or softly vocalizing/child is crying but cry is calm or whining) or 3 (child is "full-lunged crying") (Willis et al., 2003); allowing for differential weighting of these pain behaviours. Scores from 4 to 6 all represent no pain; 7 to the maximum score of 13 indicating various levels of pain.	Healthcare professionals	Use in immediate postoperative period (Suraseranivongse et al., 2001)	Scoring within categories tend to be more complex to use in busy clinical settings in comparison with other behaviour rating scales (Nilsson et al., 2008; Willis et al., 2003)
Face, Legs, Activity, Cry, Consolability Scale (FLACC) (Merkel et al., 1997)	4;0–17;11	An ordinal scale with five pain behavioural categories (facial expression; leg movement; activity; crying and consolability), each of which is scored 0–2 to provide a total score ranging from 0–10.	Healthcare professionals	Use in post-operative pain period; minor non-invasive procedures and after ear-nose–throat operations (Von Baeyer & Spagrud, 2007)	Easy to interpret.
Pediatric Pain Profile (PPP) (Hunt et al., 2004)	9;0–17;11r	20-item behaviour rating scale	Healthcare professionals	Use to assess pain in children with severe	Easy to use.

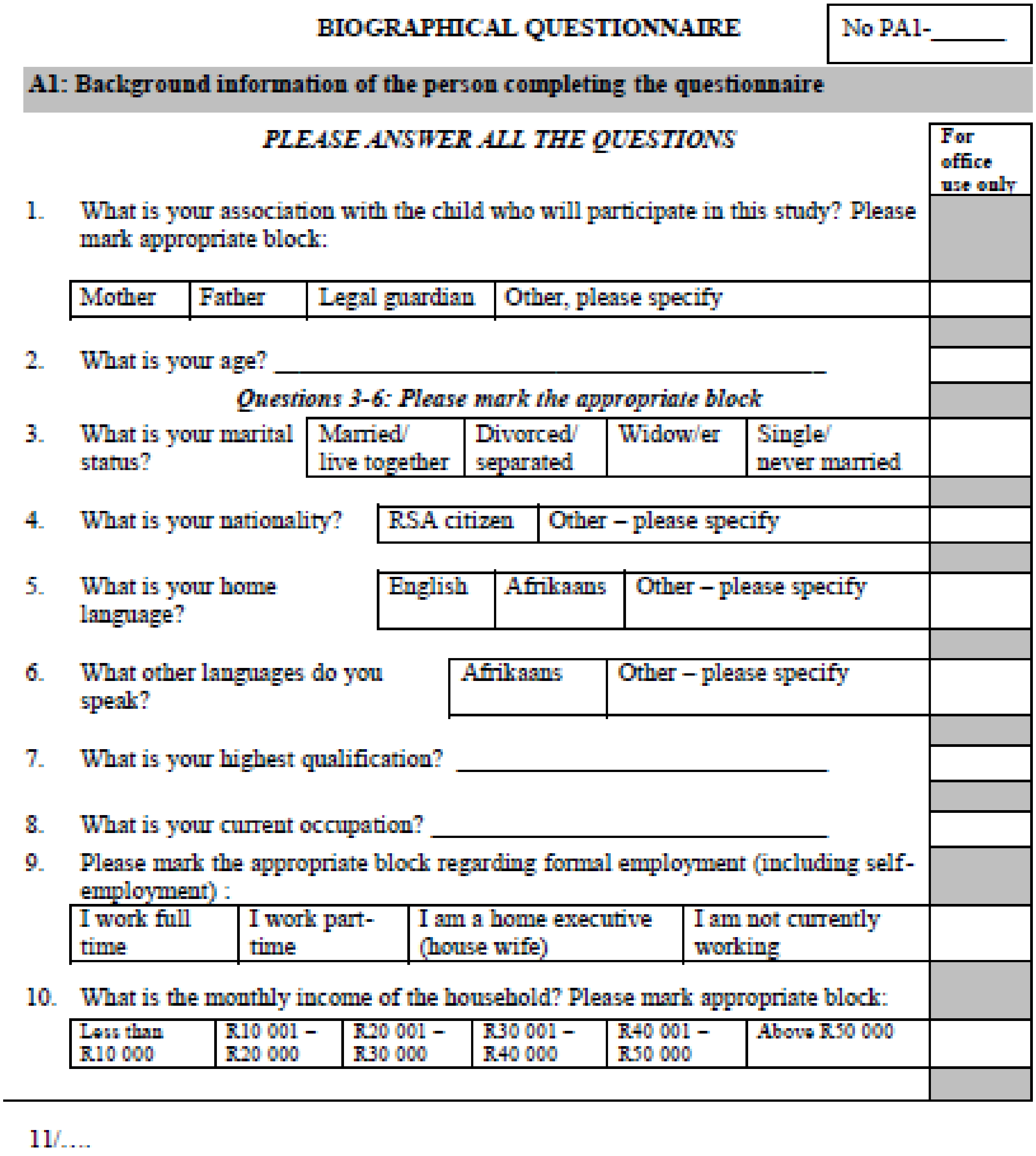
Name of measurement tool with acronym in brackets	Intended age group	Description	Administered by	Purpose	Evaluation
				neurological disability (Breau & Burkitt, 2009)	
b) Post-operative pain in hospital					
The Children's and Infants Post-operating Scale (CHIPPS) (Willis et al., 2003)	1;0-6;11	Includes 5 behavioural items (crying; facial expression; posture and trunk; posture of legs; motor restlessness) (Willis et al., 2003)	Healthcare professionals	Use in postoperative setting	Recommended to be used with infants and young children Easy to use learn and implement (Willis et al., 2003)
The Non-Communicating Children's Pain Checklist (NCCPC); Postoperative Version (NCCPC-PV); Revised (NCCPC-R) (Breau, McGrath, Camfield, & Finley, 2002)	3;0– 18;11	The original scale (NCCPC) included 30 item list with divided into 7 sub-scale categories (vocal; eating/sleeping; social; facial; activity; body/limb; physiological signs) with "yes /no" responses rated the items. The NCCPC-PV did not include the eating/sleeping items and the ratings (yes/no) were changed to ordinal ratings indicating the frequency observed by observers:" not at all (0); just a little (1); fairly often (2), very often (3)".	Healthcare professionals; parents; caregivers (O'Rourke, 2004)	Use in postoperative setting	Display good psychometric properties (Breau, Finley, McGrath, & Camfield, 2002) Translations of these scales were done for many languages. The original NCCPC was revised (NCCPC-R) to be used in home settings (Breau, McGrath, et al., 2002). Designed for children with cognitive impairments (Breau, McGrath, et al., 2002)

Name of measurement tool with acronym in brackets	Intended age group	Description	Administered by	Purpose	Evaluation
c) Post-operative pain at home (parent assessment)					
Objective Pain Scale (OPS) (Suraseranivongse et al., 2001)	0:8-13;11	Scores of 0, 1 or 2 are given for the following parameters: Systolic blood pressure; crying; movement; agitation (confused excited); complains of pain (may not be possible in younger children). Minimum score is 0 and highest 10. The higher the score, the greater the degree of pain.	Parents; caregivers	Use in postoperative home setting	The scale has been simplified to be used by parents. Blood pressure measurement has been replaced by assessment of body language or posture (Suraseranivongse et al., 2001)
Parents’ Post-operative Pain Measure (PPPM) (Chambers et al., 2003)	2;0-12;11	Consists of 15 items, which have to be scored by using either a 0 or 1.	Parents; caregivers	Use in postoperative home setting	A 10-item short form of the parents' postoperative pain measure has been developed. Easy to be implemented.
Pain Indicator for Communicatively Impaired Children (PICIC) (Stallard et al., 2002)	≥2 yr with CCN	Six core pain sets form the PICIC: Crying with or without tears; screaming, yelling, groaning or moaning; screwed up or distressed looking face; body appears stiff or tense; difficult to comfort or console; flinches or moves away if touched. Ratings done on a 4 point ordinal Likert scale (“not at all; a little; often; all the time) of how often each of the six core pain behaviours occur during a set observation period (Stallard et al., 2002).	Parents; caregivers	Use in postoperative home setting	Simple and short assessment scale; does not require specialist training; could be used to assess pain in communicatively impaired children; facial coding systems are time consuming; pain threshold cannot be determined with this scale; parents can still underestimate

Name of measurement tool with acronym in brackets	Intended age group	Description	Administered by	Purpose	Evaluation
					child's pain (Stallard et al., 2002)
d) On ventilator or in critical care					
COMFORT Scale (COMFORT) (Ambuel et al. (1992)	0–17;0	This scale has eight (8) indicators: (a) alertness; (b) calmness/agitation; (c) respiratory response; (d) physical movement' (e) blood pressure; (f) heart rate ; (g) muscle tone, and (h) facial tension. Each indicator is scored between 1– 5 based upon the behaviors showed by the patient. Observe for two minutes. The total score= add scores of each indicator.	Healthcare professionals	Use in postoperative setting	Due to the complexity of measuring blood pressure and heart rate, this scale is used primarily for patients in ICU settings
COMFORT Behavior Scale (van Dijk et al., 2005)	0-10;11	Six behavioral indicators: (a) alertness, (b) calmness, (c) respiratory response (for ventilated children) or crying (for spontaneously breathing children), (d) body movements, (e) facial tension, and (f) muscle tone. Increasing intensity of the behavior rated from 1–5. The six ratings leads to a total score ranging from 6 to 30.	Healthcare professionals	Use during medical ventilation	Adhere to 2-min observation period should in patient's interest as 30-sec COMFORT behavior scale observation could lead to underscoring the pain.
e) Distress; pain-related fear or anxiety					
Procedure Behavior Checklist (PBCL)	0–18;11	Eight items (a) muscle tension, (b) screaming, (c) crying, (d)	Healthcare professionals	Use to measure pain-related fear or anxiety	Use in three phases namely when the

Name of measurement tool with acronym in brackets	Intended age group	Description	Administered by	Purpose	Evaluation
(LeBaron and Zeltzer, (1984); Procedure Behavioral Rating Scale – Revised (PBRS-R) (Katz et al., 1980)		restraint used, (e) verbalise pain, (f) verbalise anxiety, (g) verbal stalling and (h) physical resistance. Behaviours are scored 1 if present and 0 if absent - possible total score ranging from 0 to 8 per phase and intensity (scale of 1 to 5, where 1 = ‘very mild’ and 5 = ‘extremely intense’, - possible total score ranging from 0 to 40 per phase) during three phases of the procedure.			child enters the treatment room until aspiration site cleansing, from needle insertion to removal and from needle removal to the child’s exit from the treatment room.
Revised scale of COMFORT (COMFORT-R) (Ambuel et al.,1992)	0–9;11	0–11: 11 items scored 0 or 1	Healthcare professionals	Use to measure other constructs than pain during stay in ICU setting, mechanically ventilated	Use in ICU setting

APPENDIX B: Biographical questionnaire (Parents of participating children)



BIOGRAPHICAL QUESTIONNAIRE

No PA1-______

A1: Background information of the person completing the questionnaire

PLEASE ANSWER ALL THE QUESTIONS

For office use only

1. What is your association with the child who will participate in this study? Please mark appropriate block:

Mother	Father	Legal guardian	Other, please specify

2. What is your age? ______________________________

Questions 3-6: Please mark the appropriate block

3. What is your marital status?

Married/ live together	Divorced/ separated	Widow/er	Single/ never married

4. What is your nationality?

RSA citizen	Other – please specify

5. What is your home language?

English	Afrikaans	Other – please specify

6. What other languages do you speak?

Afrikaans	Other – please specify

7. What is your highest qualification? ____________________

8. What is your current occupation? ____________________

9. Please mark the appropriate block regarding formal employment (including self-employment) :

I work full time	I work part-time	I am a home executive (house wife)	I am not currently working

10. What is the monthly income of the household? Please mark appropriate block:

Less than R10 000	R10 001 – R20 000	R20 001 – R30 000	R30 001 – R40 000	R40 001 – R50 000	Above R50 000

11/….

11. How many children do you have? ________

- Please indicate their name, age and gender
- Mark with a cross the relationship of each sibling to the participant
- Answer yes/no if they are still living with the participant

Name	Age	Gender		Relationship to participating child						Does this sibling live with the participant?
		M	F	brother	sister	half-brother	half-sister	step-brother	step-sister	
		M	F							
		M	F							
		M	F							
		M	F							
		M	F							
		M	F							

A2: Background information of the child who will participate in this study

Questions 13-6: Please mark the appropriate block

12. What is the birth date of your child who will participate in this study?

____

13. What is your child's gender? Please mark appropriate block

Male	Female

14. What is your child's home language?

English	Afrikaans	Other – please specify

15. What other languages does your child speak?

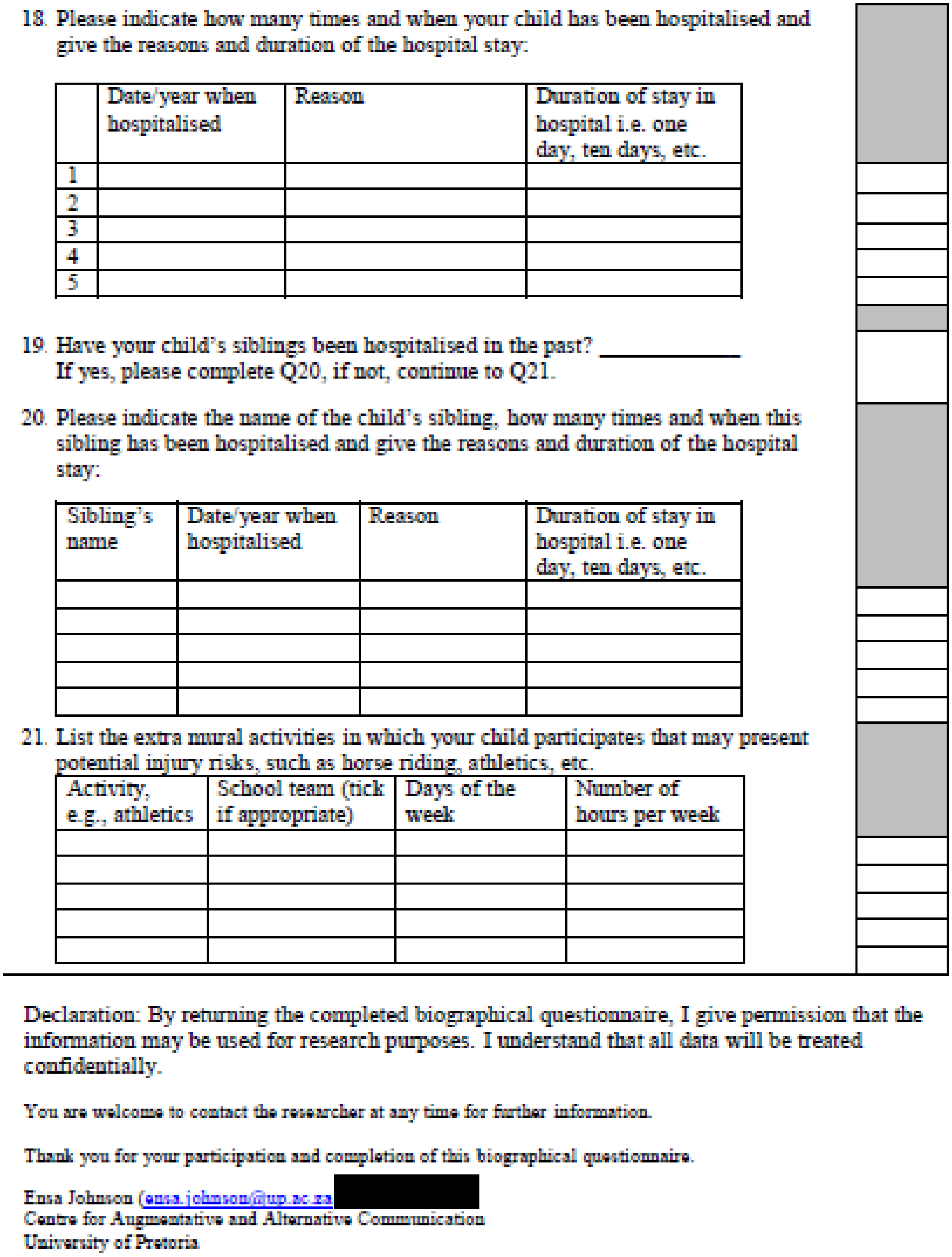
Afrikaans	Other – please specify

16. What is the birth order of your child?

First born	Second	Third	Fourth	Fifth

17. Has your child been hospitalised in the past? If yes, please complete Q18, if not, continue to Q19.

yes	no



18. Please indicate how many times and when your child has been hospitalised and give the reasons and duration of the hospital stay:

	Date/year when hospitalised	Reason	Duration of stay in hospital i.e. one day, ten days, etc.
1			
2			
3			
4			
5			

19. Have your child's siblings been hospitalised in the past? ____________
If yes, please complete Q20, if not, continue to Q21.

20. Please indicate the name of the child's sibling, how many times and when this sibling has been hospitalised and give the reasons and duration of the hospital stay:

Sibling's name	Date/year when hospitalised	Reason	Duration of stay in hospital i.e. one day, ten days, etc.

21. List the extra mural activities in which your child participates that may present potential injury risks, such as horse riding, athletics, etc.

Activity, e.g., athletics	School team (tick if appropriate)	Days of the week	Number of hours per week

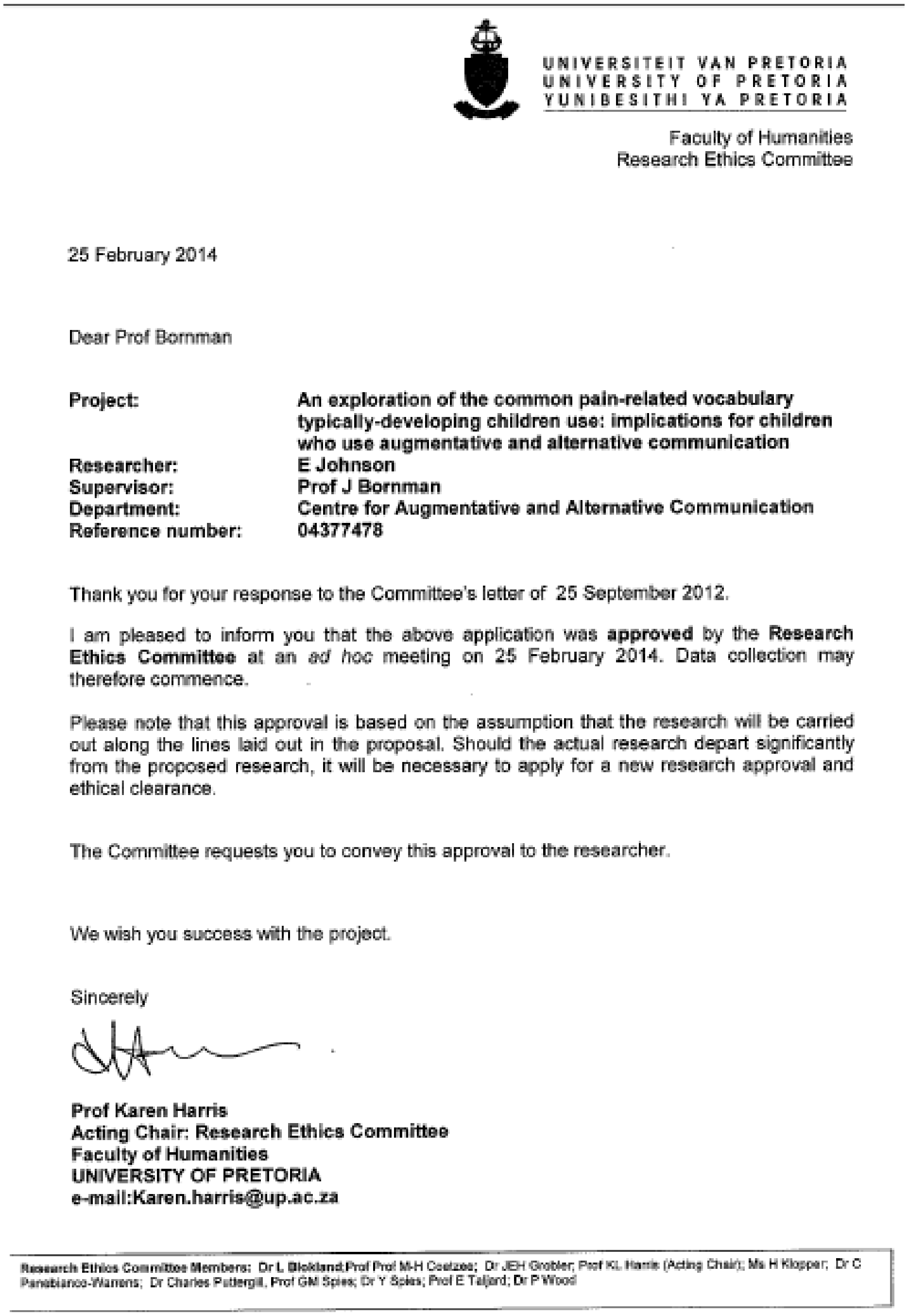
Declaration: By returning the completed biographical questionnaire, I give permission that the information may be used for research purposes. I understand that all data will be treated confidentially.

You are welcome to contact the researcher at any time for further information.

Thank you for your participation and completion of this biographical questionnaire.

Ensa Johnson (ensa.johnson@up.ac.za [redacted]
Centre for Augmentative and Alternative Communication
University of Pretoria

APPENDIX C: Ethics approval Research Ethics Committee UP



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

25 February 2014

Dear Prof Bornman

Project:	**An exploration of the common pain-related vocabulary typically-developing children use: implications for children who use augmentative and alternative communication**
Researcher:	**E Johnson**
Supervisor:	**Prof J Bornman**
Department:	**Centre for Augmentative and Alternative Communication**
Reference number:	**04377478**

Thank you for your response to the Committee's letter of 25 September 2012.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** at an *ad hoc* meeting on 25 February 2014. 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.

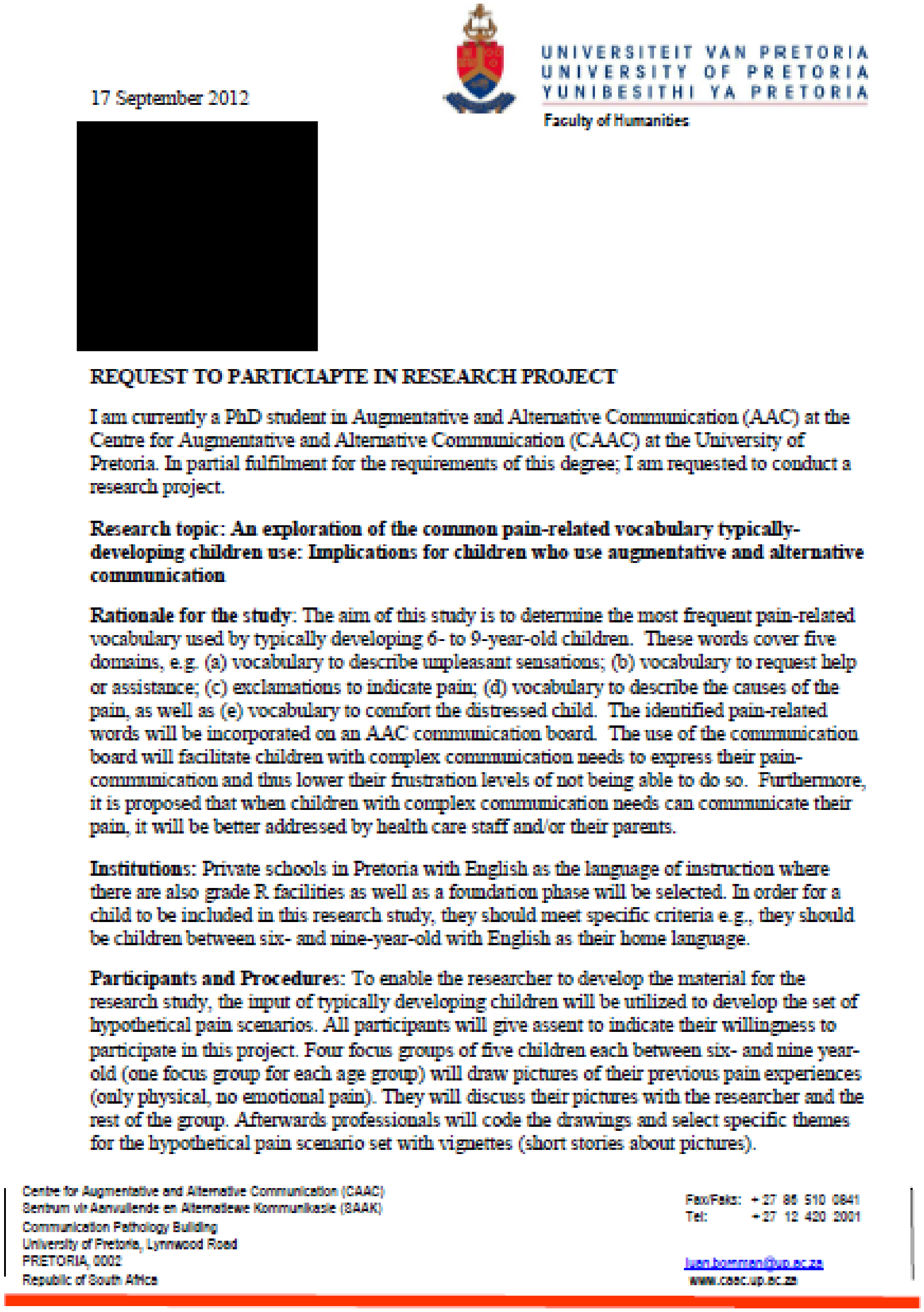
We wish you success with the project.

Sincerely

Prof Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:Karen.harris@up.ac.za

Research Ethics Committee Members: Dr L Blokland;Prof Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris (Acting Chair); Ms H Klopper; Dr C Panebianco-Warrens; Dr Charles Puttergill, Prof GM Spies; Dr Y Spies; Prof E Taljard; Dr P Wood

APPENDIX D: Consent letter school – Phase 1



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

17 September 2012

[redacted]

REQUEST TO PARTICIAPTE IN RESEARCH PROJECT

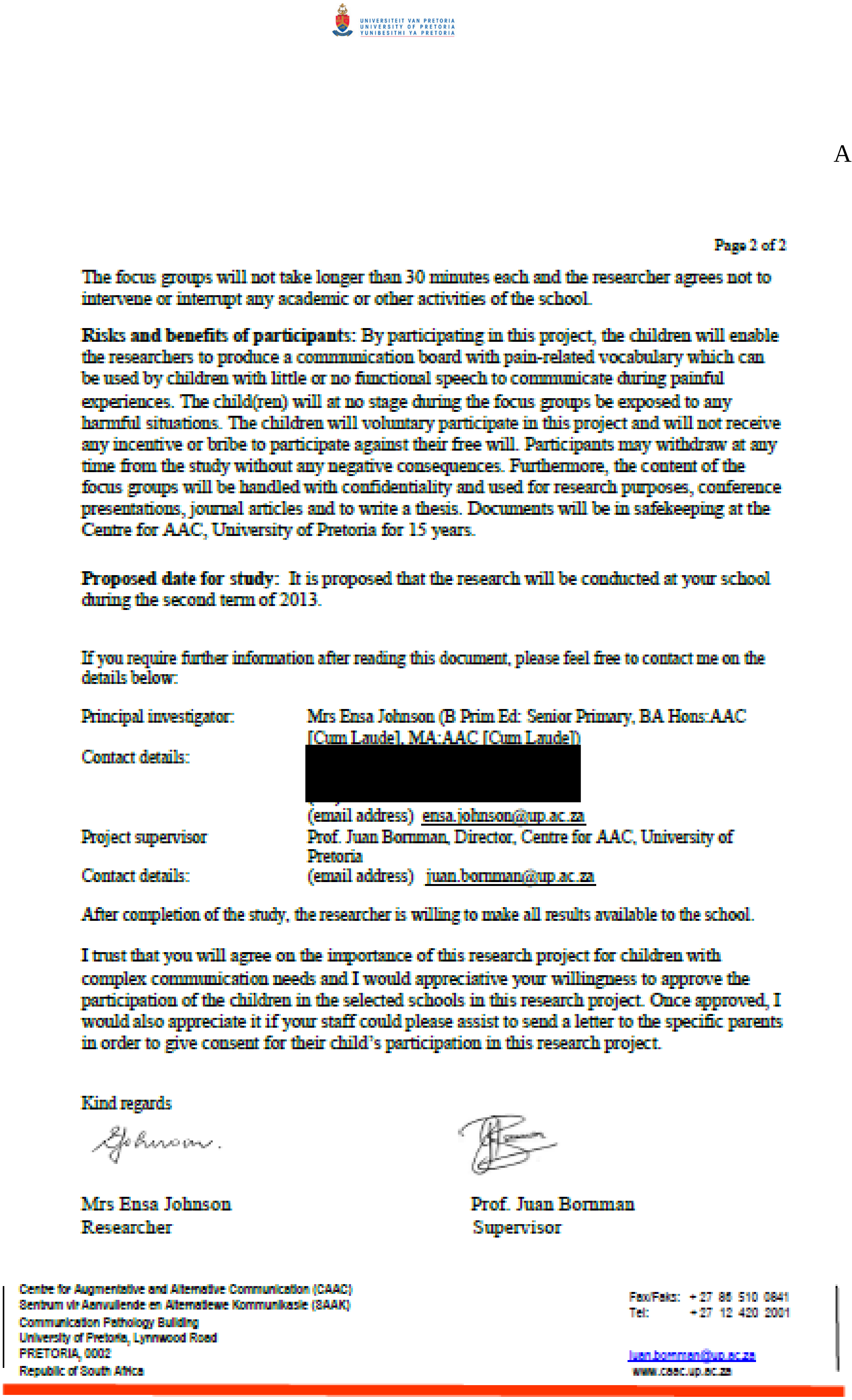
I am currently a PhD student in Augmentative and Alternative Communication (AAC) at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfilment for the requirements of this degree; I am requested to conduct a research project.

Research topic: An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use augmentative and alternative communication

Rationale for the study: The aim of this study is to determine the most frequent pain-related vocabulary used by typically developing 6- to 9-year-old children. These words cover five domains, e.g. (a) vocabulary to describe unpleasant sensations; (b) vocabulary to request help or assistance; (c) exclamations to indicate pain; (d) vocabulary to describe the causes of the pain, as well as (e) vocabulary to comfort the distressed child. The identified pain-related words will be incorporated on an AAC communication board. The use of the communication board will facilitate children with complex communication needs to express their pain-communication and thus lower their frustration levels of not being able to do so. Furthermore, it is proposed that when children with complex communication needs can communicate their pain, it will be better addressed by health care staff and/or their parents.

Institutions: Private schools in Pretoria with English as the language of instruction where there are also grade R facilities as well as a foundation phase will be selected. In order for a child to be included in this research study, they should meet specific criteria e.g., they should be children between six- and nine-year-old with English as their home language.

Participants and Procedures: To enable the researcher to develop the material for the research study, the input of typically developing children will be utilized to develop the set of hypothetical pain scenarios. All participants will give assent to indicate their willingness to participate in this project. Four focus groups of five children each between six- and nine year-old (one focus group for each age group) will draw pictures of their previous pain experiences (only physical, no emotional pain). They will discuss their pictures with the researcher and the rest of the group. Afterwards professionals will code the drawings and select specific themes for the hypothetical pain scenario set with vignettes (short stories about pictures).



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Page 2 of 2

The focus groups will not take longer than 30 minutes each and the researcher agrees not to intervene or interrupt any academic or other activities of the school.

Risks and benefits of participants: By participating in this project, the children will enable the researchers to produce a communication board with pain-related vocabulary which can be used by children with little or no functional speech to communicate during painful experiences. The child(ren) will at no stage during the focus groups be exposed to any harmful situations. The children will voluntary participate in this project and will not receive any incentive or bribe to participate against their free will. Participants may withdraw at any time from the study without any negative consequences. Furthermore, the content of the focus groups will be handled with confidentiality and used for research purposes, conference presentations, journal articles and to write a thesis. Documents will be in safekeeping at the Centre for AAC, University of Pretoria for 15 years.

Proposed date for study: It is proposed that the research will be conducted at your school during the second term of 2013.

If you require further information after reading this document, please feel free to contact me on the details below:

Principal investigator:	Mrs Ensa Johnson (B Prim Ed: Senior Primary, BA Hons:AAC [Cum Laude], MA:AAC [Cum Laude])
Contact details:	[redacted] (email address) ensa.johnson@up.ac.za
Project supervisor	Prof. Juan Bornman, Director, Centre for AAC, University of Pretoria
Contact details:	(email address) juan.bornman@up.ac.za

After completion of the study, the researcher is willing to make all results available to the school.

I trust that you will agree on the importance of this research project for children with complex communication needs and I would appreciative your willingness to approve the participation of the children in the selected schools in this research project. Once approved, I would also appreciate it if your staff could please assist to send a letter to the specific parents in order to give consent for their child's participation in this research project.

Kind regards

Mrs Ensa Johnson
Researcher

Prof. Juan Bornman
Supervisor

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
Communication Pathology Building
University of Pretoria, Lynnwood Road
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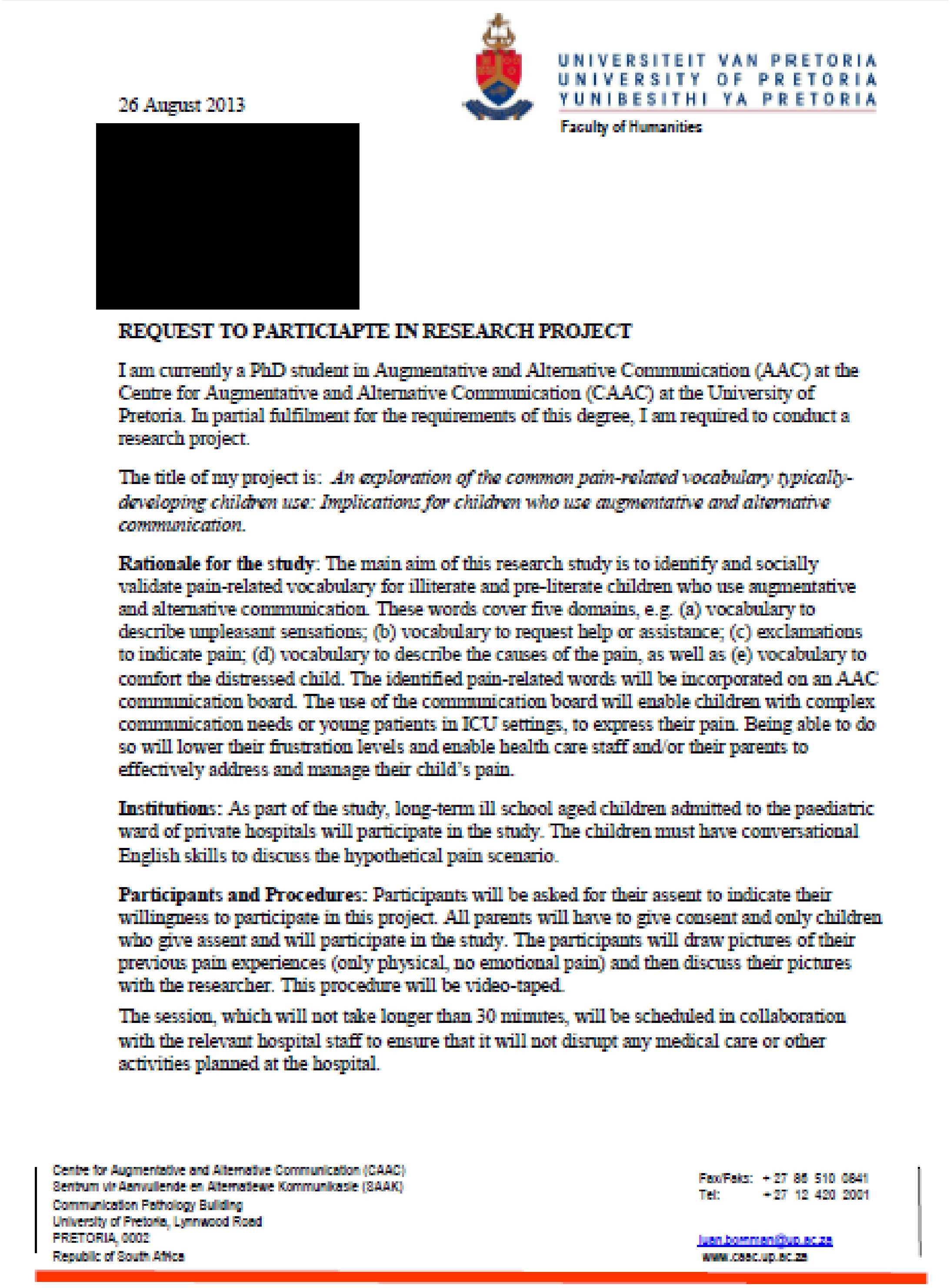
Tel: +27 12 420 2001

juan.bornman@up.ac.za
www.caac.up.ac.za

APPENDIX E: Approval Research Operational Committee Hospital Company



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

26 August 2013

[redacted]

REQUEST TO PARTICIAPTE IN RESEARCH PROJECT

I am currently a PhD student in Augmentative and Alternative Communication (AAC) at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfilment for the requirements of this degree, I am required to conduct a research project.

The title of my project is: *An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use augmentative and alternative communication.*

Rationale for the study: The main aim of this research study is to identify and socially validate pain-related vocabulary for illiterate and pre-literate children who use augmentative and alternative communication. These words cover five domains, e.g. (a) vocabulary to describe umpleasant sensations; (b) vocabulary to request help or assistance; (c) exclamations to indicate pain; (d) vocabulary to describe the causes of the pain, as well as (e) vocabulary to comfort the distressed child. The identified pain-related words will be incorporated on an AAC communication board. The use of the communication board will enable children with complex communication needs or young patients in ICU settings, to express their pain. Being able to do so will lower their frustration levels and enable health care staff and/or their parents to effectively address and manage their child's pain.

Institutions: As part of the study, long-term ill school aged children admitted to the paediatric ward of private hospitals will participate in the study. The children must have conversational English skills to discuss the hypothetical pain scenario.

Participants and Procedures: Participants will be asked for their assent to indicate their willingness to participate in this project. All parents will have to give consent and only children who give assent and will participate in the study. The participants will draw pictures of their previous pain experiences (only physical, no emotional pain) and then discuss their pictures with the researcher. This procedure will be video-taped.

The session, which will not take longer than 30 minutes, will be scheduled in collaboration with the relevant hospital staff to ensure that it will not disrupt any medical care or other activities planned at the hospital.

Centre for Augmentative and Alternative Communication (CAAC)
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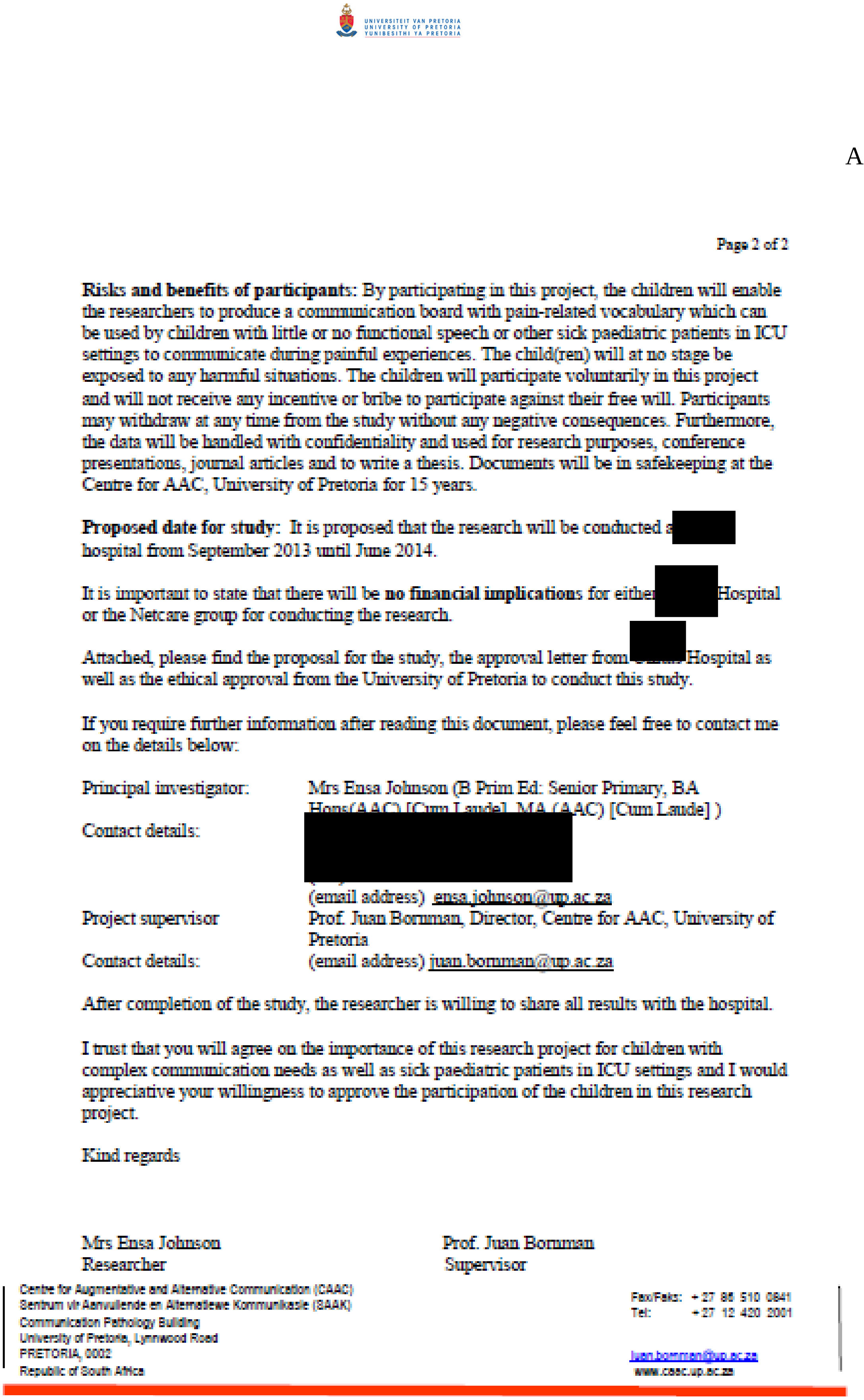

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Risks and benefits of participants: By participating in this project, the children will enable the researchers to produce a communication board with pain-related vocabulary which can be used by children with little or no functional speech or other sick paediatric patients in ICU settings to communicate during painful experiences. The child(ren) will at no stage be exposed to any harmful situations. The children will participate voluntarily in this project and will not receive any incentive or bribe to participate against their free will. Participants may withdraw at any time from the study without any negative consequences. Furthermore, the data will be handled with confidentiality and used for research purposes, conference presentations, journal articles and to write a thesis. Documents will be in safekeeping at the Centre for AAC, University of Pretoria for 15 years.

Proposed date for study: It is proposed that the research will be conducted a [redacted] hospital from September 2013 until June 2014.

It is important to state that there will be **no financial implications** for either [redacted] Hospital or the Netcare group for conducting the research.

Attached, please find the proposal for the study, the approval letter from [redacted] Hospital as well as the ethical approval from the University of Pretoria to conduct this study.

If you require further information after reading this document, please feel free to contact me on the details below:

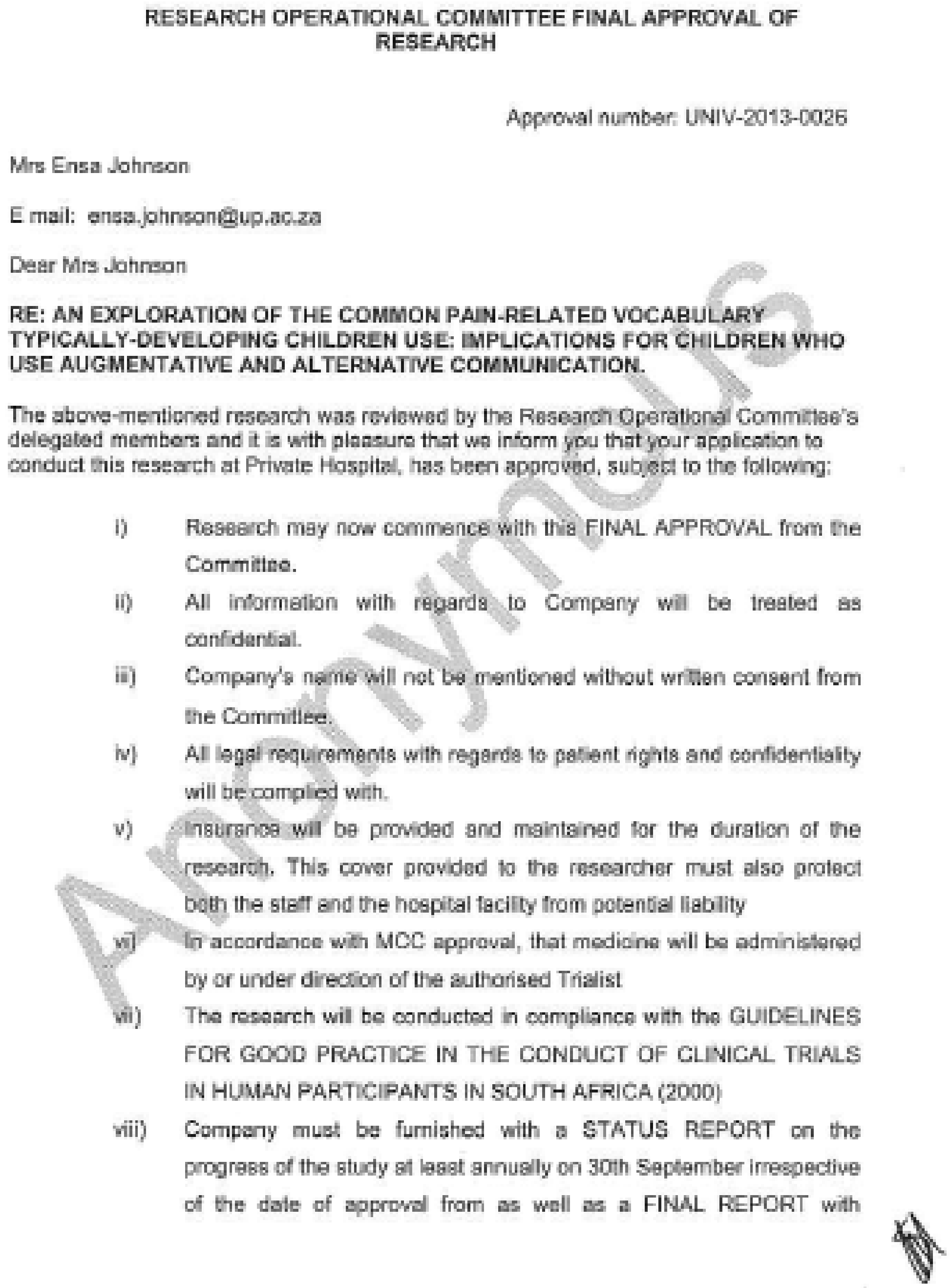
Principal investigator:	Mrs Ensa Johnson (B Prim Ed: Senior Primary, BA Hons(AAC) [Cum Laude], MA (AAC) [Cum Laude])
Contact details:	[redacted] (email address) ensa.johnson@up.ac.za
Project supervisor	Prof. Juan Bornman, Director, Centre for AAC, University of Pretoria
Contact details:	(email address) juan.bornman@up.ac.za

After completion of the study, the researcher is willing to share all results with the hospital.

I trust that you will agree on the importance of this research project for children with complex communication needs as well as sick paediatric patients in ICU settings and I would appreciative your willingness to approve the participation of the children in this research project.

Kind regards

Mrs Ensa Johnson Researcher	Prof. Juan Bornman Supervisor



RESEARCH OPERATIONAL COMMITTEE FINAL APPROVAL OF RESEARCH

Approval number: UNIV-2013-0026

Mrs Ensa Johnson

E mail: ensa.johnson@up.ac.za

Dear Mrs Johnson

RE: AN EXPLORATION OF THE COMMON PAIN-RELATED VOCABULARY TYPICALLY-DEVELOPING CHILDREN USE: IMPLICATIONS FOR CHILDREN WHO USE AUGMENTATIVE AND ALTERNATIVE COMMUNICATION.

The above-mentioned research was reviewed by the Research Operational Committee's delegated members and it is with pleasure that we inform you that your application to conduct this research at Private Hospital, has been approved, subject to the following:

i) Research may now commence with this FINAL APPROVAL from the Committee.

ii) All information with regards to Company will be treated as confidential.

iii) Company's name will not be mentioned without written consent from the Committee.

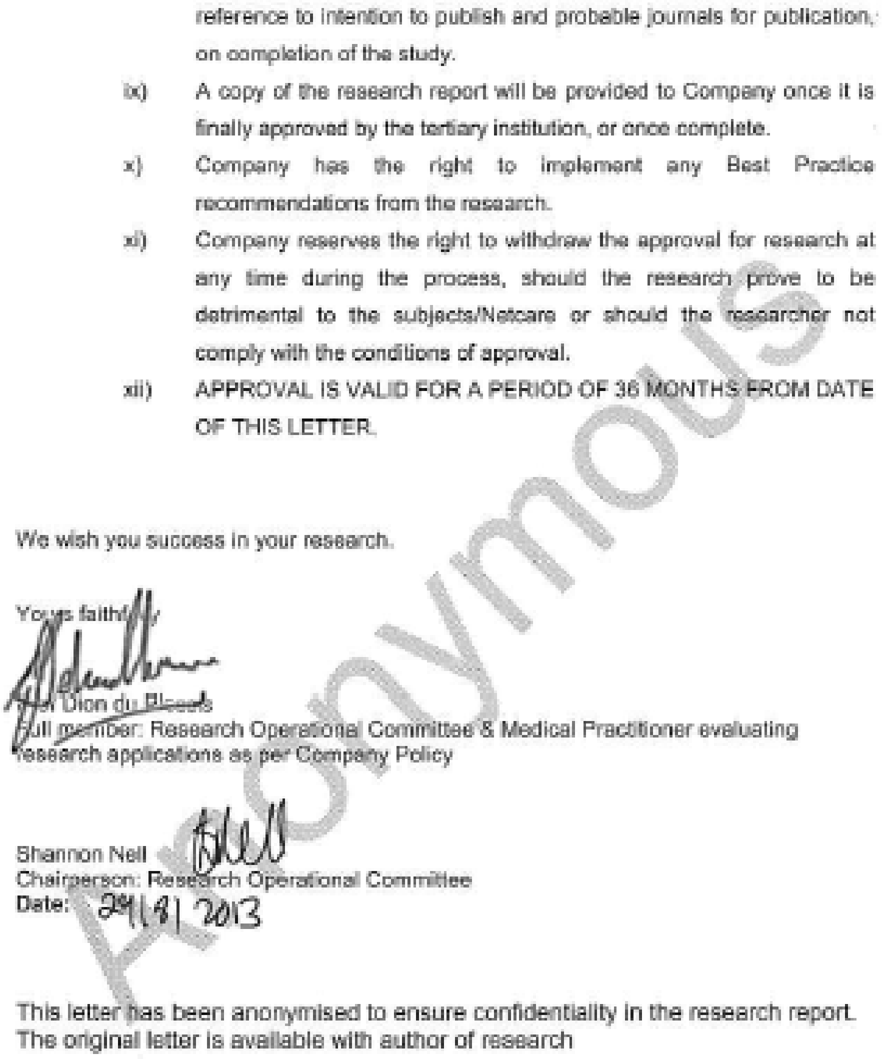
iv) All legal requirements with regards to patient rights and confidentiality will be complied with.

v) Insurance will be provided and maintained for the duration of the research. This cover provided to the researcher must also protect both the staff and the hospital facility from potential liability

vi) In accordance with MCC approval, that medicine will be administered by or under direction of the authorised Trialist

vii) The research will be conducted in compliance with the GUIDELINES FOR GOOD PRACTICE IN THE CONDUCT OF CLINICAL TRIALS IN HUMAN PARTICIPANTS IN SOUTH AFRICA (2000)

viii) Company must be furnished with a STATUS REPORT on the progress of the study at least annually on 30th September irrespective of the date of approval from as well as a FINAL REPORT with



reference to intention to publish and probable journals for publication, on completion of the study.

- ix) A copy of the research report will be provided to Company once it is finally approved by the tertiary institution, or once complete.
- x) Company has the right to implement any Best Practice recommendations from the research.
- xi) Company reserves the right to withdraw the approval for research at any time during the process, should the research prove to be detrimental to the subjects/Netcare or should the researcher not comply with the conditions of approval.
- xii) APPROVAL IS VALID FOR A PERIOD OF 36 MONTHS FROM DATE OF THIS LETTER.

We wish you success in your research.

Yours faithfully

Dion du Plessis
Full member: Research Operational Committee & Medical Practitioner evaluating research applications as per Company Policy

Shannon Nell
Chairperson: Research Operational Committee
Date: 24|8|2013

This letter has been anonymised to ensure confidentiality in the research report.
The original letter is available with author of research

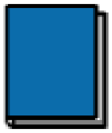
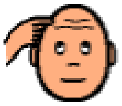
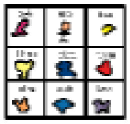
APPENDIX F: Consent letter and form parents (school) – Phase 1

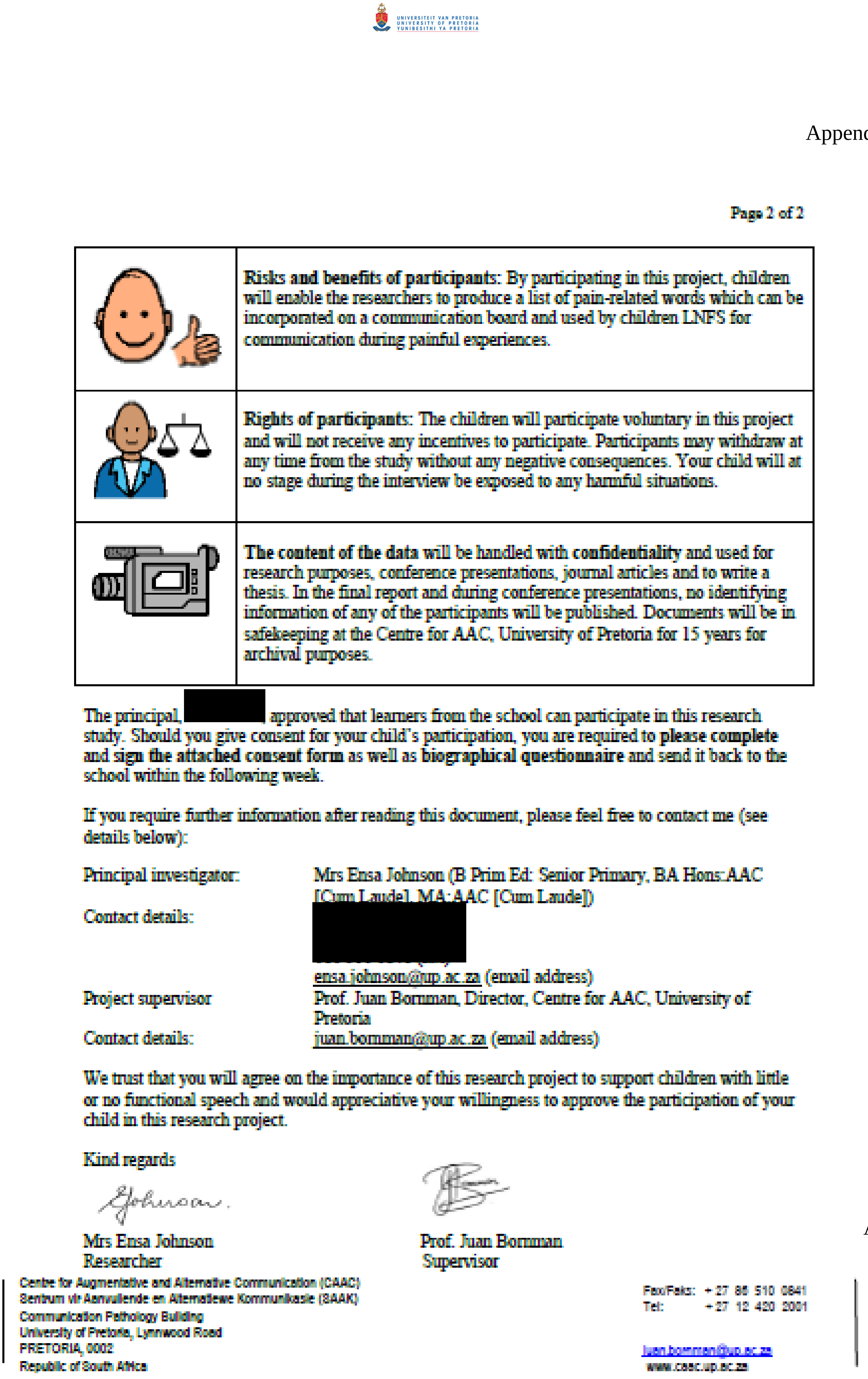
UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

12 August 2013

Dear Parent

I am currently a PhD student in Augmentative and Alternative Communication (AAC) at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfillment for the requirements of this degree, I am required to conduct a research project. I would be grateful for your child's participation in this project.

	**Research topic:** An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use augmentative and alternative communication
	**Rationale for the study**: The aim of this study is to determine the most common pain-related vocabulary used by typically developing 6- to 9-year-old children. These words cover five domains, e.g. (a) words to describe unpleasant sensations; (b) words to request help or assistance; (c) exclamations to indicate pain; (d) words to describe the causes of the pain, as well as (e) words to comfort the distressed child. The identified pain-related words will be incorporated on an AAC communication board. The use of the communication board will enable children with little to no functional speech (LNFS) to communicate about pain. Being able to do so will lower their frustration levels and allow health care staff and/or their parents to effectively address and manage the child's pain.
	**Procedure:** The children who meet the selection criteria and give assent to participate in this research project will be asked to draw pictures of their previous physical pain experiences. They will discuss their drawings with the rest of the group of children from their class. The session will not take longer than 30 minutes. Sessions will be scheduled in collaboration with teachers to ensure that they do not disrupt any academic or other activities at the school. Numbers will be allocated to the participants' drawings to ensure anonymity. The process will be video- and audio taped. The content will be transcribed and coded by myself and one other professional.



	Risks and benefits of participants: By participating in this project, children will enable the researchers to produce a list of pain-related words which can be incorporated on a communication board and used by children LNFS for communication during painful experiences.
	Rights of participants: The children will participate voluntary in this project and will not receive any incentives to participate. Participants may withdraw at any time from the study without any negative consequences. Your child will at no stage during the interview be exposed to any harmful situations.
	The content of the data will be handled with **confidentiality** and used for research purposes, conference presentations, journal articles and to write a thesis. In the final report and during conference presentations, no identifying information of any of the participants will be published. Documents will be in safekeeping at the Centre for AAC, University of Pretoria for 15 years for archival purposes.

The principal, [redacted] approved that learners from the school can participate in this research study. Should you give consent for your child's participation, you are required to **please complete and sign the attached consent form** as well as **biographical questionnaire** and send it back to the school within the following week.

If you require further information after reading this document, please feel free to contact me (see details below):

Principal investigator:	Mrs Ensa Johnson (B Prim Ed: Senior Primary, BA Hons:AAC [Cum Laude], MA:AAC [Cum Laude])
Contact details:	[redacted] ensa.johnson@up.ac.za (email address)
Project supervisor	Prof. Juan Bornman, Director, Centre for AAC, University of Pretoria
Contact details:	juan.bornman@up.ac.za (email address)

We trust that you will agree on the importance of this research project to support children with little or no functional speech and would appreciative your willingness to approve the participation of your child in this research project.

Kind regards

EJohnson.

Mrs Ensa Johnson
Researcher

Prof. Juan Bornman
Supervisor

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
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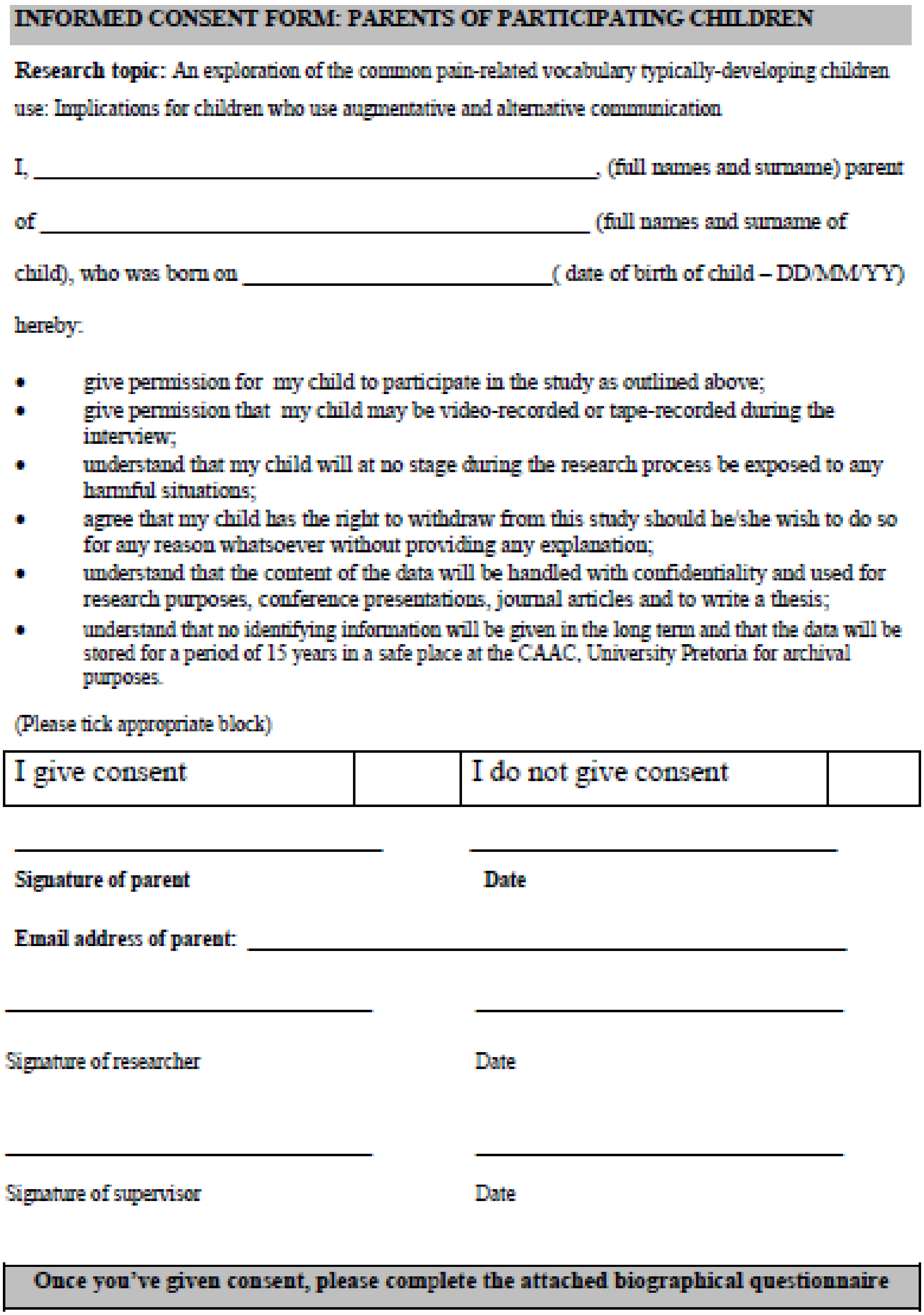


INFORMED CONSENT FORM: PARENTS OF PARTICIPATING CHILDREN

Research topic: An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use augmentative and alternative communication

I, ____, (full names and surname) parent

of ____ (full names and surname of

child), who was born on ______________________(date of birth of child – DD/MM/YY)

hereby:

- give permission for my child to participate in the study as outlined above;
- give permission that my child may be video-recorded or tape-recorded during the interview;
- understand that my child will at no stage during the research process be exposed to any harmful situations;
- agree that my child has the right to withdraw from this study should he/she wish to do so for any reason whatsoever without providing any explanation;
- understand that the content of the data will be handled with confidentiality and used for research purposes, conference presentations, journal articles and to write a thesis;
- understand that no identifying information will be given in the long term and that the data will be stored for a period of 15 years in a safe place at the CAAC, University Pretoria for archival purposes.

(Please tick appropriate block)

I give consent		I do not give consent	

__________________________ __________________________

Signature of parent **Date**

Email address of parent: ____

__________________________ __________________________

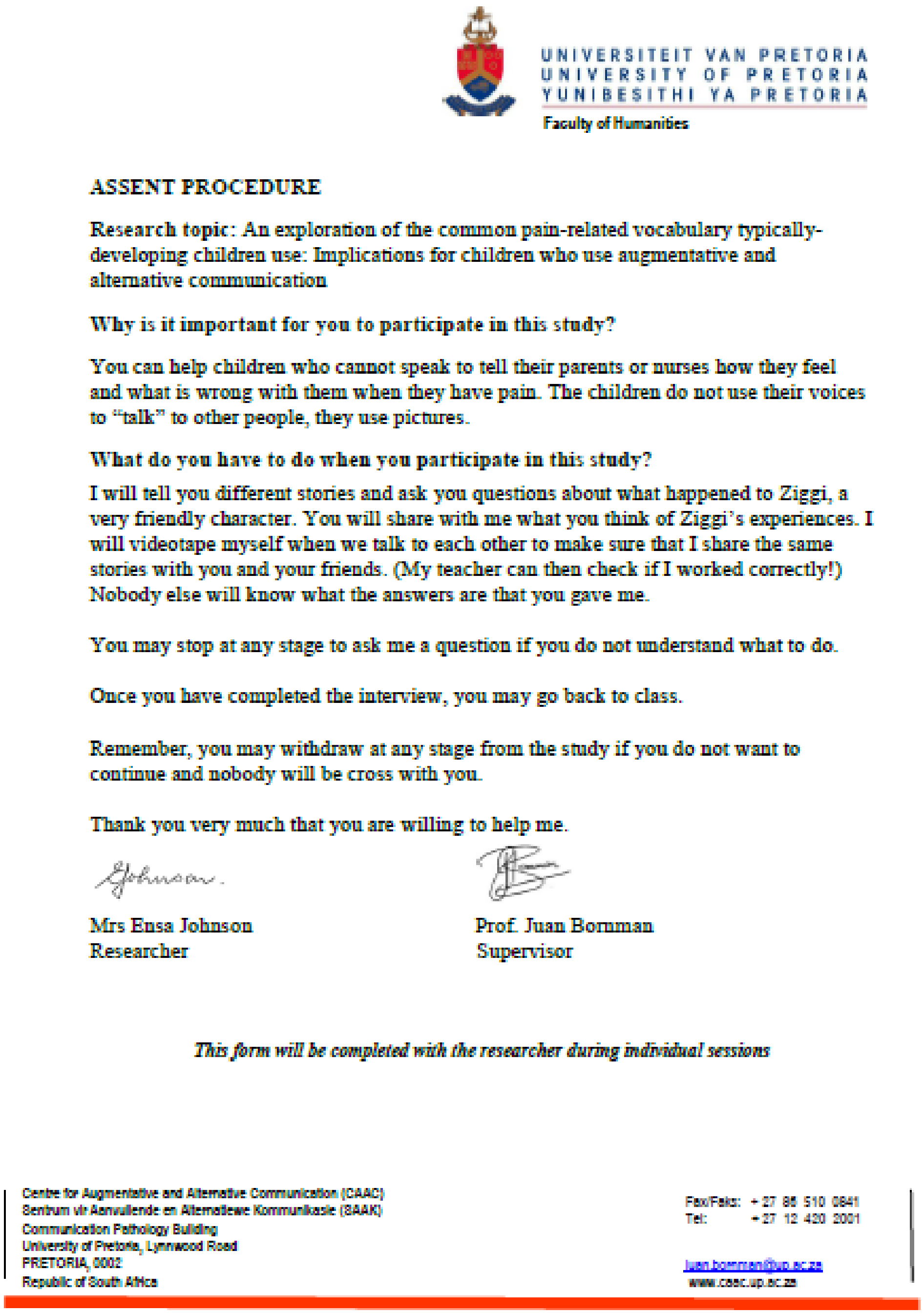
Signature of researcher Date

__________________________ __________________________

Signature of supervisor Date

Once you've given consent, please complete the attached biographical questionnaire

APPENDIX G: Assent letter and form children – Phases 1, 2, and 3



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Faculty of Humanities

ASSENT PROCEDURE

Research topic: An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use augmentative and alternative communication

Why is it important for you to participate in this study?

You can help children who cannot speak to tell their parents or nurses how they feel and what is wrong with them when they have pain. The children do not use their voices to "talk" to other people, they use pictures.

What do you have to do when you participate in this study?

I will tell you different stories and ask you questions about what happened to Ziggi, a very friendly character. You will share with me what you think of Ziggi's experiences. I will videotape myself when we talk to each other to make sure that I share the same stories with you and your friends. (My teacher can then check if I worked correctly!) Nobody else will know what the answers are that you gave me.

You may stop at any stage to ask me a question if you do not understand what to do.

Once you have completed the interview, you may go back to class.

Remember, you may withdraw at any stage from the study if you do not want to continue and nobody will be cross with you.

Thank you very much that you are willing to help me.

Johnson.

Mrs Ensa Johnson
Researcher

Prof. Juan Bornman
Supervisor

This form will be completed with the researcher during individual sessions

Centre for Augmentative and Alternative Communication (CAAC)
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Republic of South Africa

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Tel: +27 12 420 2001

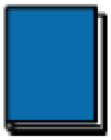
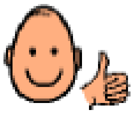
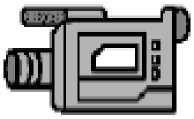
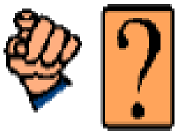
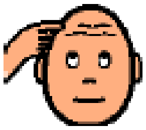
juan.bornman@up.ac.za
www.caac.up.ac.za

CHILD ASSENT FORM

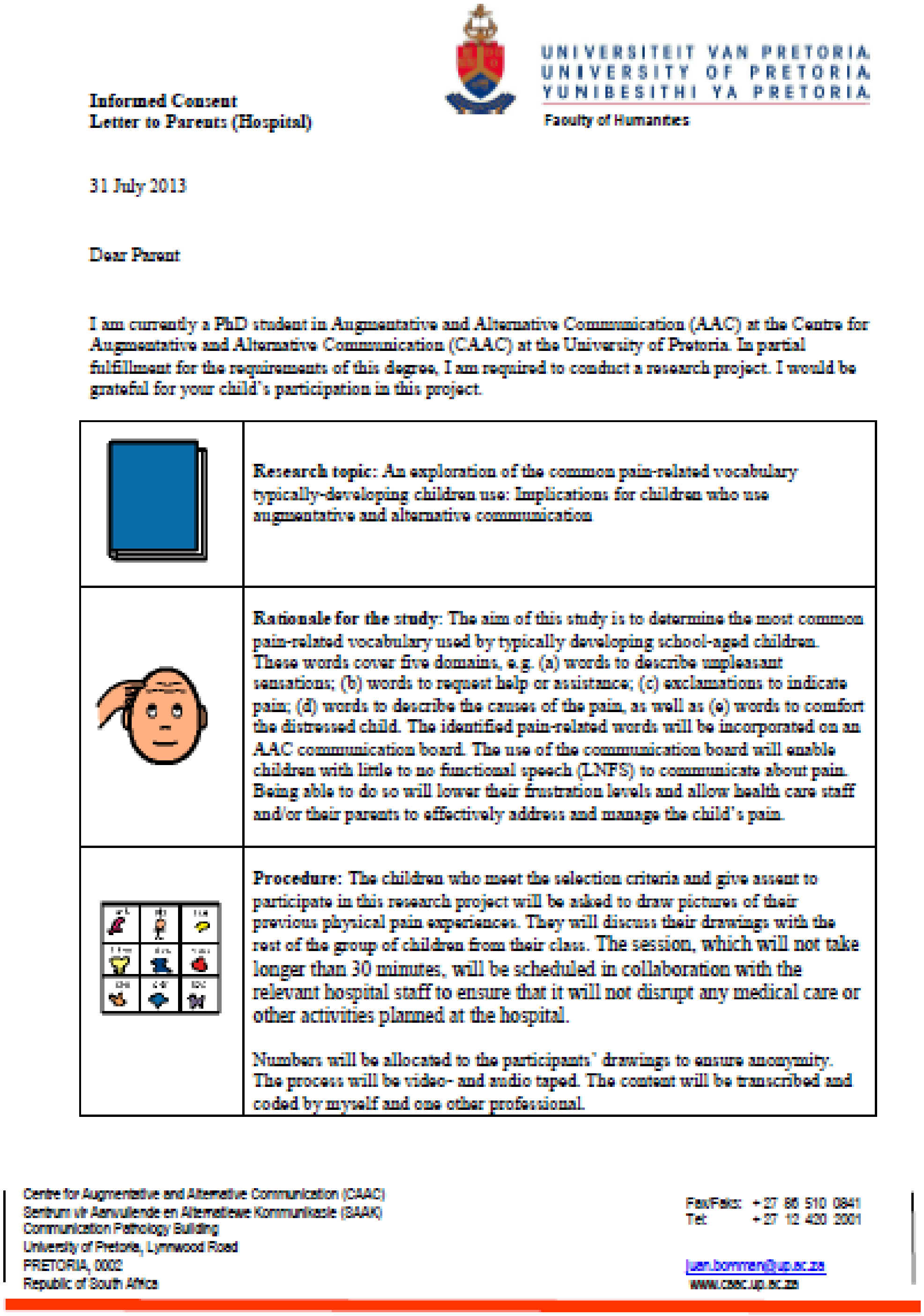
Date: ____

Name of child: ______________________________ Age: ________

Make a tick next to the one that you choose:

	Did somebody read the letter to you and explain to you what you will have to do today?		
	Yes	**Unsure**	**No**
	Do you understand that you may choose to help me?		
	Yes	**Unsure**	**No**
	Do you understand that you may stop when you want to?		
	Yes	**Unsure**	**No**
	Will you allow me to video record you?		
	Yes	**Unsure**	**No**
	Do you have any questions to ask me?		
	Yes	**Unsure**	**No**
	Do you understand what I explained to you?		
	Yes	**Unsure**	**No**
	Would you like to help me today?		
	Yes	**Unsure**	**No**

APPENDIX H: Consent letter and form parents (hospital) – Phase 1



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

Informed Consent
Letter to Parents (Hospital)

31 July 2013

Dear Parent

I am currently a PhD student in Augmentative and Alternative Communication (AAC) at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfillment for the requirements of this degree, I am required to conduct a research project. I would be grateful for your child's participation in this project.

Research topic: An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use augmentative and alternative communication

Rationale for the study: The aim of this study is to determine the most common pain-related vocabulary used by typically developing school-aged children. These words cover five domains, e.g. (a) words to describe unpleasant sensations; (b) words to request help or assistance; (c) exclamations to indicate pain; (d) words to describe the causes of the pain, as well as (e) words to comfort the distressed child. The identified pain-related words will be incorporated on an AAC communication board. The use of the communication board will enable children with little to no functional speech (LNFS) to communicate about pain. Being able to do so will lower their frustration levels and allow health care staff and/or their parents to effectively address and manage the child's pain.

Procedure: The children who meet the selection criteria and give assent to participate in this research project will be asked to draw pictures of their previous physical pain experiences. They will discuss their drawings with the rest of the group of children from their class. The session, which will not take longer than 30 minutes, will be scheduled in collaboration with the relevant hospital staff to ensure that it will not disrupt any medical care or other activities planned at the hospital.

Numbers will be allocated to the participants' drawings to ensure anonymity. The process will be video- and audio taped. The content will be transcribed and coded by myself and one other professional.

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
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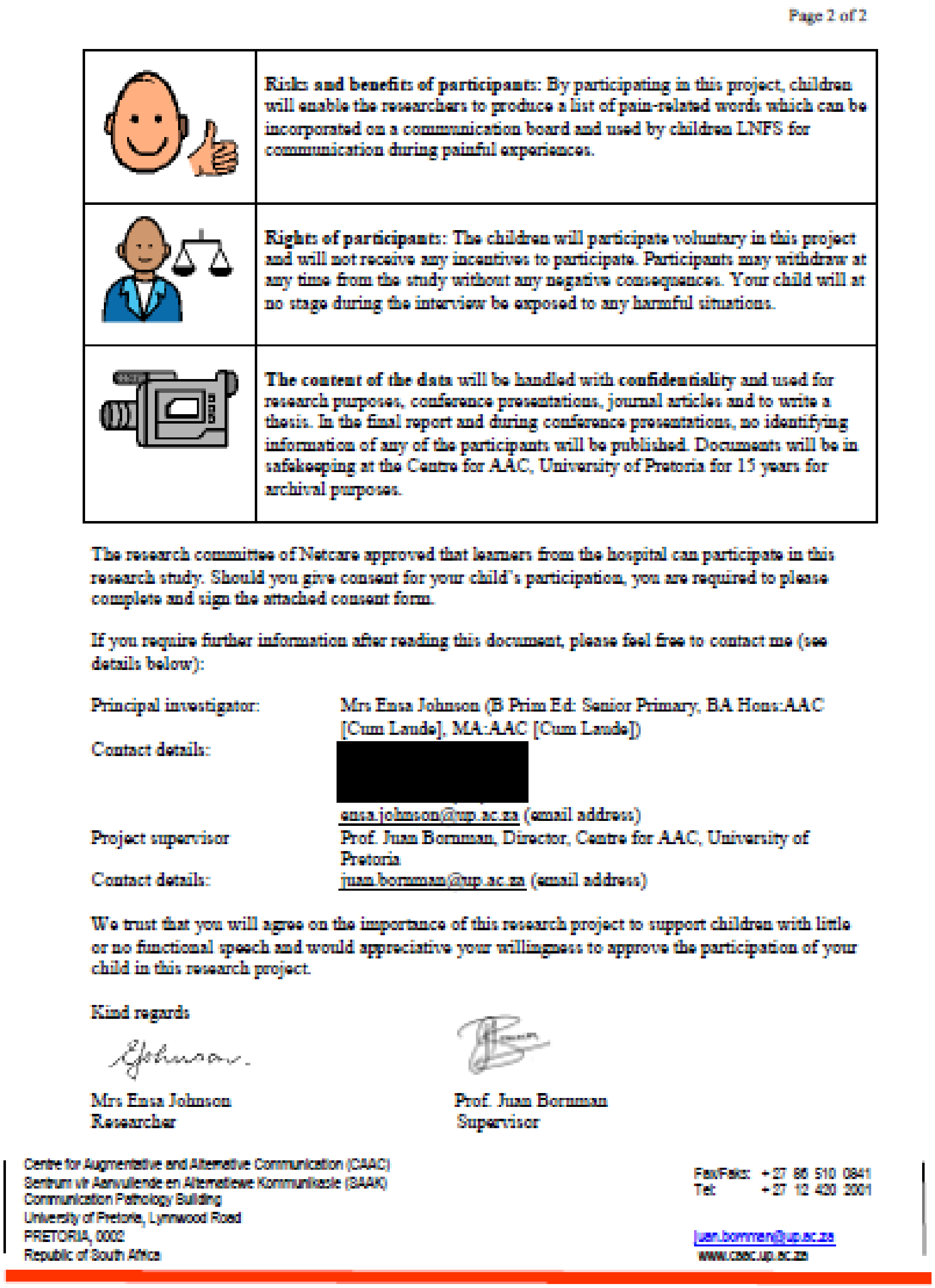

Page 2 of 2

	Risks and benefits of participants: By participating in this project, children will enable the researchers to produce a list of pain-related words which can be incorporated on a communication board and used by children LNFS for communication during painful experiences.
	Rights of participants: The children will participate voluntary in this project and will not receive any incentives to participate. Participants may withdraw at any time from the study without any negative consequences. Your child will at no stage during the interview be exposed to any harmful situations.
	The content of the data will be handled with confidentiality and used for research purposes, conference presentations, journal articles and to write a thesis. In the final report and during conference presentations, no identifying information of any of the participants will be published. Documents will be in safekeeping at the Centre for AAC, University of Pretoria for 15 years for archival purposes.

The research committee of Netcare approved that learners from the hospital can participate in this research study. Should you give consent for your child's participation, you are required to please complete and sign the attached consent form.

If you require further information after reading this document, please feel free to contact me (see details below):

Principal investigator:	Mrs Ensa Johnson (B Prim Ed: Senior Primary, BA Hons:AAC [Cum Laude], MA:AAC [Cum Laude])
Contact details:	[redacted] ensa.johnson@up.ac.za (email address)
Project supervisor	Prof. Juan Bornman, Director, Centre for AAC, University of Pretoria
Contact details:	juan.bornman@up.ac.za (email address)

We trust that you will agree on the importance of this research project to support children with little or no functional speech and would appreciative your willingness to approve the participation of your child in this research project.

Kind regards

EJohnson.

Mrs Ensa Johnson
Researcher

Prof. Juan Bornman
Supervisor

Centre for Augmentative and Alternative Communication (CAAC)
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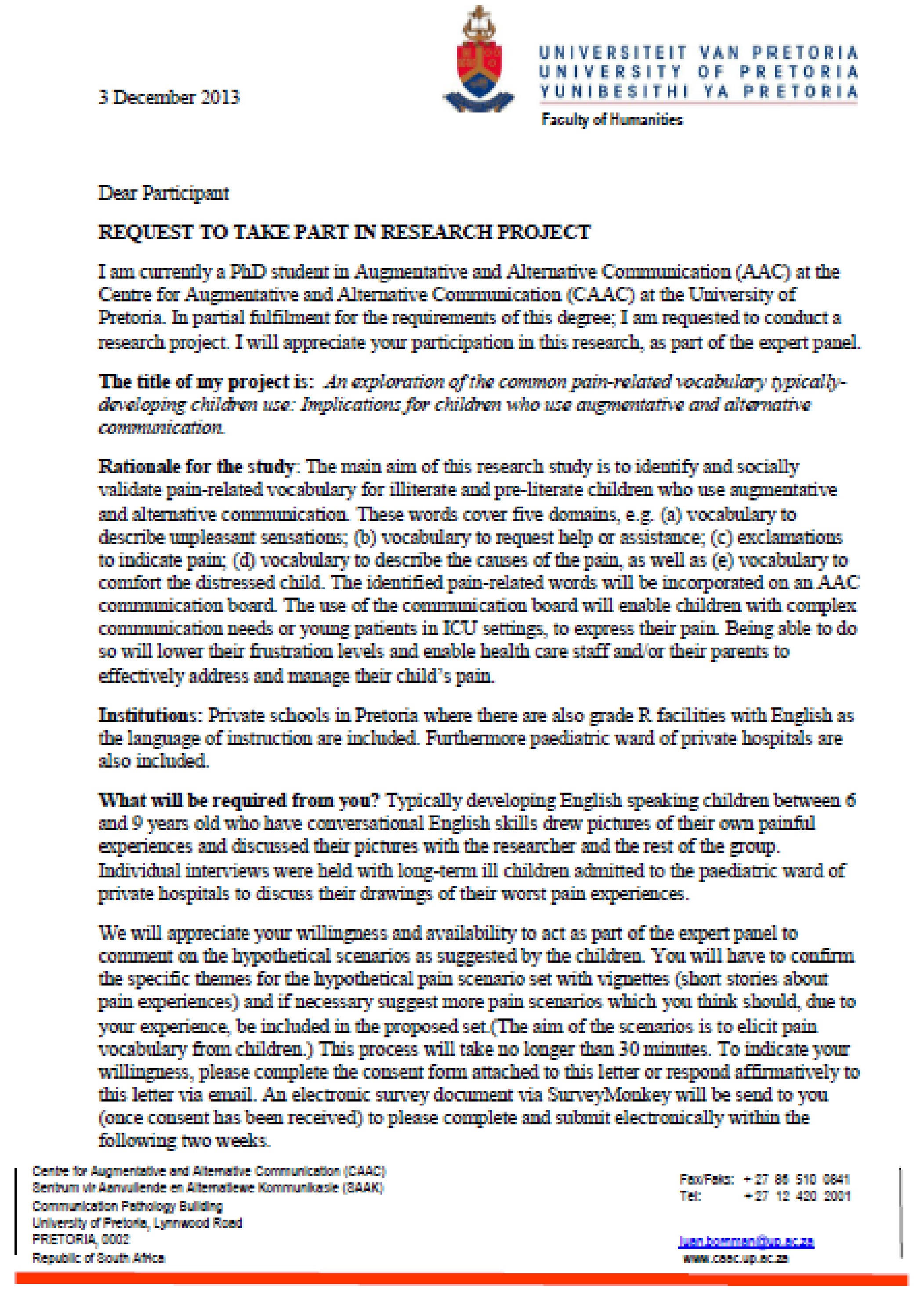
APPENDIX I: Consent letter and form expert panel



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

3 December 2013

Dear Participant

REQUEST TO TAKE PART IN RESEARCH PROJECT

I am currently a PhD student in Augmentative and Alternative Communication (AAC) at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfilment for the requirements of this degree; I am requested to conduct a research project. I will appreciate your participation in this research, as part of the expert panel.

The title of my project is: *An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use augmentative and alternative communication.*

Rationale for the study: The main aim of this research study is to identify and socially validate pain-related vocabulary for illiterate and pre-literate children who use augmentative and alternative communication. These words cover five domains, e.g. (a) vocabulary to describe unpleasant sensations; (b) vocabulary to request help or assistance; (c) exclamations to indicate pain; (d) vocabulary to describe the causes of the pain, as well as (e) vocabulary to comfort the distressed child. The identified pain-related words will be incorporated on an AAC communication board. The use of the communication board will enable children with complex communication needs or young patients in ICU settings, to express their pain. Being able to do so will lower their frustration levels and enable health care staff and/or their parents to effectively address and manage their child's pain.

Institutions: Private schools in Pretoria where there are also grade R facilities with English as the language of instruction are included. Furthermore paediatric ward of private hospitals are also included.

What will be required from you? Typically developing English speaking children between 6 and 9 years old who have conversational English skills drew pictures of their own painful experiences and discussed their pictures with the researcher and the rest of the group. Individual interviews were held with long-term ill children admitted to the paediatric ward of private hospitals to discuss their drawings of their worst pain experiences.

We will appreciate your willingness and availability to act as part of the expert panel to comment on the hypothetical scenarios as suggested by the children. You will have to confirm the specific themes for the hypothetical pain scenario set with vignettes (short stories about pain experiences) and if necessary suggest more pain scenarios which you think should, due to your experience, be included in the proposed set.(The aim of the scenarios is to elicit pain vocabulary from children.) This process will take no longer than 30 minutes. To indicate your willingness, please complete the consent form attached to this letter or respond affirmatively to this letter via email. An electronic survey document via SurveyMonkey will be send to you (once consent has been received) to please complete and submit electronically within the following two weeks.

Centre for Augmentative and Alternative Communication (CAAC)
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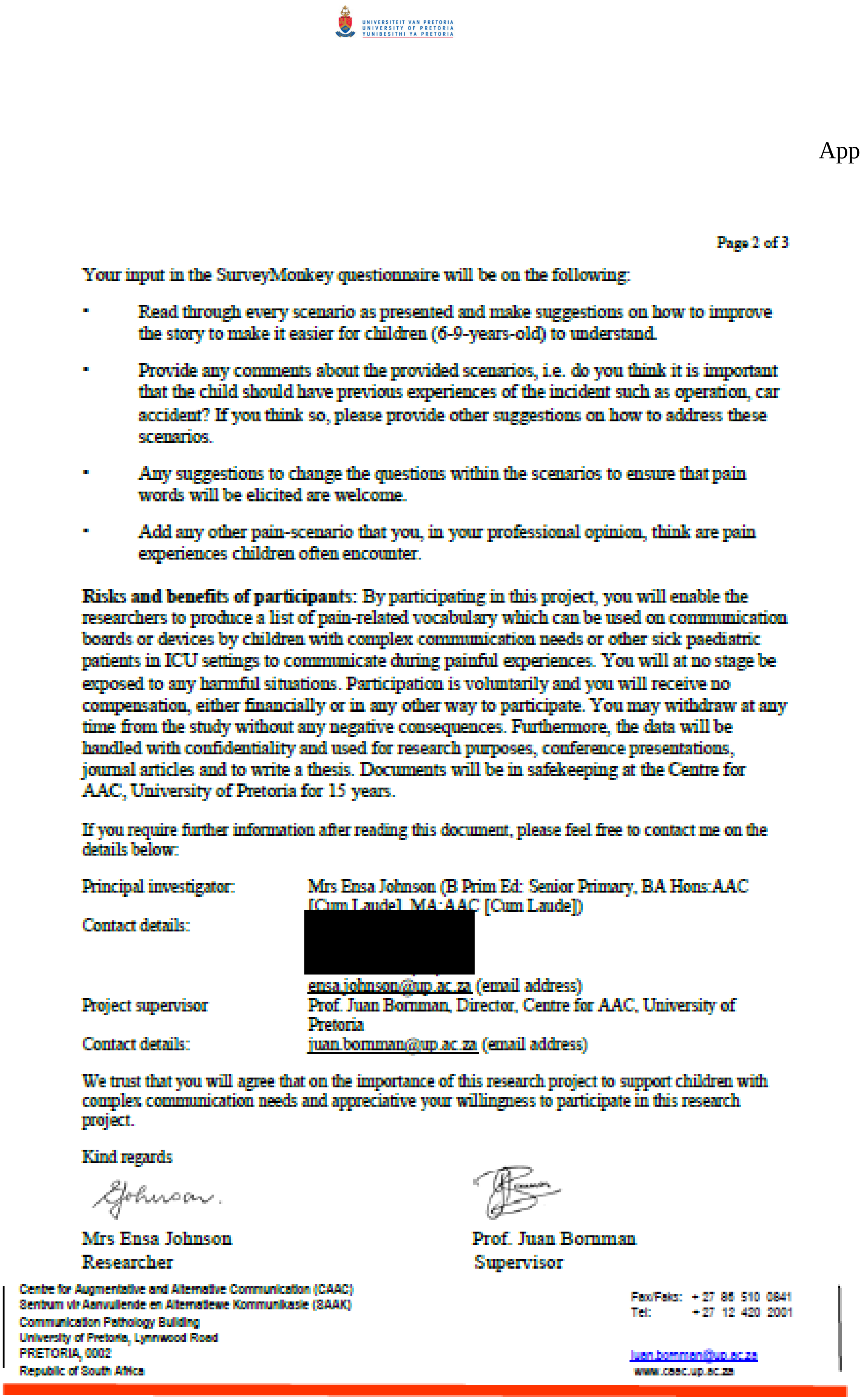

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Page 2 of 3

Your input in the SurveyMonkey questionnaire will be on the following:

- Read through every scenario as presented and make suggestions on how to improve the story to make it easier for children (6-9-years-old) to understand.
- Provide any comments about the provided scenarios, i.e. do you think it is important that the child should have previous experiences of the incident such as operation, car accident? If you think so, please provide other suggestions on how to address these scenarios.
- Any suggestions to change the questions within the scenarios to ensure that pain words will be elicited are welcome.
- Add any other pain-scenario that you, in your professional opinion, think are pain experiences children often encounter.

Risks and benefits of participants: By participating in this project, you will enable the researchers to produce a list of pain-related vocabulary which can be used on communication boards or devices by children with complex communication needs or other sick paediatric patients in ICU settings to communicate during painful experiences. You will at no stage be exposed to any harmful situations. Participation is voluntarily and you will receive no compensation, either financially or in any other way to participate. You may withdraw at any time from the study without any negative consequences. Furthermore, the data will be handled with confidentiality and used for research purposes, conference presentations, journal articles and to write a thesis. Documents will be in safekeeping at the Centre for AAC, University of Pretoria for 15 years.

If you require further information after reading this document, please feel free to contact me on the details below:

Principal investigator:	Mrs Ensa Johnson (B Prim Ed: Senior Primary, BA Hons:AAC [Cum Laude], MA:AAC [Cum Laude])
Contact details:	[redacted] ensa.johnson@up.ac.za (email address)
Project supervisor	Prof. Juan Bornman, Director, Centre for AAC, University of Pretoria
Contact details:	juan.bornman@up.ac.za (email address)

We trust that you will agree that on the importance of this research project to support children with complex communication needs and appreciative your willingness to participate in this research project.

Kind regards

Johnson.

Mrs Ensa Johnson
Researcher

Prof. Juan Bornman
Supervisor

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INFORMED CONSENT FORM: PROFESSIONAL: EXPERT PANEL1

Research topic: An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use AAC

I, ____(full names and surname), hereby confirm that I am a professional working with children on a continuous basis and give consent to the following:

- Agree that I will voluntary participate in the study as outlined above and that I have the freedom of choice to participate or not.
- I understand that there are no risks for me to participate in this study.
- I understand that I have the right to withdraw from this study should I wish to do so for any reason whatsoever without providing any explanation
- I understand that there is no direct benefit or financial gain when participating in this research. However, information collected will ensure that children with little or no functional speech can also have a way to communicate their pain and discomfort.
- I understand that the data will be handled with utmost confidentiality and will be used for research purposes, conference presentations, journal articles and to write a thesis. The data will be stored for a period of 15 years in a safe place at the CAAC, University Pretoria.

(Please tick appropriate block)

I give consent		I do not give consent	

_________________________________ _________________________________
Signature of professional Date

_________________________________ _________________________________
Signature of researcher Date

_________________________________ _________________________________
Signature of supervisor Date

ONCE YOU'VE GIVEN CONSENT, PLEASE COMPLETE THE ATTACHED BIOGRAPHICAL QUESTIONNAIRE

APPENDIX J: Questionnaire (Expert Panel)

BIOGRAPHICAL QUESTIONNAIRE

No ProEP1-______

For office use only

PLEASE ANSWER ALL THE QUESTIONS.

Please answer each of the following questions by selection the option deemed most appropriate or according to the specified instructions.

Thank you for your time taking to respond.

1. What is your current profession?

Child Life Specialist	Medical doctor	Nurse/Sister	Occupational Therapist
Psychologist	Social Worker/Medical Social Worker	Speech Therapist/Speech Language Pathologist	Physiotherapist
Teacher (Pre-school: 3-6-year-olds)	Teacher (Foundation phase: 7-9-year-olds)	Teacher (Senior phase: 10-12-year-olds)	

2. What is your current work setting?

Private Hospital	Public Hospital	Private School	Public School
Private Practice	Private clinic	Public clinic	Rehabilitation Centre
Other, please specify.			

3. What is your gender?

Female	Male

4. What is your first language?

Afrikaans	English	isiNdebele	isiXhosa
isiZulu	Sesotho sa Loboa	Sesotho	Setswana
siSwati	Tshivenda	Xitsonga	Other, please specify

5. What other languages do you speak?

Afrikaans	English	isiNdebele	isiXhosa
isiZulu	Sesotho sa Loboa	Sesotho	Setswana
siSwati	Tshivenda	Xitsonga	Other, please specify

6. What is your nationality?

RSA citizen	Other, please specify

7. What is your age? ____

8. How many years experience do you have working with children? _________

9. Are you registered with the hpcsa or any other professional body?

Yes	No

10. If you are registered with the HPCSA or other professional body, please provide your registration number.

____

11. Please mark the appropriate choice regarding your formal employment/self-employment:

Full time	Half day	Few hours a week	Other – please specify

12. What is your highest qualification? (Please specify the exact degree i.e. BEd Hons)

____

13.	Do you have any previous experience with children who cannot speak either due to their illness or as a result of a disability?	Yes	No

If you have any previous experience, please describe how you take care of children who cannot speak either due to their illness of as a result of a disability (ie how do you get input from them on issues such as pain, their needs, etc?)

____

____

____

(Please continue to the following page.)

Dear Participant

Below are the hypothetical pain scenarios as suggested by children themselves. The aim of the scenarios is to elicit pain vocabulary from children. Furthermore, parents and professionals will complete questionnaires based on these scenarios to determine what they think the words will be that children will use when they are in similar scenarios. A cartoon-type character (which does not depict gender or race) will be used as the “main character” in the story. One drawing per scenario (with the main character featuring in each) will be displayed on an iPad when the stories are discussed with the children during in-depth interviews.

Please read through every scenario as presented below and make suggestions that you think will improve the story to make it easier for children (6-9-years-old) to understand.

- Please provide any comments about the provided scenarios, i.e. do you think it is important that the child should have previous experiences of the incident such as operation, car accident? If you think so, please provide other suggestions on how to address the scenario.
- Please add any other pain-scenario that you, in your professional opinion, think are also pain experiences children often encounter.
- Any suggestions to change the questions within the scenarios to ensure that pain words will be elicited would be welcomed. (In some incidences two possible questions are provided – please indicate which one you think would be the best option.)
- You can add your comments in the comment box provided with each scenario.

(Please note: 'A' = name of character (ideas for a name welcome please!); his/her - depends on the gender of the child.)

Table 1.

Pain Scenarios as Suggested By Children.

Original scenarios as suggested by children	**Recommendations by professionals**
Scenario 1 (falls out of a tree) It is holiday time. The sun shines bright and 'A' and his/her friend are playing outside in the garden. They are climbing a tree. Suddenly a branch breaks off and 'A' falls out of the tree. His/her arm is very sore and he cannot move it. His/her friend runs to call 'A's mommy. *Tell me what do you think A will tell his/her mommy about the pain in his/her arm? What will happen now?* He/she is going to the hospital and the doctor takes X rays to see if the arm is broken. What do you think the doctor will find? The arm is broken and the doctor puts a cast on the arm and 'A' feels much better.	
Scenario 2 (falls from bicycle) 'A' is riding bicycle to the shop to buy some sweets. It is a gravel road. The bicycle skids on some sand, and 'A' falls. There is blood all over his/her knees and the palms of his/her hands. *Tell me what do you think 'A' will tell his/her mommy about the pain he/she may have. / Tell me more about the pain 'A' may feel.*	
Scenario 3 (car accident) 'A' is very excited. It is his/her granny's birthday and the family on their way to her birthday party. Suddenly a car skips the robot and crashes into the side of the car where 'A' is sitting. 'A' is full of blood. There are cuts on his/her face and his body hurts –*Tell me about the pain 'A' may have.*	
Scenario 4 (hit by ball) 'A' is so glad to be at a game of his favourite soccer team. So far 'A's team is winning. They have one goal to nil. Suddenly the ball comes directly to 'A'! He/She is too slow to get out of the way of the ball or try to catch it. The ball hits him/her hard and strikes his/her finger. *Tell me what do you think 'A' will tell his/her mommy about the pain he/she may have in his/her finger. / Tell me more about the pain in*	

Original scenarios as suggested by children	**Recommendations by professionals**
A's finger.	
Scenario 5 (thorn bush) It is break time at school. 'A' and his/her friends are playing with a tennis ball. One of the children throws the ball very hard. 'A' runs to catch it while keeping his/her eyes on the ball. Oh oh – do you see what I am seeing? Yes, there is a thorn bush and 'A' doesn't see it! He/she runs into the thorn bush. The thorns scratch his/her arms and some even get stuck under his/her skin. *Tell me more about the pain that 'A' may have./ Tell me what do you think 'A' will tell his/her teacher about the pain he/she may have.*	
Scenario 6 (burn wound) It is winter and it's freezing cold outside. 'A's daddy lights a fire in the fire place to warms up the room. 'A' wants to warm his/her hands and feet but comes too close to the fire. Oh no, do you also see that small piece of red-hot burning coal on the floor? I hope 'A' sees it... Let's see what happens now... 'A' steps on the small piece of very hot coal and burns his/her foot. *Tell me more about 'A's pain in his/her foot.*	
Scenario 7 (bodily pain) A' is not feeling well today and struggles to work in class. His/her teacher wants him/her to do maths in his/her workbook, but he/she just can't. He/she has a headache, his/her back is sore and his/her stomach aches so much that he/she thinks he/she is going to vomit. *Tell me what you think 'A' would say to you to describe his/her pain.*	
Scenario 8 (operation) 'A' wakes up in his/her hospital bed after the doctor removed his/her tonsils. He/she thought the doctor was going to take the pain in his/her throat away. But still he/she doesn't feel well. *Tell me more about the pain 'A' have.* His/her mommy and the nurses tell him/her that he/she will feel much better after a few spoons of ice cream or jelly...	
Scenario 9 (drip) 'A' is very sick in hospital because the doctor says he/she has an illness that can make other people also sick. 'A' needs to get medicine to make him/her better. The medicine is given to him/her through a drip – this is when a needle is being put into your vein that the medicine can flows directly into your blood. This way 'A' can become better much	

Original scenarios as suggested by children	Recommendations by professionals
faster. The nurse tries to puts a drip in 'A's arm but keeps missing and has to try again and again. It is very sore. Tell me more about the pain 'A' may have. Once the drip is in his vein, the pain is better!	

Please add any other pain experiences that the children you are working with experience often that can be included as another pain scenario in this set:

____

____

Declaration: By returning the completed questionnaire via SurveyMonkey, I give permission that the information may be used for research purposes.

APPENDIX K: HPPS-P

HPPS: QUESTIONNAIRE

Section A

Background information

For office use only

Please answer each of the following questions by selection the option deemed most appropriate or according to the specified instructions.

Thank you for your time taking to respond.

1. What is your relation to the child who will participate in this study? Please mark appropriate block:

Mother	Father	Legal guardian	Other, please specify

2. What is your age? ____

Questions 3,4,7,8,10: please mark the appropriate block

3. What is your relationship status?

In permanent relationship	Single parent

4. What is your home language? ____________________________________

5. What is your highest qualification? ______________________________

6. What is your current occupation? _________________________________

7. Please mark the appropriate block regarding formal employment (including self-employment) :

I work full time	I work part-time	I am a home executive (house wife)	I am not currently working

8. Please indicate if you have a private medical aid or go to a government hospital

Private medical aid	Government hospital

9. How many children do you have? _________________

10.	What is the birth order of your child who is involved in this study?	First born	Second	Third	Fourth	Fifth	

SECTION B

Information on children's pain vocabulary

Please read the statements think about the words you child would say. Try to list at least 2 words per question. Should you feel to use a word more than once, please try to limit repetition of words to the minimum.

SCENARIO 1: Your child falls and hurts him/herself.

1. What would your child say to describe pain?
2. What would your child say to request help or assistance?
3. What exclamations would your child use to express pain?
4. What would your child say to describe the causes of the pain?
5. What would your child say to comfort him/her?

SCENARIO 2: Your child is hit by a ball.

1. What would your child say to describe pain?
2. What would your child say to request help or assistance?
3. What exclamations would your child use to express pain?
4. What would your child say to describe the causes of the pain?
5. What would your child say to comfort him/her?

SCENARIO 3: Your child wakes up after an operation to remove his/her tonsils.

Did your child have a tonsil operation before? If no, please continue with the following question. If yes, please continue with the next scenario on the following page.

1. What would your child say to describe pain?
2. What would your child say to request help or assistance?
3. What exclamations would your child use to express pain?
4. What would your child say to describe the causes of the pain?
5. What would your child say to comfort him/her?

SCENARIO 4: A thorn of splinter gets into a body part of your child (such as his/her foot or hand)

1. What would your child say to describe pain?

2. What would your child say to request help or assistance?
3. What exclamations would your child use to express pain?
4. What would your child say to describe the causes of the pain?
5. What would your child say to comfort him/her?

SCENARIO 5: Your child has a bodily pain such as head- or stomach ache.

1. What would your child say to describe pain?
2. What would your child say to request help or assistance?
3. What exclamations would your child use to express pain?
4. What would your child say to describe the causes of the pain?
5. What would your child say to comfort him/her?

SCENARIO 6: Your child burns him/her.

1. What would your child say to describe pain?
2. What would your child say to request help or assistance?
3. What exclamations would your child use to express pain?
4. What would your child say to describe the causes of the pain?
5. What would your child say to comfort him/her?

SCENARIO 7: A bee stings him/her.

1. What would your child say to describe pain?
2. What would your child say to request help or assistance?
3. What exclamations would your child use to express pain?
4. What would your child say to describe the causes of the pain?
5. What would your child say to comfort him/her?

SCENARIO 8: Your child gets an injection or drip.

1. What would your child say to describe pain?
2. What would your child say to request help or assistance?
3. What exclamations would your child use to express pain?
4. What would your child say to describe the causes of the pain?
5. What would your child say to comfort him/her?

Note: This questionnaire (HPPS-P) was made available online via SurveyMonkey®.

APPENDIX L: HPPS-T

HPPS-T: QUESTIONNAIRE

SECTION A

BACKGROUND INFORMATION

PLEASE ANSWER ALL THE QUESTIONS.

Please answer all the questions. Tick the appropriate answer.

Thank you for your time.

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1.	Where do you currently teach?	Government school	Private school	
2.	What grade do you teach	Gr 1	Gr 3	
3.	What is your gender?	Female	Male	

4.	What is your home language(s)?	English	Afrikaans	Both English and Afrikaans	Other, please specify:	

5. In which other languages can you conduct a conversation?

- ☐ Afrikaans
- ☐ English
- ☐ isiNdebele
- ☐ isiXhosa
- ☐ isiZulu
- ☐ Sesotho sa loboa

☐ Sesotho
☐ Setswana
☐ SiSwati
☐ Tshivenda
☐ Xitsonga
☐ Other, please specify: ____

6. What is your nationality?

RSA citizen	Other, please specify

7. What is your age? ____

8. How many total years experience do you have working as a teacher? ___________

9. How many years experience do you have working with learners this specific age?
____

10. Please list all your teaching qualifications
____

11. Are you a parent of a child/children between the ages of 6- and 9 years?

Yes	No

12. Please note that you also have to complete Section B of this questionnaire.

SECTION B

Information on learner’s pain vocabulary as reported by their teachers

Please read the 5 scenarios and think about the words learners in your class would say/use. Try to list at least 2 words per question. It is quite possible that some words might be repeated across scenarios.

SCENARIO 1: The learner falls and hurts him/herself.

1. What would the learner say to describe pain?

2. What would the learner say to request help or assistance?

3. What exclamations would the learner use to express pain?

4. What would the learner say to describe the causes of the pain?

5. What would the learner say to comfort himself/herself?

SCENARIO 2: The learner is hit by a ball.

1. What would the learner say to describe pain?

2. What would the learner say to request help or assistance?

3. What exclamations would the learner use to express pain?

4. What would the learner say to describe the causes of the pain?

5. What would the learner say to comfort himself/herself?

SCENARIO 3: A thorn of splinter gets into a body part of the learner (such as his/her foot or hand)

1. What would the learner say to describe pain?

2. What would the learner say to request help or assistance?

3. What exclamations would the learner use to express pain?

4. What would the learner say to describe the causes of the pain?

5. What would the learner say to comfort himself/herself?

SCENARIO 4: The learner has a bodily pain such as head- or stomach ache.

1. What would the learner say to describe pain?

2. What would the learner say to request help or assistance?

3. What exclamations would the learner use to express pain?

4. What would the learner say to describe the causes of the pain?

5. What would the learner say to comfort himself/herself?

SCENARIO 5: A bee stings the learner.

1. What would the learner say to describe pain?

2. What would the learner say to request help or assistance?

3. What exclamations would the learner use to express pain?

4. What would the learner say to describe the causes of the pain?

5. What would the learner say to comfort himself/herself?

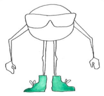
Declaration: by returning the completed biographical questionnaire, i give permission that the information may be used for research purposes. I understand that all data will be treated confidentially.

You are welcome to contact the researcher at any time for further information.
Thank you for your participation and completion of this biographical questionnaire.

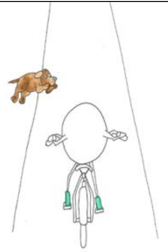
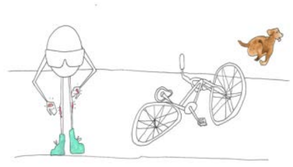
Ensa Johnson (ensa.johnson@up.ac.za / [redacted]

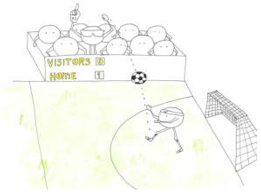
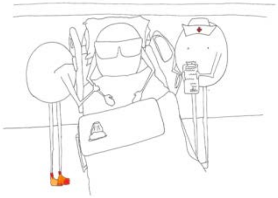
Centre for Augmentative and Alternative Communication, University of Pretoria

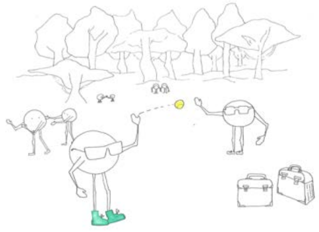
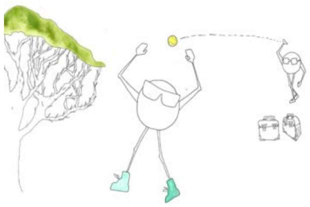
APPENDIX M: Scripted interview guide for HPPS-C

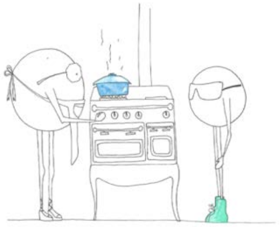
Welcome	• Set participant at ease	✓ *Thank you that you are willing to talk to me.*
	• Introduce yourself.	✓ *Hello, my name is Ensa. What is your name? [child answers] Do you know that I am also still learning like you do?*
	• Get informed assent	✓ *Now I need you to help me to help children who cannot speak how to tell us how they feel when they are hurt/when they have pain. I will share some stories with you and then we will talk about it. Would you like to help me? [ ] If so, let us quickly complete the following [Complete child assent form] (If the child is not willing to give assent, the interview will stop here.)*
	• To test the participant's language ability	✓ *Now we will quickly talk about the pictures in this little booklet (Do the PPVT as indicated in the guidelines for the test)*
	• To introduce the character in the vignettes of the set of hypothetical physical pain scenarios	 *This is Ziggi. Today we will hear a lot of stories about Ziggi. Ziggi goes to many interesting places and some strange things happen to Ziggi. But poor Ziggi, he/she always seems to get hurt… but wait… I don't want to let out any secrets! Are you aready to hear about Ziggi's first advaneture?*
Discussion	The researcher will follow the script of the vignettes in the set of hypothetical physical pain-scenarios while showing the illustrations on the iPad.	

Story grammar structure	Story	Illustration on iPad
Title	**Scenario 1** (Ziggi falls out of a tree).	 
Setting (Where and when)	It is holiday time. The sun shines bright.	
Initiating event	Ziggi and his/her friend play outside in the garden. They climb a tree	
Problem	Suddenly a branch breaks off. Ziggi falls out of the tree. His/her arm is very sore and swollen. He/she cannot move his/her arm.	
Plan or attempts	Ziggi's mommy comes to help.	
Questions	What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) What would Ziggi say to her mommy about her hurt? What would Ziggi say or do to make it better? What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?)	

		Has something like this – falling from a tree or something else - ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)	
	Title	**Scenario 2** (Ziggi falls from his/her bicycle)	 
	Setting (Where and when)	Ziggi rides his/her bicycle.	
	Initiating event	She wants to buy some sweets at the shop.	
	Problem	A dog runs across the road.	
	Plan or attempts	Ziggi wants to brake. He/she pulls the brakes too hard. Ziggi falls.	
	Question	1. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) 2. What would Ziggi say to her mommy about her hurt? 3. What would Ziggi say or do to make it better? 4. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?) **5.** Has something like this – falling from a bicycle - ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)	
	Title	**Scenario 3** (Ziggi is involved in a car accident)	 
	Setting (Where and when)	It is his/her granny's birthday. Ziggi is very excited.	
	Initiating event	The family is in their car, on their way to the birthday party.	
	Problem	Suddenly a big truck skips the robot. It crashes into the side of the car where Ziggi is sitting.	
	Plan or attempts	His/her whole body hurts.	
	Questions	1. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) 2. What would Ziggi say to her mommy about her hurt? 3. What would Ziggi say or do to make it better? 4. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?)	

		5. Has something like this – being in a car accident – ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)	
	Title	**Scenario 4** (Ziggi is hit by a ball)	 
	Setting (Where and when)	Ziggi's is very happy to be at a the soccer game.	
	Initiating event	His/her favourite team is playing – and guess what? They are winning! They have one goal to zero.	
	Problem	Suddenly the ball comes directly to Ziggi'!	
	Plan or attempts	He/She is too slow to get out of the ball's way. He/she can't even catch it! The ball hits him/her hard on his/her finger.	
	Questions	1. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) 2. What would Ziggi say to her mommy about her hurt? 3. What would Ziggi say or do to make it better? 4. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?) **5.** Has something like this – being hit by a ball – ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)	
	Title	**Scenario 5** (Ziggi had an operation)	
	Setting (Where and when)	Ziggi wakes up in his/her hospital bed.	
	Initiating event	The doctor removed his/her tonsils.	
	Problem	He/she doesn't feel well.	
	Plan or attempts	He/She struggles to speak to his/her mommy.	
	Questions	1. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) 2. What would Ziggi say to her mommy about her hurt? 3. What would Ziggi say or do to make it better?	

		4. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?) **5.** Has something like this – getting an operation - ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)	
	Title	**Scenario 6** (Ziggi runs into a thorn bush)win	  
	Setting (Where and when)	It is break time at school. Ziggi and his/her friends are playing "catch" with a tennis ball.	
	Initiating event	Someone throws the ball very hard. Ziggi runs to catch it and keeps his/her eyes on the ball the whole time.	
	Problem	Ziggi does not see the thorn tree! He/she runs into a branch of a thorn tree. The thorns scratch his/her arms and some even get stuck under his/her skin.	
	Plan or attempts		
	Questions	1. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) 2. What would Ziggi say to her mommy about her hurt? 3. What would Ziggi say or do to make it better? 4. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?) **5.** Has something like this - when a thorn or splinter got stuck in your skin - ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)	
	Title	**Scenario 7** (Ziggi has a headache - bodily pain)	
	Setting (Where and when)	Ziggi struggles to do his work in class. He/she is really not feeling well	
	Initiating event	His/her teacher wants him/her to work in his/her books. He/she just can't.	

	Problem	He/she has a headache, He/she wants to vomit.	
	Plan or attempts	He/she walks to the teacher.	
	Questions	1. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) 2. What would Ziggi say to her mommy about her hurt? 3. What would Ziggi say or do to make it better? 4. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?) **5.** Has something like this – a headache – ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)	
	Title	**Scenario 8** (Ziggi gets a burn wound)	 
	Setting (Where and when)	Ziggi's mommy cooks supper.	
	Initiating event	Ziggi is very hungry. He/she wants to look in the pot to see what they will eat tonight.	
	Problem	When he/she lifts the lid, the warm lid burns him/her hand .	
	Plan or attempts	He/she drops the lid and see the blister on his hand??	
	Questions	1. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) 2. What would Ziggi say to her mommy about her hurt? 3. What would Ziggi say or do to make it better? 4. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?) **5.** Has something like this – a burn wound - ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)	
	Title	**Scenario 9** (Ziggi is stung by a bee!)	
	Setting (Where and when)	It is a hot summers day.	
	Initiating event	Ziggi drinks cold drink from a can. Suddenly a bee stings him/her.	
	Problem	She does not see the bee! Suddenly the bee stings her on the lip.	

	Plan or attempts	n.a.	
	Questions	1. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) 2. What would Ziggi say to her mommy about her hurt? 3. What would Ziggi say or do to make it better? 4. What do you think will happen next in this story ? (Prompting question: If you would like to end this story, how will it end?) **5.** Has something like –a bee sting - ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)	
	Title	**Scenario 10** (Ziggi gets a drip)	
	Setting (Where and when)	Ziggi is very sick in hospital.	
	Initiating event	Ziggi needs medicine to make him/her better. The medicine is given to him/her through a drip – They have to put a thin needle in his/her arm to get the medicine in his/her body.	
	Problem	The nurse tries to puts a drip in Ziggi's arm. She keeps missing the vein where she has to put the needle in.	
	Plan or attempts	She has to try again and again.	
	Questions	1. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) 2. What would Ziggi say to her mommy about her hurt? 3. What would Ziggi say or do to make it better? 4. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?) **5.** Has something like this such a getting a drip or injection ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)	
Closing the session	Don't you think that Ziggi has had enough pain now? Shame, he/she really had a few bad experiences! I think Ziggi and you deserve a sticker now! Thank you very much for helping me to help children who cannot speak.		

APPENDIX N: Procedural checklist

Name of child: ____________________________Participant number: _________________

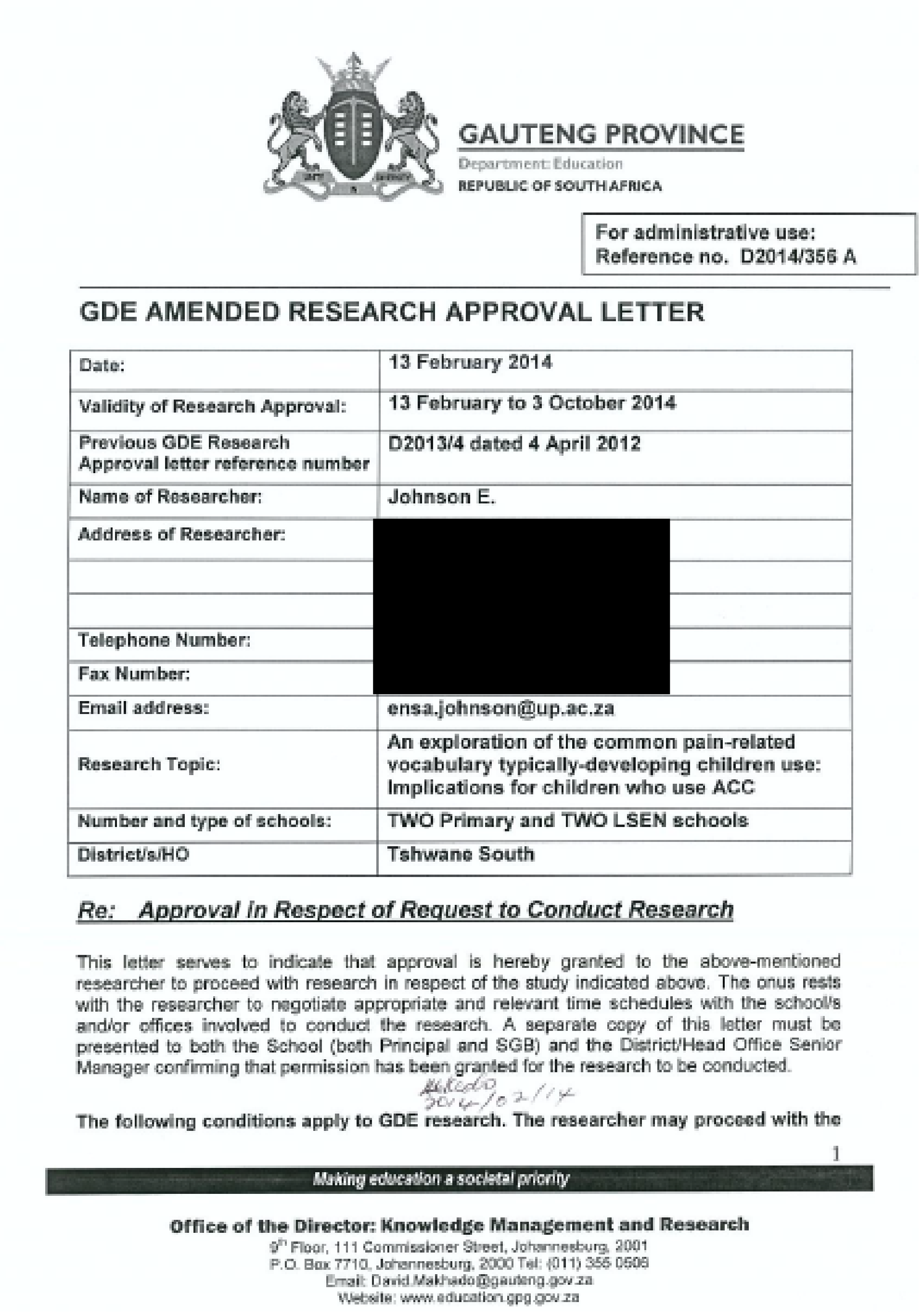
	Procedure	Completed Yes/No	For office use only
Welcome	- Set participant at ease		1
	- Researcher introduces herself to participant.		2
	- Explains to participant what he/she will do during the interview.		3
	- Get informed assent from child (Child completes child assent form).		4
	- Conduct PPVT as indicated in guidelines for the test		5
	- Researcher introduces the character, Ziggi who are in all the hypothetical pain scenarios to the participant.		6
Discussion	The researcher follows the script of the hypothetical pain-scenarios while showing the illustrations on the iPad.		
	Story		
	Scenario 1 (Ziggi falls out of a tree).		7
	Researcher introduces story		8
	Illustration on iPad or laptop visible to the child		9
	Child attends to story		10
	What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.)		11
	What would Ziggi say to her mommy about her hurt?		12
	What would Ziggi say or do to make it better?		13
	What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?)		14
	Has something like this – falling from a tree or something else - ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)		15
	Scenario 2 (Ziggi falls from his/her bicycle)		16
	Researcher introduces story		17
	Illustration on iPad or laptop visible to the child		18
	Child attends to story		19
	6. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.)		20
	7. What would Ziggi say to her mommy about her hurt?		21
	8. What would Ziggi say or do to make it better?		22
	9. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?)		23
	10. Has something like this – falling from a bicycle - ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)		24
	Scenario 3 (Ziggi is involved in a car accident)		25

	Procedure	**Completed Yes/No**	**For office use only**
	Researcher introduces story		26
	Illustration on iPad or laptop visible to the child		27
	Child attends to story		28
	6. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.)		29
	7. What would Ziggi say to her mommy about her hurt?		30
	8. What would Ziggi say or do to make it better?		31
	9. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?)		32
	10. Has something like this – being in a car accident – ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)		33
	Scenario 4 (Ziggi is hit by a ball)		34
	Researcher introduces story		35
	Illustration on iPad or laptop visible to the child		36
	Child attends to story		37
	6. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.)		38
	7. What would Ziggi say to her mommy about her hurt?		39
	8. What would Ziggi say or do to make it better?		40
	9. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?)		41
	10. Has something like this – being hit by a ball – ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)		42
	Scenario 5 (Ziggi had an operation)		43
	Researcher introduces story		44
	Illustration on iPad or laptop visible to the child		45
	Child attends to story		46
	6. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.)		47
	7. What would Ziggi say to her mommy about her hurt? 8. What would Ziggi say or do to make it better?		48
	9. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?)		49
	10. Has something like this – getting an operation - ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)		50
	Scenario 6 (Ziggi runs into a thorn bush)win		51
	Researcher introduces story		52
	Illustration on iPad or laptop visible to the child		53
	Child attends to story		54
	6. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.)		55

	Procedure	Completed Yes/No	For office use only
	7. What would Ziggi say to her mommy about her hurt?		56
	8. What would Ziggi say or do to make it better?		57
	9. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?)		58
	10. Has something like this - when a thorn or splinter got stuck in your skin - ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)		59
	Scenario 7 (Ziggi has a headache - bodily pain)		60
	Researcher introduces story		61
	Illustration on iPad or laptop visible to the child		62
	Child attends to story		63
	6. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.)		64
	7. What would Ziggi say to her mommy about her hurt?		65
	8. What would Ziggi say or do to make it better?		66
	9. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?)		67
	10. Has something like this – a headache – ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)		68
	Scenario 8 (Ziggi gets a burn wound)		69
	Researcher introduces story		70
	Illustration on iPad or laptop visible to the child		71
	Child attends to story		72
	6. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.)		73
	7. What would Ziggi say to her mommy about her hurt?		74
	8. What would Ziggi say or do to make it better?		75
	9. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?)		76
	10. Has something like this – a burn wound - ever happened to you before? ...Would		77
	11. you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)		78
	Scenario 9 (Ziggi is stung by a bee!)		79
	Researcher introduces story		80
	Illustration on iPad or laptop visible to the child		81
	Child attends to story		82
	6. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.)		83
	7. What would Ziggi say to her mommy about her hurt?		84
	8. What would Ziggi say or do to make it better?		85
	9. What do you think will happen next in this story ? (Prompting question:		86

	Procedure	**Completed Yes/No**	**For office use only**
	If you would like to end this story, how will it end?)		
	10. Has something like –a bee sting - ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)		87
	Scenario 10 (Ziggi gets a drip)		88
	Researcher introduces story		89
	Illustration on iPad or laptop visible to the child		90
	Child attends to story		91
	6. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.)		92
	7. What would Ziggi say to her mommy about her hurt?		93
	8. What would Ziggi say or do to make it better?		94
	9. What do you think will happen next in this story? (Prompting question: If you would like to end this story, how will it end?)		95
	10. Has something like this such a getting a drip or injection ever happened to you before? ...Would you like to tell me more about it? (Prompting questions: How did it feel? What did you do or say to make it better?)		96
Closing the session	Thanks the child for participation and gives sticker of Ziggi as token of appreciation.		97

APPENDIX O: Approval Gauteng Department of Education



GAUTENG PROVINCE
Department: Education
REPUBLIC OF SOUTH AFRICA

For administrative use:
Reference no. D2014/356 A

GDE AMENDED RESEARCH APPROVAL LETTER

Date:	13 February 2014
Validity of Research Approval:	13 February to 3 October 2014
Previous GDE Research Approval letter reference number	D2013/4 dated 4 April 2012
Name of Researcher:	Johnson E.
Address of Researcher:	[redacted]
	[redacted]
	[redacted]
Telephone Number:	[redacted]
Fax Number:	[redacted]
Email address:	ensa.johnson@up.ac.za
Research Topic:	An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use ACC
Number and type of schools:	TWO Primary and TWO LSEN schools
District/s/HO	Tshwane South

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

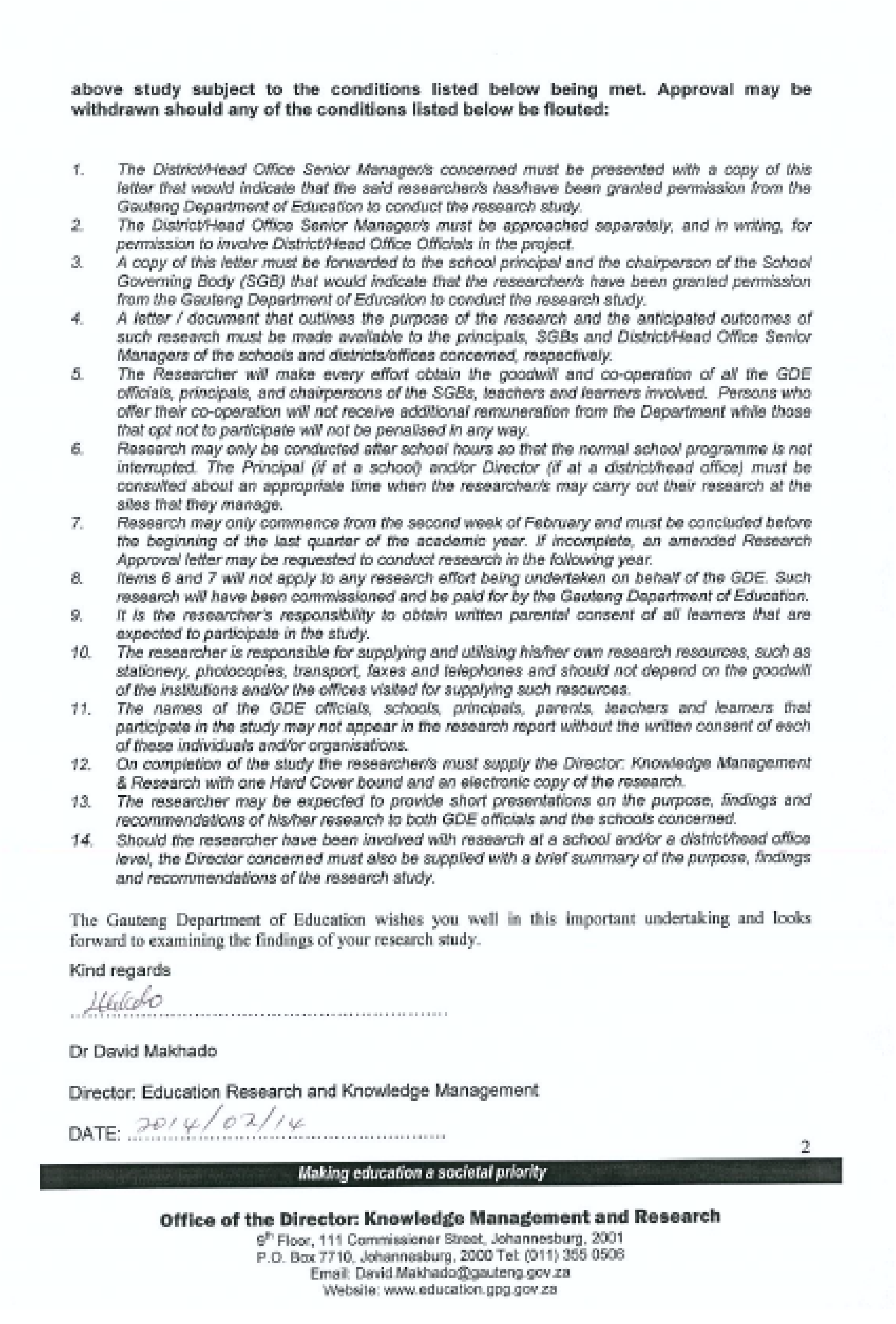
2014/02/14

The following conditions apply to GDE research. The researcher may proceed with the

1

Making education a societal priority

Office of the Director: Knowledge Management and Research
9th Floor, 111 Commissioner Street, Johannesburg, 2001
P.O. Box 7710, Johannesburg, 2000 Tel: (011) 355 0506
Email: David.Makhado@gauteng.gov.za
Website: www.education.gpg.gov.za



above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

1. *The District/Head Office Senior Manager/s concerned must be presented with a copy of this letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study.*
2. *The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.*
3. *A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.*
4. *A letter / document that outlines the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.*
5. *The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.*
6. *Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.*
7. *Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year.*
8. *Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.*
9. *It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.*
10. *The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.*
11. *The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.*
12. *On completion of the study the researcher/s must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.*
13. *The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.*
14. *Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.*

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

....

Dr David Makhado

Director: Education Research and Knowledge Management

DATE: 2014/02/14...

2

Making education a societal priority

Office of the Director: Knowledge Management and Research

9th Floor, 111 Commissioner Street, Johannesburg, 2001
P.O. Box 7710, Johannesburg, 2000 Tel: (011) 355 0506
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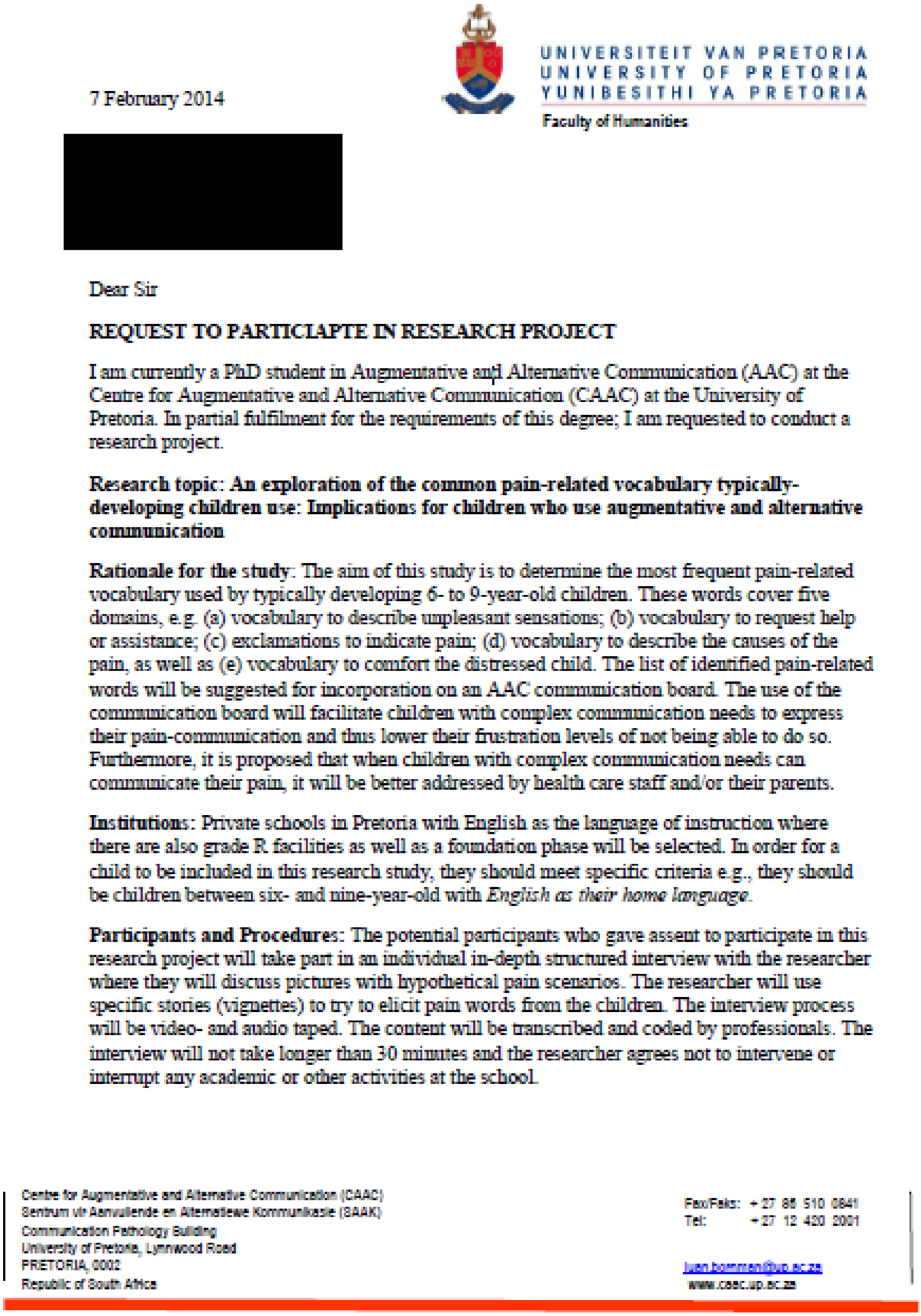
Website: www.education.gpg.gov.za

APPENDIX P: Transcription rules

1. The children's utterances made during the interviews with the children will be transcribed verbatimly.
2. If contractions were used by participants it will be typed as a single word as they were spoken (e.g., ‘‘don't’’, ‘‘won't’’).
3. If colloquial substitutions such as "gonna" for "going to" were used by participants, it will be typed as they were spoken.
4. Exclamations such as "ouch", "ow" were represented in the transcriptions as these were part of the pain-related words.
5. Vocalizations that were not actual words (such as mhmmm or uhh) and not related to pain, will not be represented and transcribed.
6. All duplications (exact same words or phrases within one scenario, i.e. repeat same answer for different questions in scenario) will be removed from the transcriptions.
7. All sentences not related to pain (such as unrelated stories children added during the discussion) will be omitted.
8. Answers which clearly indicated that the participant misinterpreted the question(s) will be omitted.
9. The final transcription will be checked with the "spell check" application of the word processing program.

APPENDIX Q: Consent letter school



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

7 February 2014

[redacted]

Dear Sir

REQUEST TO PARTICIAPTE IN RESEARCH PROJECT

I am currently a PhD student in Augmentative and Alternative Communication (AAC) at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfilment for the requirements of this degree; I am requested to conduct a research project.

Research topic: An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use augmentative and alternative communication

Rationale for the study: The aim of this study is to determine the most frequent pain-related vocabulary used by typically developing 6- to 9-year-old children. These words cover five domains, e.g. (a) vocabulary to describe unpleasant sensations; (b) vocabulary to request help or assistance; (c) exclamations to indicate pain; (d) vocabulary to describe the causes of the pain, as well as (e) vocabulary to comfort the distressed child. The list of identified pain-related words will be suggested for incorporation on an AAC communication board. The use of the communication board will facilitate children with complex communication needs to express their pain-communication and thus lower their frustration levels of not being able to do so. Furthermore, it is proposed that when children with complex communication needs can communicate their pain, it will be better addressed by health care staff and/or their parents.

Institutions: Private schools in Pretoria with English as the language of instruction where there are also grade R facilities as well as a foundation phase will be selected. In order for a child to be included in this research study, they should meet specific criteria e.g., they should be children between six- and nine-year-old with *English as their home language*.

Participants and Procedures: The potential participants who gave assent to participate in this research project will take part in an individual in-depth structured interview with the researcher where they will discuss pictures with hypothetical pain scenarios. The researcher will use specific stories (vignettes) to try to elicit pain words from the children. The interview process will be video- and audio taped. The content will be transcribed and coded by professionals. The interview will not take longer than 30 minutes and the researcher agrees not to intervene or interrupt any academic or other activities at the school.

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
Communication Pathology Building
University of Pretoria, Lynnwood Road
PRETORIA, 0002
Republic of South Africa

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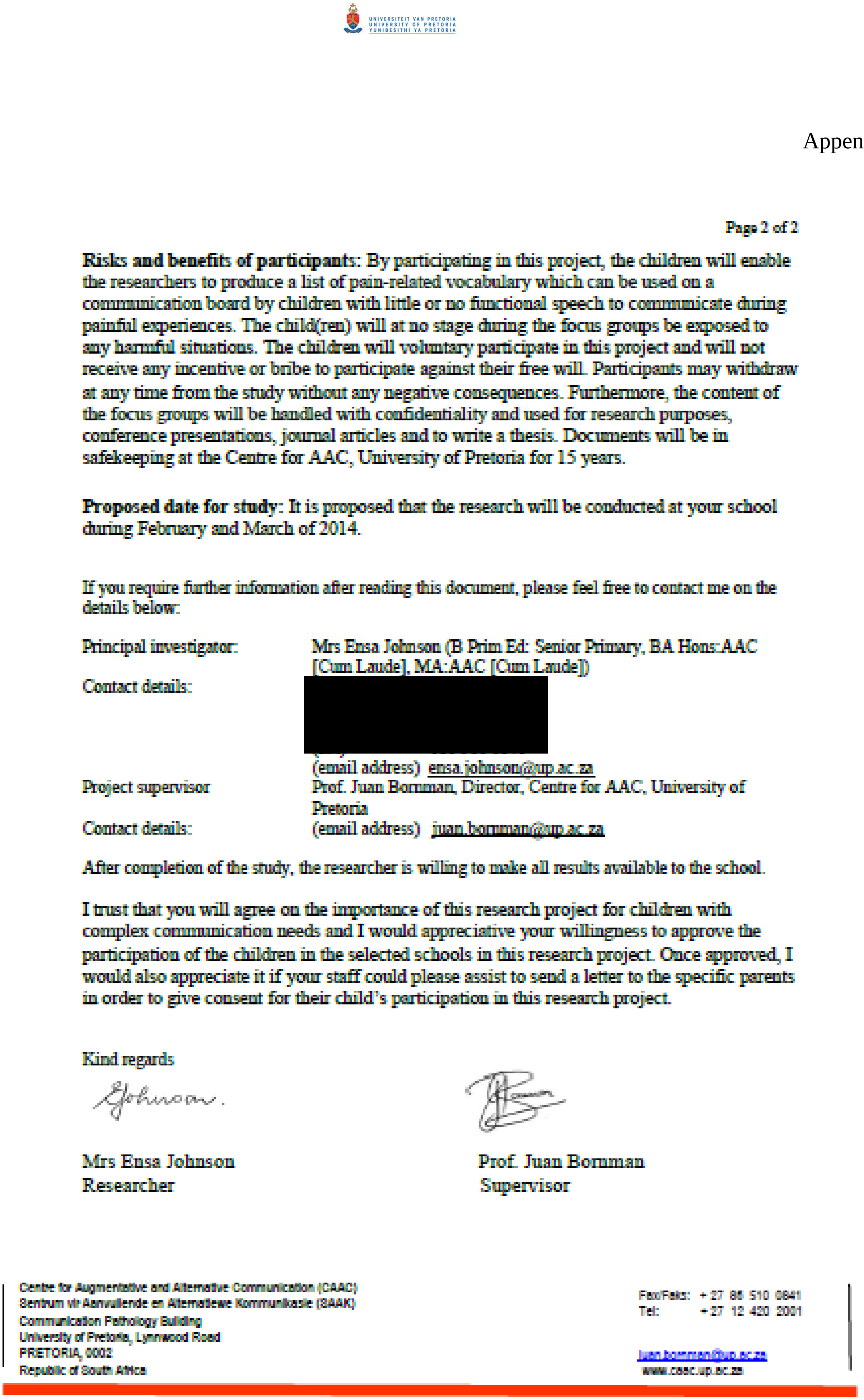

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YUNIBESITHI YA PRETORIA

Page 2 of 2

Risks and benefits of participants: By participating in this project, the children will enable the researchers to produce a list of pain-related vocabulary which can be used on a communication board by children with little or no functional speech to communicate during painful experiences. The child(ren) will at no stage during the focus groups be exposed to any harmful situations. The children will voluntary participate in this project and will not receive any incentive or bribe to participate against their free will. Participants may withdraw at any time from the study without any negative consequences. Furthermore, the content of the focus groups will be handled with confidentiality and used for research purposes, conference presentations, journal articles and to write a thesis. Documents will be in safekeeping at the Centre for AAC, University of Pretoria for 15 years.

Proposed date for study: It is proposed that the research will be conducted at your school during February and March of 2014.

If you require further information after reading this document, please feel free to contact me on the details below:

Principal investigator:	Mrs Ensa Johnson (B Prim Ed: Senior Primary, BA Hons:AAC [Cum Laude], MA:AAC [Cum Laude])
Contact details:	[redacted] (email address) ensa.johnson@up.ac.za
Project supervisor	Prof. Juan Bornman, Director, Centre for AAC, University of Pretoria
Contact details:	(email address) juan.bornman@up.ac.za

After completion of the study, the researcher is willing to make all results available to the school.

I trust that you will agree on the importance of this research project for children with complex communication needs and I would appreciative your willingness to approve the participation of the children in the selected schools in this research project. Once approved, I would also appreciate it if your staff could please assist to send a letter to the specific parents in order to give consent for their child's participation in this research project.

Kind regards

Johnson.

Mrs Ensa Johnson
Researcher

Prof. Juan Bornman
Supervisor

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
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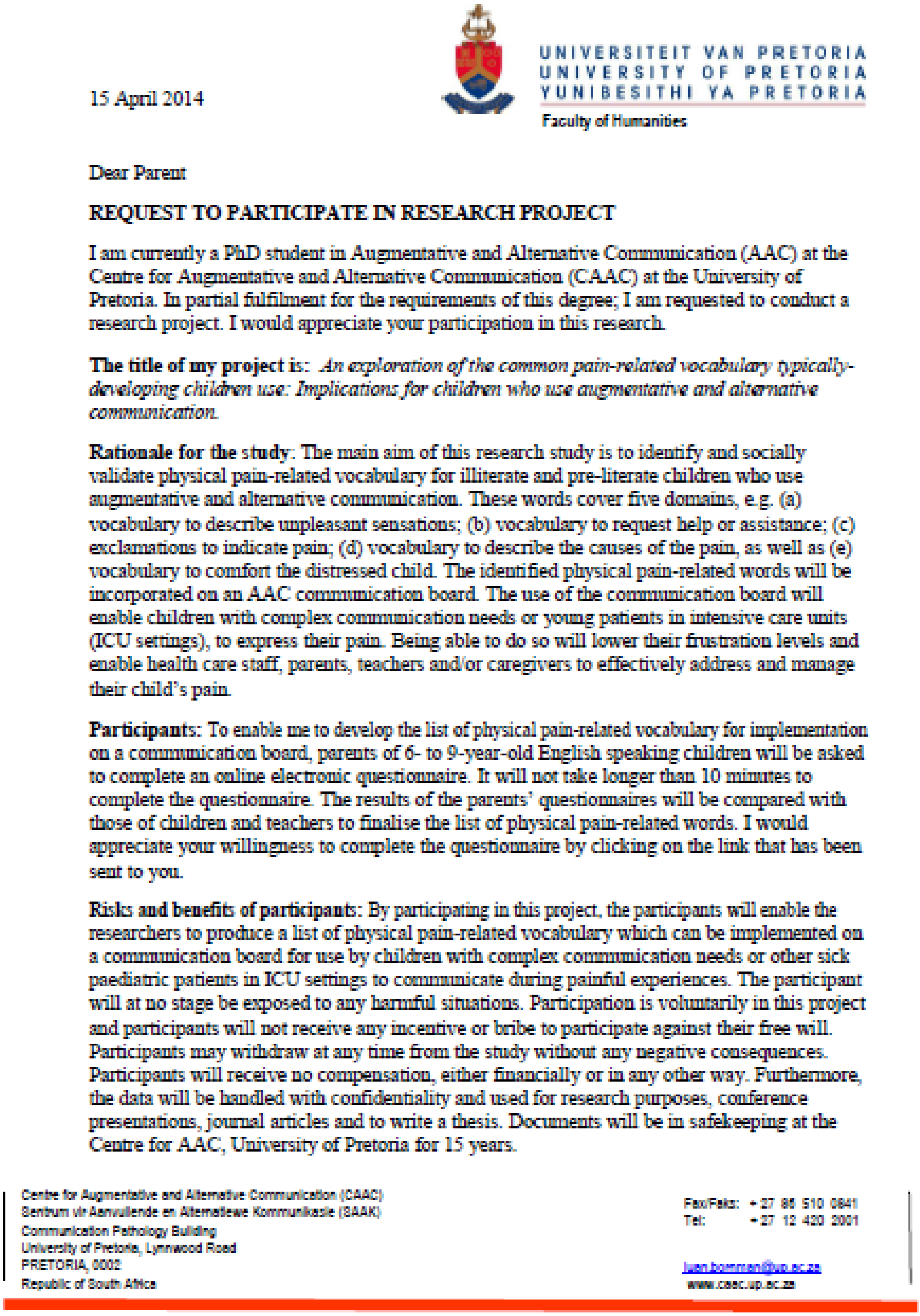
APPENDIX R: Consent letter and form parents – Phase 3



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

15 April 2014

Dear Parent

REQUEST TO PARTICIPATE IN RESEARCH PROJECT

I am currently a PhD student in Augmentative and Alternative Communication (AAC) at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfilment for the requirements of this degree; I am requested to conduct a research project. I would appreciate your participation in this research.

The title of my project is: *An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use augmentative and alternative communication.*

Rationale for the study: The main aim of this research study is to identify and socially validate physical pain-related vocabulary for illiterate and pre-literate children who use augmentative and alternative communication. These words cover five domains, e.g. (a) vocabulary to describe unpleasant sensations; (b) vocabulary to request help or assistance; (c) exclamations to indicate pain; (d) vocabulary to describe the causes of the pain, as well as (e) vocabulary to comfort the distressed child. The identified physical pain-related words will be incorporated on an AAC communication board. The use of the communication board will enable children with complex communication needs or young patients in intensive care units (ICU settings), to express their pain. Being able to do so will lower their frustration levels and enable health care staff, parents, teachers and/or caregivers to effectively address and manage their child's pain.

Participants: To enable me to develop the list of physical pain-related vocabulary for implementation on a communication board, parents of 6- to 9-year-old English speaking children will be asked to complete an online electronic questionnaire. It will not take longer than 10 minutes to complete the questionnaire. The results of the parents' questionnaires will be compared with those of children and teachers to finalise the list of physical pain-related words. I would appreciate your willingness to complete the questionnaire by clicking on the link that has been sent to you.

Risks and benefits of participants: By participating in this project, the participants will enable the researchers to produce a list of physical pain-related vocabulary which can be implemented on a communication board for use by children with complex communication needs or other sick paediatric patients in ICU settings to communicate during painful experiences. The participant will at no stage be exposed to any harmful situations. Participation is voluntarily in this project and participants will not receive any incentive or bribe to participate against their free will. Participants may withdraw at any time from the study without any negative consequences. Participants will receive no compensation, either financially or in any other way. Furthermore, the data will be handled with confidentiality and used for research purposes, conference presentations, journal articles and to write a thesis. Documents will be in safekeeping at the Centre for AAC, University of Pretoria for 15 years.

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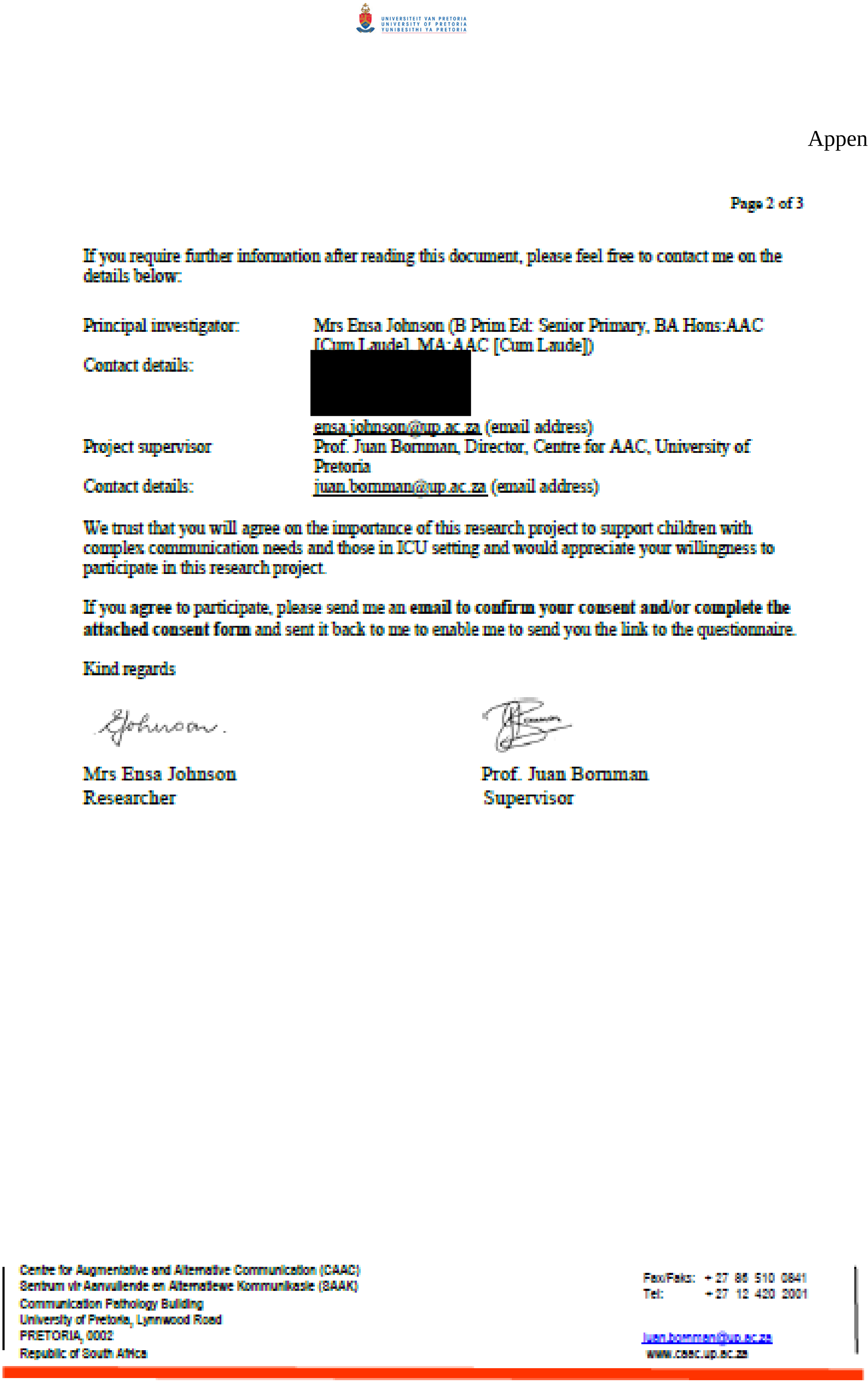

UNIVERSITEIT VAN PRETORIA
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YUNIBESITHI YA PRETORIA

If you require further information after reading this document, please feel free to contact me on the details below:

Principal investigator:	Mrs Ensa Johnson (B Prim Ed: Senior Primary, BA Hons:AAC [Cum Laude], MA:AAC [Cum Laude])
Contact details:	[redacted] ensa.johnson@up.ac.za (email address)
Project supervisor	Prof. Juan Bornman, Director, Centre for AAC, University of Pretoria
Contact details:	juan.bornman@up.ac.za (email address)

We trust that you will agree on the importance of this research project to support children with complex communication needs and those in ICU setting and would appreciate your willingness to participate in this research project.

If you agree to participate, please send me an **email to confirm your consent and/or complete the attached consent form** and sent it back to me to enable me to send you the link to the questionnaire.

Kind regards

EJohnson.

Mrs Ensa Johnson
Researcher

Prof. Juan Bornman
Supervisor

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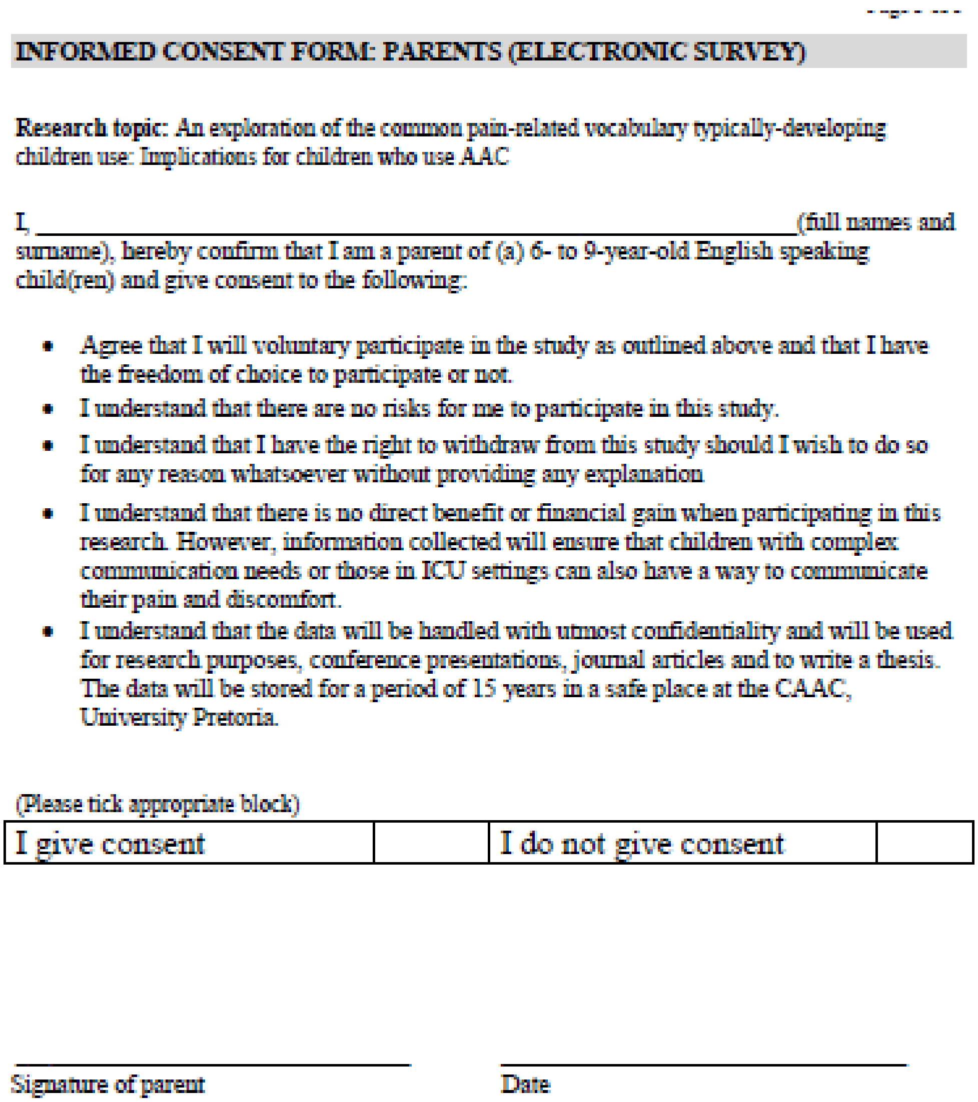


INFORMED CONSENT FORM: PARENTS (ELECTRONIC SURVEY)

Research topic: An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use AAC

I, ____(full names and surname), hereby confirm that I am a parent of (a) 6- to 9-year-old English speaking child(ren) and give consent to the following:

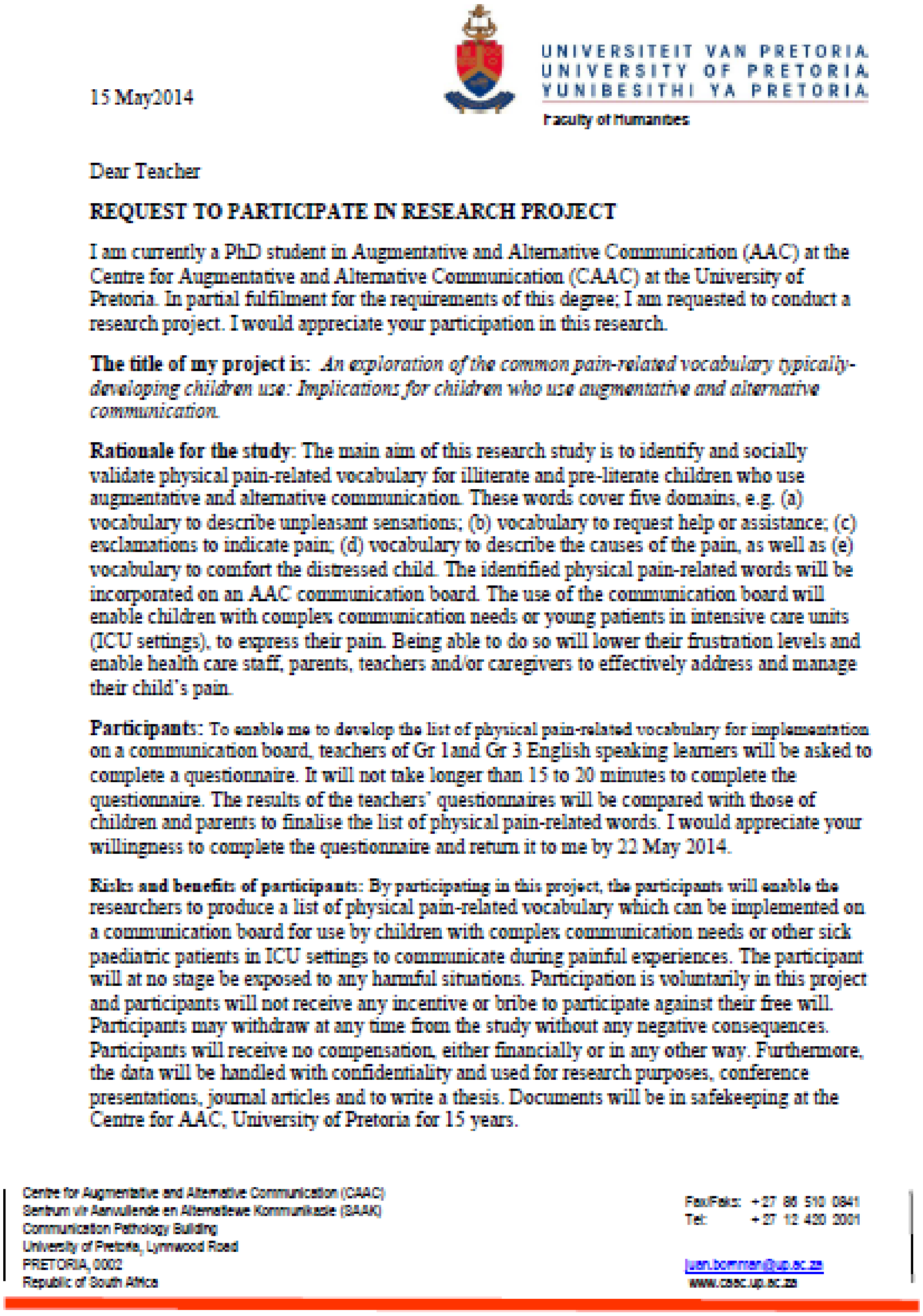
- Agree that I will voluntary participate in the study as outlined above and that I have the freedom of choice to participate or not.
- I understand that there are no risks for me to participate in this study.
- I understand that I have the right to withdraw from this study should I wish to do so for any reason whatsoever without providing any explanation
- I understand that there is no direct benefit or financial gain when participating in this research. However, information collected will ensure that children with complex communication needs or those in ICU settings can also have a way to communicate their pain and discomfort.
- I understand that the data will be handled with utmost confidentiality and will be used for research purposes, conference presentations, journal articles and to write a thesis. The data will be stored for a period of 15 years in a safe place at the CAAC, University Pretoria.

(Please tick appropriate block)

I give consent		I do not give consent	

______________________________ ______________________________
Signature of parent Date

APPENDIX S: Consent letter and form teachers – Phases 2 and 3



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

15 May2014

Dear Teacher

REQUEST TO PARTICIPATE IN RESEARCH PROJECT

I am currently a PhD student in Augmentative and Alternative Communication (AAC) at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfilment for the requirements of this degree; I am requested to conduct a research project. I would appreciate your participation in this research.

The title of my project is: *An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use augmentative and alternative communication.*

Rationale for the study: The main aim of this research study is to identify and socially validate physical pain-related vocabulary for illiterate and pre-literate children who use augmentative and alternative communication. These words cover five domains, e.g. (a) vocabulary to describe unpleasant sensations; (b) vocabulary to request help or assistance; (c) exclamations to indicate pain; (d) vocabulary to describe the causes of the pain, as well as (e) vocabulary to comfort the distressed child. The identified physical pain-related words will be incorporated on an AAC communication board. The use of the communication board will enable children with complex communication needs or young patients in intensive care units (ICU settings), to express their pain. Being able to do so will lower their frustration levels and enable health care staff, parents, teachers and/or caregivers to effectively address and manage their child's pain.

Participants: To enable me to develop the list of physical pain-related vocabulary for implementation on a communication board, teachers of Gr 1and Gr 3 English speaking learners will be asked to complete a questionnaire. It will not take longer than 15 to 20 minutes to complete the questionnaire. The results of the teachers' questionnaires will be compared with those of children and parents to finalise the list of physical pain-related words. I would appreciate your willingness to complete the questionnaire and return it to me by 22 May 2014.

Risks and benefits of participants: By participating in this project, the participants will enable the researchers to produce a list of physical pain-related vocabulary which can be implemented on a communication board for use by children with complex communication needs or other sick paediatric patients in ICU settings to communicate during painful experiences. The participant will at no stage be exposed to any harmful situations. Participation is voluntarily in this project and participants will not receive any incentive or bribe to participate against their free will. Participants may withdraw at any time from the study without any negative consequences. Participants will receive no compensation, either financially or in any other way. Furthermore, the data will be handled with confidentiality and used for research purposes, conference presentations, journal articles and to write a thesis. Documents will be in safekeeping at the Centre for AAC, University of Pretoria for 15 years.

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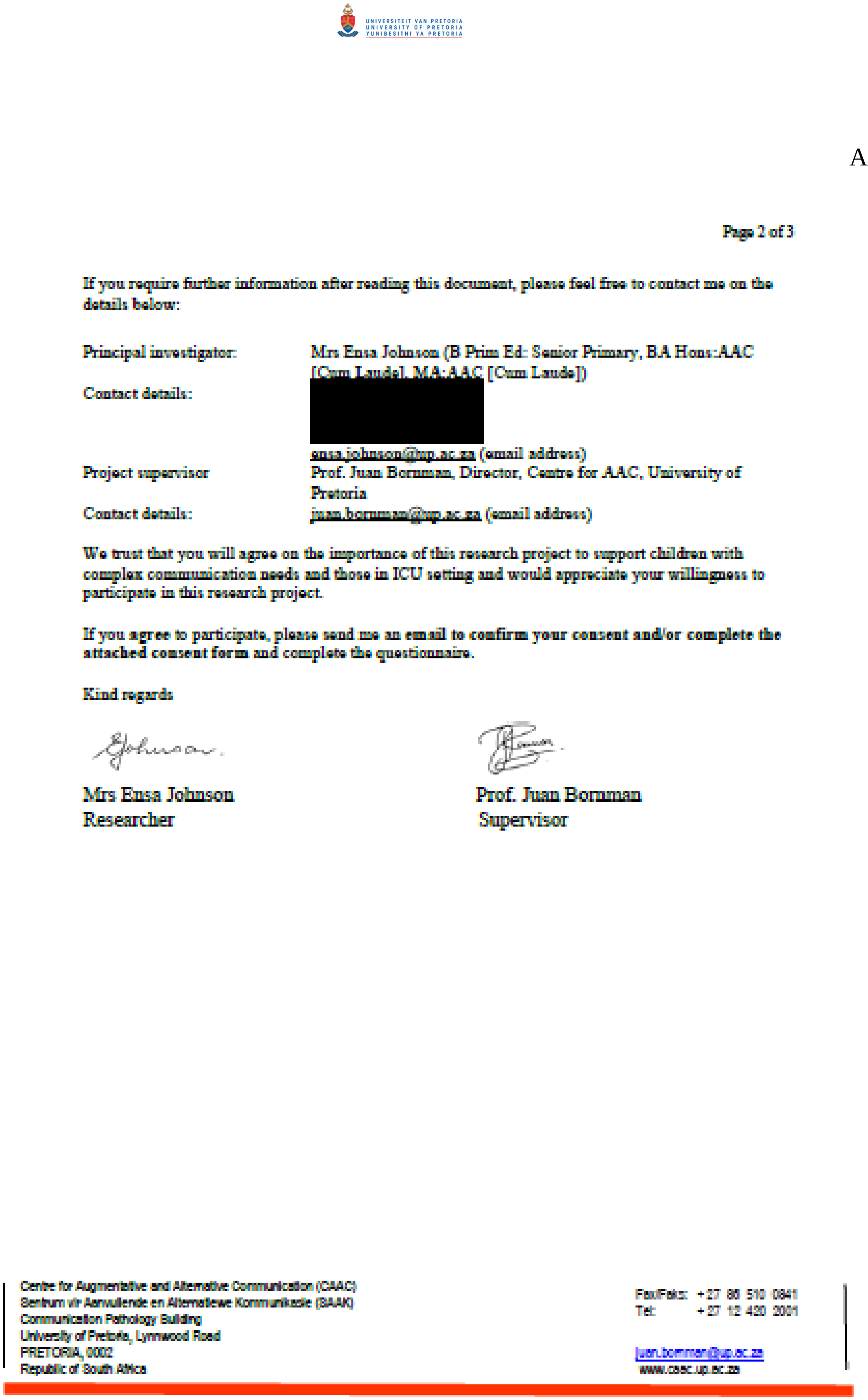

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UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Page 2 of 3

If you require further information after reading this document, please feel free to contact me on the details below:

Principal investigator: Mrs Ensa Johnson (B Prim Ed: Senior Primary, BA Hons:AAC [Cum Laude], MA:AAC [Cum Laude])
Contact details: [redacted]
ensa.johnson@up.ac.za (email address)
Project supervisor: Prof. Juan Bornman, Director, Centre for AAC, University of Pretoria
Contact details: juan.bornman@up.ac.za (email address)

We trust that you will agree on the importance of this research project to support children with complex communication needs and those in ICU setting and would appreciate your willingness to participate in this research project.

If you agree to participate, please send me an email to confirm your consent and/or complete the attached consent form and complete the questionnaire.

Kind regards

Mrs Ensa Johnson
Researcher

Prof. Juan Bornman
Supervisor

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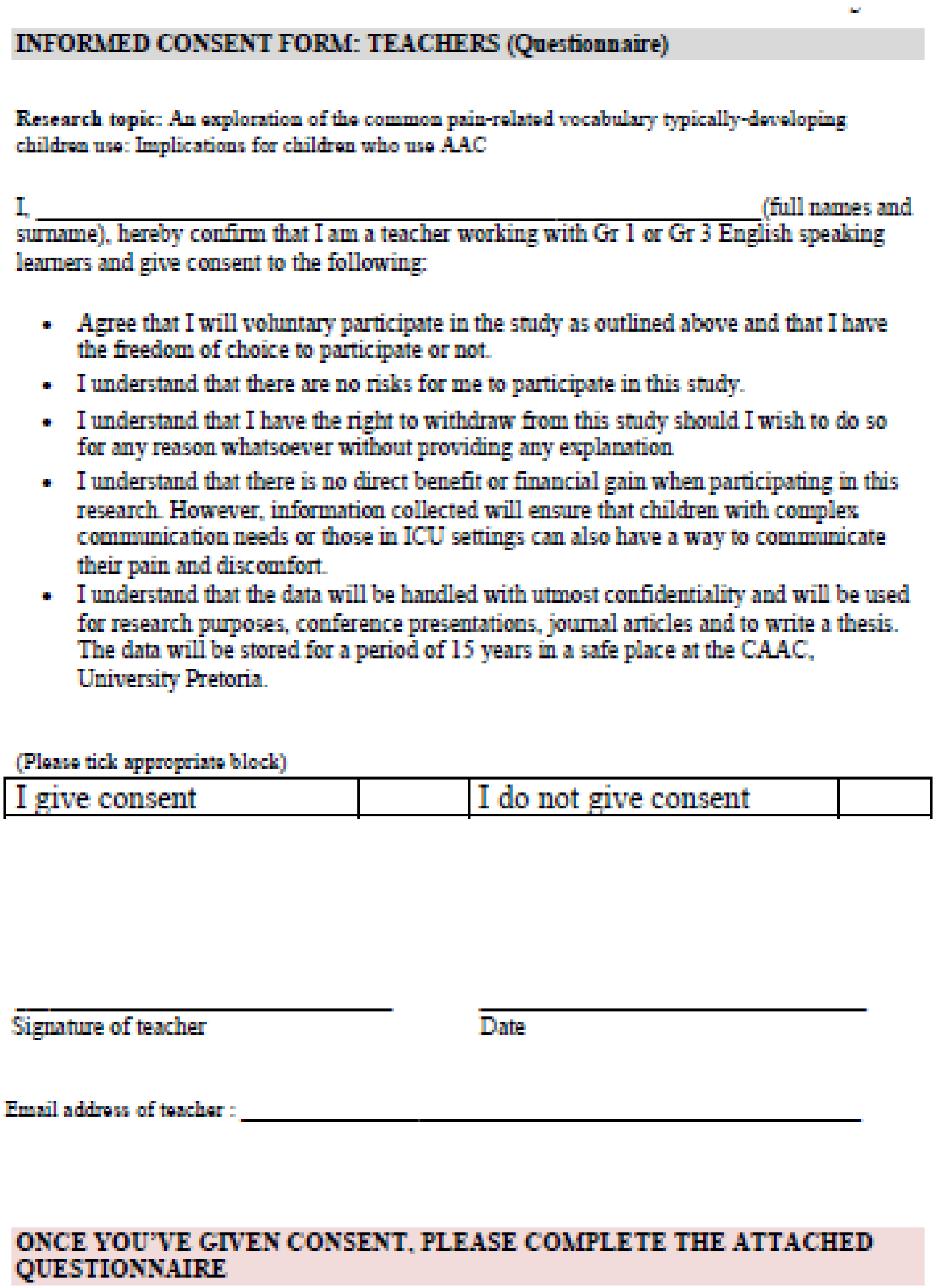


INFORMED CONSENT FORM: TEACHERS (Questionnaire)

Research topic: An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use AAC

I, ____(full names and surname), hereby confirm that I am a teacher working with Gr 1 or Gr 3 English speaking learners and give consent to the following:

- Agree that I will voluntary participate in the study as outlined above and that I have the freedom of choice to participate or not.
- I understand that there are no risks for me to participate in this study.
- I understand that I have the right to withdraw from this study should I wish to do so for any reason whatsoever without providing any explanation.
- I understand that there is no direct benefit or financial gain when participating in this research. However, information collected will ensure that children with complex communication needs or those in ICU settings can also have a way to communicate their pain and discomfort.
- I understand that the data will be handled with utmost confidentiality and will be used for research purposes, conference presentations, journal articles and to write a thesis. The data will be stored for a period of 15 years in a safe place at the CAAC, University Pretoria.

(Please tick appropriate block)

I give consent		I do not give consent	

________________________________ ________________________________
Signature of teacher Date

Email address of teacher : ________________________________

ONCE YOU'VE GIVEN CONSENT, PLEASE COMPLETE THE ATTACHED QUESTIONNAIRE

APPENDIX T: Pain-related categories

Table 1

Categories, Definitions, Sub-Categories, Definitions and Examples of Pain-Related Vocabulary Children Use to Express Pain

7 Pain-related main categories and definitions	23 Sub-categories and definitions	629 Word or phrase obtained from data
A Vocabulary to describe pain (134): Words or phrases that explain the physical feeling of how the pain is experienced *(Pain expression – socio communication model of pain)*	A1 ***Exclamation*** (13): A sudden cry or remark, to specifically express surprise, anger, or pain.	ouch, ‘eina’, ouchie, ow; ‘eish’; oh no; aaahh; oh my; oh oh; o wow; yoop/whoops; shew; ouwa
	A2 ***Vocalisations and verbalisations*** (13): Utterances/noises to express pain	agh; ah aaaahhh; cry/cries/crying; groan; hum hmmmm; moan; ooosshh; pffff; scream(ed); I shout(ed); tssss/ssssss/sssshhh; uh uuuhh; uugghh/ uurgh
	A3 ***Descriptors*** (26): Vocabulary used to describe a pain experience or feelings of pain	bruise; blood; (my) blood is bubbling; booboo/boobie; cramp/cramping; concussion; feels dead; digging in; doef-doef; funny feeling; graze; hurt; I feel ill; lip gets fat; my ears are ringing; no blood; painful; poke/pokey; pounding; swollen; scratch; scrape; throbbing; sore; (head is) tired; wobbly
	A4 ***Sensory words*** (n=10): Vocabulary related to sensation or the physical senses; transmitted or perceived by the senses	burning; hot; itchy; numb; pinch; sting/stingy; squishy; sharp; tickles; warm
	A5 ***Intensifiers*** (31): Vocabulary that indicate the intensity/severity of the pain experience	big pain; extremely painful; hurt too much; hurts very bad; hurt a lot; I feel enough pain; I'm dead (because it is sore); I'm gonne die (because of bee sting); intense; it is more sore when it is not bleeding; much worse than before; pain very much; painful; really bad; really hurt; really, really angry (because I got hurt); really, really hot; super pain(ful); super sore; very burning; very painful/so painful; very sad; very sick; very sore/really sore/so sore; very, very cold; very, very hot; very, very painful; very, very sad; very, very sick; very, very sore/ extremely sore/really, really sore

7 Pain-related main categories and definitions	23 Sub-categories and definitions	629 Word or phrase obtained from data
	A6 **Comparisons or methaphors** (21): Vocabulary used to compare the feeling of pain with something else i.e. "like ...." or "feels as if ..."	it feels like squeezing; (headache) felt like a porcupine just threw spikes at me; (the burn) felt like the skin pop ; (the burn) felt like there is fire on your hands/it feels as if my hand is on fire; feel like biting; headache feels as if somebody is shaking me very bad.; headache feels like I ran into a thorn bush; it (bee sting) felt like a thorn; it (burn wound) feels like how hot boiling water is when you boil the kettle; it (headache) feels as if my head explodes; it (headache) feels like my heart is beating on my forehead; it (needle pricks) feels like a bee sting; it doesn't feel nice like when you busy working it doesn't feel right in your head; it feels like I lost my arm; it feels like when you slam your finger in the door (blue mark); it feels like your skull was broke; it felt like darts going into my head; my thumb feels like smashed, like one rock smashed into this side and one rock smashed into that side; the bee sting feels like a very bad sting; the bee sting stings like hell; the headache was not like full head; when it is more noisy, it always feel like it is "worser" and "worser"
	A7 ***Evaluative words*** (20): Vocabulary to evaluate/assess the pain experience	a bit okay; (body part) feels dead; doesn't feel right in your head; don't feel well; feeling eekie; funny feeling; head has a lot of noise; I can't feel my (body part) / don't feel; I don't know how the burn will feel like; it (bee sting) is very poisonous; it feels weird; it will be a lot worse; kind of/little bit/kinda sore; not fine/not that fine; not nice/ don't feel nice; something very strange come down my throat; sometimes it (pain) is really bad and sometimes it isn't that bad; the poison were running in my hand; there is a big problem (I got hurt); you can die when you get stung too many times
B Vocabulary to direct other's actions in response to the pain/injury/illness (140): Words or phrases that specify to others what to do, or not do when the child is in pain - these include requests for help or assistance; specifications of how treatment should be done; protests from the child and remedies to be given to ease the pain of the child *(Decodiing – socio-communication model of pain)*	B1 ***Action*** (72): Vocabulary to indicate to others' what to do when child is in pain	bring me a teddy bear (then pain will feel better); call adult (mommy/daddy/teacher); tell adult; call an ambulance; call mom to come and fetch me from school; call mommy to pick me up; check if everything is okay; clean it; clean the wound; cover it (the place of injury); cuddle me (because I got hurt); do I need to eat? (because I don't feel well); do not bust it (the blister); do something (to help me); don't push it, because the poison goes in; don't hurt me (because I got hurt); don't play rough because it is sore; don't touch (the sore); excuse me, can you actually get it right?; fix it; get a magnifying glass (to look at the bee sting); get a tweezer (to take out the thorns) get an x-ray to make sure all is right; get it over with; get rid of everything (that cause the hurt); get the first aid kit give me a/I need a hug; give me crutches; give me sweets; hold my hand; I am (highly) allergic to bees; I am thirsty; I need/want ; I want to drink (water/something); I want to eat / give me something to eat; I want to eat something sweet; I want to stand up/get up; just put it in on the right place now!; kiss it; leave it (leave the sore); leave me (I want to be

7 Pain-related main categories and definitions	23 Sub-categories and definitions	629 Word or phrase obtained from data
		alone); let another nurse do it (put the needle in vein); lift arm high up (to make it feel; better); look (mommy/daddy/teacher look what happened); make it better; make sure all is right; make sure I am alright; mommy can you please keep me company; my (body part)! My (body part)! (show body part that got hurt to adult); my arm is sore. Go to the doctor and make it straight; my legs are broken, give me a wheelchair; never mind, I don't want it out!; no! no!; please help; please may you aim properly?; pop the blister; put the needle in my arm (for drip); remove it (thorns/splinter); rinse it under cold water; somebody needs to scrape out the bee sting, because if you just pull it out the poison will make the sting badly; squeeze the sore ; stop hurting/poking me; take away (the bee sting); take it (thorns/splinter) out / pull off the thorns/splinter; tell the doctor where to put it (needle) in; try again to put it (needle) in; try to stop the bleeding; use needle to take thorn out; wait until it is better; wash germs away; wipe off the blood; you find the stinking vein already?; you're going in the wrong place, just look for it
	B2 ***Places*** (15): Vocabulary to indicate where child wants to/should go when in pain	can I leave the classroom?; come running (to adult for help); get me outa here!; go to sickroom/office/principal; go to the doctor; go to the hospital; I want to get out of the hospital; I want to go back to class; I want to go to another doctor; run to/go to adult (mommy/daddy/teacher); rush to the hospital; take me out of this hospital; take me somewhere/go somewhere; take me to the chemist (to put some cream on); when am I coming out of this hospital?
	B3 ***Remedy*** (53): Vocabulary to indicate what medicine or treatment should be provided when child is in pain	a lot of ice/medicine; don't move (the arm); drink water/put water on the sore; get bee pollinator things; give me a vitamine; give me Allergex; give some ointment; have antihistamine; I must like keep mouth warm; I need some syrup; I need to take tablets; I think I need a Rescue tablet; I took antibiotics; massage (body part); medicine/medication; Panado; please bring my Celestamine; put a wet cloth on the sore; put Arnica on; put BioOil on; put cold cloth/bag on my head; put cold water on it; put cotton wool on it; put honey on the sore; put ice on her lip because the bee sting is warm, and if she put a warm thing on, it will be a lot worse; put it under cold water; put muti on; put on a splint; put on bandage; put on band-aid; put on Burn shield (on burn wound); put on cast; put on Dettol; put on ice/ice pack; put on ointment; put on plaster; put on something; put some cream/special cream (on); put some kind of liquid on the sore; put some liquid on; put some spray on the sore; put something cold on; put something over it to keep the pressure; put stitches in; put stuff on the sore; ran cold water over it; run/put (sore) under cold water; strap it (injured body part); take pill(s); things to make me better; use wire to put her bones back; when you put something cold over hot it makes it better; wrap

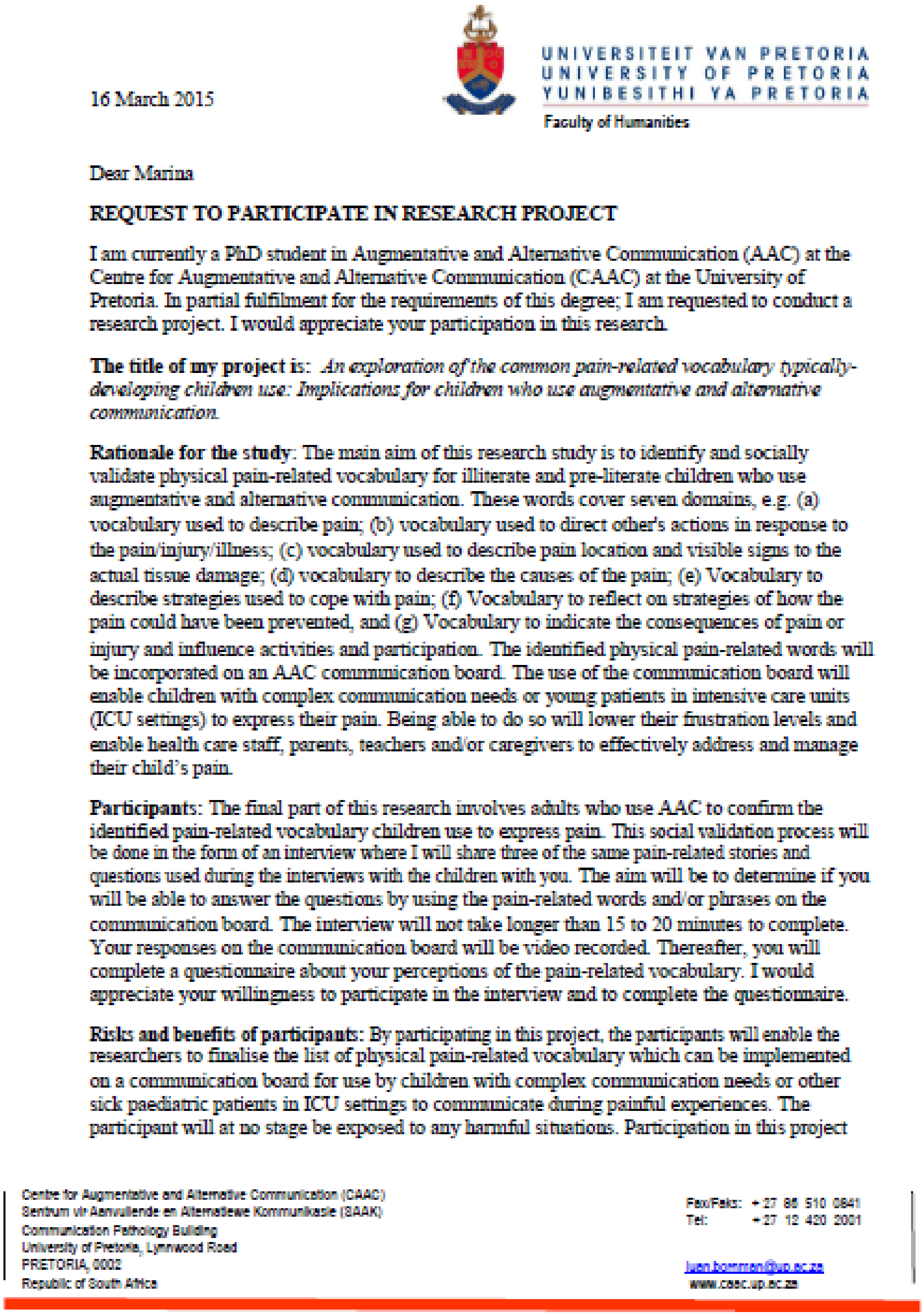
7 Pain-related main categories and definitions	23 Sub-categories and definitions	629 Word or phrase obtained from data
		whole body
C Vocabulary to describe pain location and visible signs to the actual tissue damage a result of the physical injury (42): Words or phrases to give an account of all characteristics or features of the place of injury – both internally and externally as well as how the injury looks like and how this injury affects the body structure and functions of the child. *(Physical trauma, encoding – socio-communication model of pain)*	C1 ***Site of injury*** (7): Vocabulary to indicate the place of injury on the body	a lot of spit in my throat; in my mouth; just on one side; my eye was like a blob; my whole body is crushed; there are thorns in body part (head/skin/leg, etc); whole head pains on the top
	C2 ***Visible signs of injury*** (35): Vocabulary to give an account of the characteristics and features – both internally and externally – of the actual tissue damage as a result of physical injury	blister; break ; bruise; bubble (blister); crack; got a big bump (after ; the bee stung me); grazes ; everywhere; it (swelling) goes down; It (swollen lip) feels a bit big; it grow big; it is red; lip gets fat; my finger snapped; my hand was (cut) open and bleeding; only a small sore; scratches; skin is off (due to the fall); small burn; small eina; sore is blue; sore is dry; sore is purple; sore looks horrible; sore looks ugly; squishy; still got the mark (of the burn wound); swell goes down; swollen; there are scrapes on my arm; there is no blood; thorns are very deep/too deep; thorns were deep; tore a ligament; very big/heavy; very swollen
D Vocabulary to describe the causes of the pain (75): Words or phrases that describe the incident that led to the pain experience, including reasons and explanations of actions that resulted in the injury *(Intrapersonal factors and encoding– socio communication model of pain)*	D1 ***Internal causes of pain*** (27): Vocabulary to describe the incident due to own mistake that led to the pain experience (could have avoided injury/cause of pain)	drank too fast (that is why I am sick); I bend (body part and got hurt); I could not catch it (the ball); I cut myself; I fell; I get car sick; I had a concussion; I have a fever; I have a headache; I have a stomach bug; I knocked my ….; I opened the pot with the food in; I ride my bicycle; I skipped and fell; I slid and cut my leg; I slipped and fell down; I struggled to balance on my bike; I touched the warm pot/kettle/iron; I tried to look inside the pot; I tripped; I tumbled; I twist (twisted) my foot; I wanted to see what we are having tonight; I was coughing too much; I was frying onions; I was injured; I was swimming (when the bee stung me)
	D2 ***External causes of pain*** (48): Vocabulary to describe the incident inflicted by others' thus outside own control that led to the pain experience (could not have avoided injury/cause of pain)	a car crashed into our car; a dog ran across the street; a thorn got stuck into body; all the sweeties (that made me sick); all the work (cause the pain); he kicked me; he throw the ball at me; I only got one (bee sting) on my foot ; I bumped into …(the thorn tree)/The car bumped into my side; I flipped when the car hit the motor bike; I got hurt by accident/accidentally; I had a drip; I had an operation; I hit my.../ball hit me; I ran into a thorn tree; I sat on a bee; I stepped onto the thorn; I was hit by a ball; it (the ball) whacked me; it is a bad bee; it was a big thorn; it was him (blame somebody else); it was the apple she gave me (that made me sick); it was the stairs; my finger got smashed in the door; push (i.e. someone pushed me); the bee bit me; the bee stung me; the bees went crazy (and stung me); the cross bee/ angry bee stung me); the naughty bee stung me; the needle has gone in so many times; the needle pinched me; the nurse keeps on sticking it (the needle); the

7 Pain-related main categories and definitions	23 Sub-categories and definitions	629 Word or phrase obtained from data
		nurse was hitting the needle everywhere in my arm and not looking were the vein is; the pot lid fell on her hand; the silly bee stung me; the stupid bee stung me; the truck hit car/car hit our car; there is a splinter in my skin; these little thorns went into my head; they are putting the needle in the drip; they draw blood / take blood; they gave injection/inject; they kicked/threw the ball very hard; they struggle to find the vein; they took my tonsils out; we were playing
E **Vocabulary to describe strategies used to cope with pain (101):** Words and/or phrases of attempts or actions to deal with pain *(Intrapersonal factors– socio-communication model of pain)*	E1 ***Self-talk*** (44): Vocabulary used as a form of self-regulation strategy to deal better with pain	at least the bee is dead now; don't say anything; don't worry (I am okay); give it a shot; how long are you going to take?; I am okay; I can do this; I can't belief I got hurt; I didn't actually need a plaster; I don't need to go to the office; I got it (thorn/splinter/sting) out; I need something to cheer me up; I say something nice to make me feel better; I want my tonsils back; I want sit down a little bit; I will be acting tough; I wish I could get better; I'm a big boy/girl; I'm fine/ it is fine; I'm not even crying; I'm the best (I can handle this); is it done?; it (injection) will be over soon; it (needle for drip or injection) is not really sore; it (pain) is okay but not too bad; it (the burn wound) will stop burning; it (where the ball hit me) was not so hard; it could have been worse; it didn't hurt that much; it is not a big thing (thorn in foot); it is not so bad when they put it (needle) in, but when they pull the needle out; it is not sore at all/wasn't that sore; it wasn't so sore, but it was sore/ sore but not that sore; luckily I'm not allergic to bees; luckily it (bones) is not broken; luckily it (the ball) didn’t (break my glasses/hit my head); plasters don't always help (when you got hurt); stay calm; the pain will go away; the sore is not that bad; the sore will heal (and be better); what's wrong?; why did you do that to me?; will it hurt if you take it out?
	E2 ***Actions to cope with pain*** (33): Vocabulary used to indicate what to do to deal effectively with pain	can I go to the toilet/bathroom?; can I sit by you?; do not use (body part); do nothing/don't do anything (when in pain); don't be active (when in pain); don't talk for 10 minutes so that it can be better; exercise (body part); I blow it (on the sore); I can still (hop/move …); I carry on (what was done before the injury); I hold (it)/hold on hurt; I rub it; I want go to bed; I want to go home; I want to go out; I want to sleep/go to sleep (when in pain and to feel better afterwards); I will have to write with left hand; jump up and down (when in pain); just relax (when in pain); keep it (sore) still for a while/stay still; keep quiet because my throat is sore; lie down (when in pain); lie in bed; move around (when it is sore); move hand a litle bit (to make it feel better); rest for a little bit; rock themselves (when they got hurt); shake body part (when in pain); suck it (the sore); take a bath to wash the blood away; take a break (before they try again to put the drip in); take a nap (when in pain and to feel better afterwards); take a snooze (because of headache)

7 Pain-related main categories and definitions	23 Sub-categories and definitions	629 Word or phrase obtained from data
	E3 ***Positive outcomes*** (8): Vocabulary to affirm that the pain will become better	after a while the pokes will be gone; doctor will help to make it better; doctor will see what is wrong; feel better; happy ending; I belief in good luck; pray to God/Allah to make it better; once the sting is out…
	E4 ***Distractions*** (16): A thing/action that deflect attention from pain	bubblegum might help; close my eyes when they want to inject me; don't think about it/don't worry; forget about it; go somewhere else; look up (when they put needle in); have a friend; have a nice day; ignore it; make a little card; play; read a story; sit somewhere and draw pictures; trying to work; watch TV/movie; what am I going to do?
F **Vocabulary to reflect on how the pain could have been prevented (31):** Words or phrases that shows that the child thought carefully about how the pain could have been avoided or lessons learnt for the future. *(Encoding– socio communication model of pain)*	F1 ***Reflect on what happened that could have been prevented*** (past) (18): Vocabulary to reflect on how what happened that caused the pain could have been prevented	do I have to get my tonsils remove?; did not look (where I was going/what I was doing); did not see the …; I ate too much/eat too much; I couldn't wait; I did not wear a seat belt/safety belt; I kept focus on the ball instead of the thorn tree; I kept my eye on the ball; I must have eaten something bad; I never saw… (the…); I was not focusing/looking/supposed to do it; I was too fast; I was too slow; I wasn't looking; I wish that it has never happened; it happened to me; it was on purpose; I've pulled the brakes too hard
	F2 ***Reflect on how to prevent pain*** (13): Vocabulary to indicate how the pain can be avoided in the future	don't do that again; I don't want to get my tonsils out; I should be more careful; I should have… (been slower/just waited); I shouldn't have (done that); I was not supposed to (do ….); I was supposed to …(do something); I will never again (do this); I will not do that again; it is better to listen to mom; next time; play a bit further from the thorn tree; they only give you an injection because they want to look in your body for something is not supposed to be there
G **Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation (106):** Words or phrases that indicate the outcome(s) or results of the pain or injury which affect (a) the child's participation in activities – these include not being able to participate in activities; (b)	G1 ***Physical outcome*** (62): Vocabulary to indicate the physical consequences or influence of participation in activities as a result of pain (Can't do something as a result of pain/pain denies child of....)	can't do anything (because it is sore); can't move (body part); droopy eyes (when they got hurt); facial expressions/grimace (show they are in pain); I am hungry; I am scared of the needle; I can't bend (body part); I can't breathe/ struggle to breath; I can't concentrate on my work; I can't do it (take thorn out); I can't drink anything/can't eat (because it is sore); I can't get it (thorn/splinter) out/ can't take all out (couldn't take it out); I can't get out of bed (because of the pain); I can't go to the party; I can't play/no play (it is too sore); I can't sit up (because of pain); I can't sleep (because of the pain); I can't talk/speak (because it is sore); I can't think of/couldn't think of) (because it is too sore); I can't use my (body part); I can't work/write (because of the pain); I couldn't open my eyes (because of bad headache); I couldn't walk because it is too sore;

7 Pain-related main categories and definitions	23 Sub-categories and definitions	629 Word or phrase obtained from data
rewards received as a result of the injury; and (c) emotional responses and reflections as a result of the pain/injury *(Encoding – socio-communication model of pain)*		I did not do homework; I did not know what to do; I don't want to go to school (because of headache); I don't want to work when I am in pain; I feel depressed (because of the pain); I felt nauseous; I got a fright; I had to get a moon boot; I kept leaning against the walls (because of bad headache); I kept on collapsing (because I had a headache); I need to puke/I felt like puking; I skip school (because I have a headache); I want to throw up; I want to vomit; I was trying to work; I was unconscious; I will not play outside; I will panic; It is gross when they take it (needle) out; it is not good for your blood pressure (when there are thorns under your skin); It was a long time before it was better; may I stop working? (I feel sore); point at/show (the place of injury); pull up shoulder (can't say what happened); stay at home; stay home for a day or two from school (because you are in pain); stay in bed (when in pain); that is hard to move my (body part); the blister might get infected; the doctor signed me off; uncomfortable (when arm/leg is broken); use sign language (because I couldn't speak because of the sore throat); want to miss school; what happened? (that I got hurt); whenever I touched my head it (headache) comes back; where am I?; why am I in the hospital?; why do I have this bad pain?; you can get brain damage or arm damage (when in an accident)
	G2 ***Secondary gain*** (34): Vocabulary to explain the extra "rewards" received as a result of the pain experience (such as getting attention or receive something as a result of pain)	drink a cup of tea (to feel better); drink Coke; drink hot chocolate; drink soup; eat as much ice cream as you want to make throat better; eat jelly; eat jelly so your throat feels nice; go back (home/to play); granny will come to visit me after the operation; I can go to the party (because it will be better); I eat custard with jelly; I felt very good afterwards (after I vomited); I got a lollipop; I got cookies; I got hot chocolate; I got juice; I got KinderJoys; I got some chips to eat; I want to stay in hospital; I will be all happy; I will be smiling; if I want sweet things the mommy bring it; jump of joy when I am better; mommy fetch whatever I want; my friends will laugh at me; my mom bought me a little Spiderman toy; please buy/bring me a present; please don't smack me (because I got hurt); simple (whatever object caused the pain); they gave me star for being brave; they give me a sticker; they will have lots of fun; when his arm is back to normal (he can play again); when I am better, I will do my homework
	G3 ***Emotional response as result of pain*** (10): Vocabulary to describe emotions due to pain experience	afraid/scared; angry at them (blame them); 'askies'/sorry; embarrassing; don't like it/hate it; I hate feeling like this; I hate to wear a moonboot; I am sad; I know how it feels; panic

APPENDIX U: Consent letter and form social validation process



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

16 March 2015

Dear Marina

REQUEST TO PARTICIPATE IN RESEARCH PROJECT

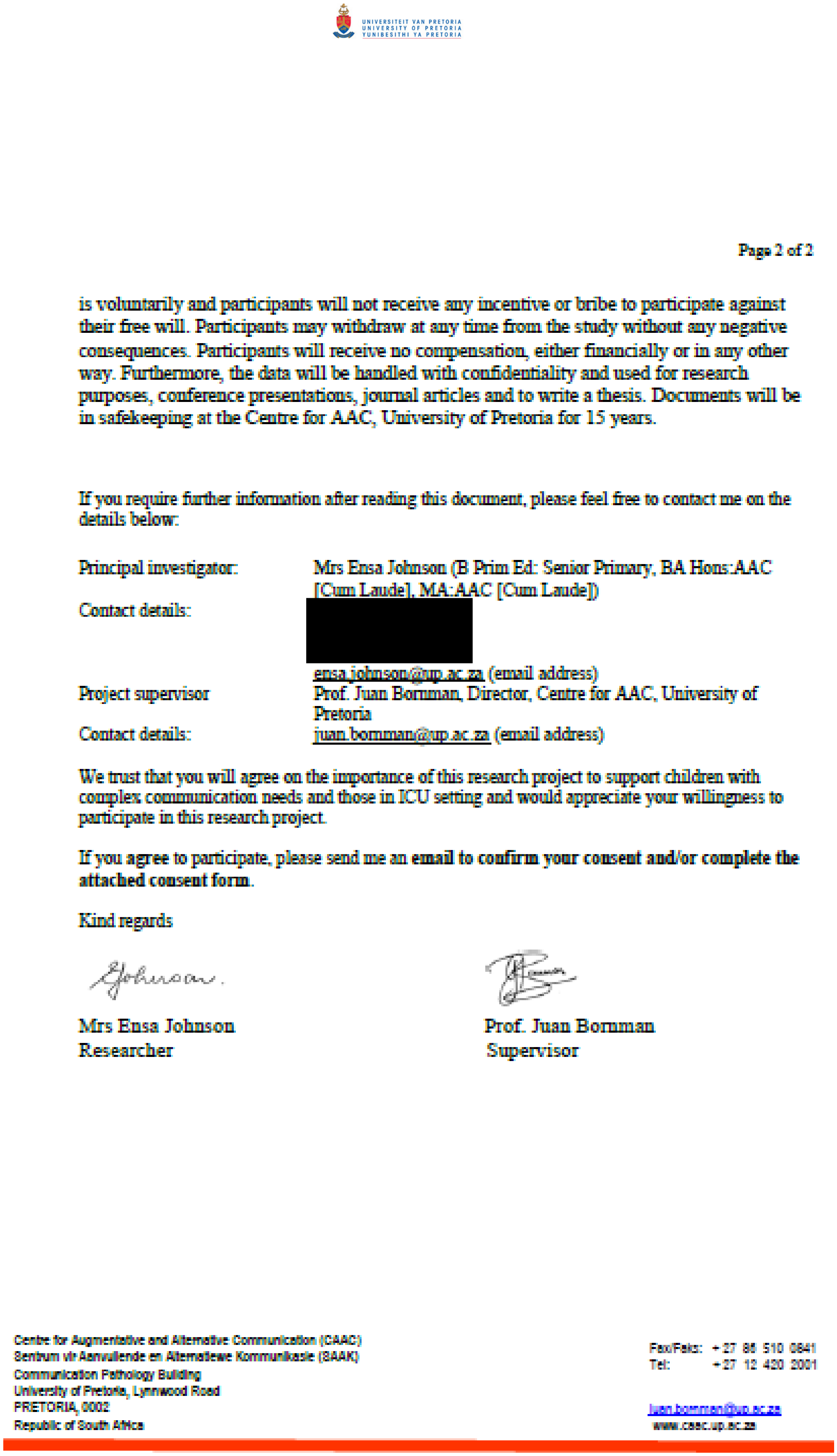
I am currently a PhD student in Augmentative and Alternative Communication (AAC) at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfilment for the requirements of this degree; I am requested to conduct a research project. I would appreciate your participation in this research.

The title of my project is: *An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use augmentative and alternative communication.*

Rationale for the study: The main aim of this research study is to identify and socially validate physical pain-related vocabulary for illiterate and pre-literate children who use augmentative and alternative communication. These words cover seven domains, e.g. (a) vocabulary used to describe pain; (b) vocabulary used to direct other's actions in response to the pain/injury/illness; (c) vocabulary used to describe pain location and visible signs to the actual tissue damage; (d) vocabulary to describe the causes of the pain; (e) Vocabulary to describe strategies used to cope with pain; (f) Vocabulary to reflect on strategies of how the pain could have been prevented, and (g) Vocabulary to indicate the consequences of pain or injury and influence activities and participation. The identified physical pain-related words will be incorporated on an AAC communication board. The use of the communication board will enable children with complex communication needs or young patients in intensive care units (ICU settings) to express their pain. Being able to do so will lower their frustration levels and enable health care staff, parents, teachers and/or caregivers to effectively address and manage their child's pain.

Participants: The final part of this research involves adults who use AAC to confirm the identified pain-related vocabulary children use to express pain. This social validation process will be done in the form of an interview where I will share three of the same pain-related stories and questions used during the interviews with the children with you. The aim will be to determine if you will be able to answer the questions by using the pain-related words and/or phrases on the communication board. The interview will not take longer than 15 to 20 minutes to complete. Your responses on the communication board will be video recorded. Thereafter, you will complete a questionnaire about your perceptions of the pain-related vocabulary. I would appreciate your willingness to participate in the interview and to complete the questionnaire.

Risks and benefits of participants: By participating in this project, the participants will enable the researchers to finalise the list of physical pain-related vocabulary which can be implemented on a communication board for use by children with complex communication needs or other sick paediatric patients in ICU settings to communicate during painful experiences. The participant will at no stage be exposed to any harmful situations. Participation in this project



Page 2 of 2

is voluntarily and participants will not receive any incentive or bribe to participate against their free will. Participants may withdraw at any time from the study without any negative consequences. Participants will receive no compensation, either financially or in any other way. Furthermore, the data will be handled with confidentiality and used for research purposes, conference presentations, journal articles and to write a thesis. Documents will be in safekeeping at the Centre for AAC, University of Pretoria for 15 years.

If you require further information after reading this document, please feel free to contact me on the details below:

Principal investigator:	Mrs Ensa Johnson (B Prim Ed: Senior Primary, BA Hons:AAC [Cum Laude], MA:AAC [Cum Laude])
Contact details:	[redacted] ensa.johnson@up.ac.za (email address)
Project supervisor	Prof. Juan Bornman, Director, Centre for AAC, University of Pretoria
Contact details:	juan.bornman@up.ac.za (email address)

We trust that you will agree on the importance of this research project to support children with complex communication needs and those in ICU setting and would appreciate your willingness to participate in this research project.

If you agree to participate, please send me an **email to confirm your consent and/or complete the attached consent form**.

Kind regards

Johnson

Mrs Ensa Johnson
Researcher

Prof. Juan Bornman
Supervisor

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INFORMED CONSENT FORM: PERSON WHO USES AAC

Research topic: An exploration of the common pain-related vocabulary typically-developing children use: Implications for children who use AAC

I, ____(full names and surname), hereby confirm that I am a person with complex communication needs who uses AAC and give consent to the following:

- Agree that I will voluntary participate in the study as outlined above and that I have the freedom of choice to participate or not.
- I understand that there are no risks for me to participate in this study.
- I understand that I have the right to withdraw from this study should I wish to do so for any reason whatsoever without providing any explanation
- I understand that there is no direct benefit or financial gain when participating in this research. However, information collected will ensure that children with complex communication needs or those in ICU settings can also have a way to communicate their pain and discomfort.
- I understand that the data will be handled with utmost confidentiality and will be used for research purposes, conference presentations, journal articles and to write a thesis. The data will be stored for a period of 15 years in a safe place at the CAAC, University Pretoria.

(Please tick appropriate block)

I give consent		I do not give consent	

______________________________ ______________________________

Signature of person who uses AAC Date

Email address of person who uses AAC:____

APPENDIX V: Social validation questionnaire

No AAC-______

QUESTIONNAIRE: PERSON WHO USES AAC

SECTION A

Part 1: Background information

Please answer all the questions.
Where applicable, please mark the appropriate block

For office use only

11. What is your gender? Please mark appropriate block:

Female	Male	

12. What is your age? ____

13. What is your first language?

Afrikaans	English	isiNdebele	
IsiXhosa	isiZulu	Sesotho sa loboa	
Sesotho	Setswana	SiSwati	
Tshiveda	Xitsonga	Other – please specify	

14. What is your highest level of education you have completed?

Not applicable	Primary school grade 7	High school grade 9 or less	
High school grade 12 or less	1 or 2 years post school	3 or 4years post school	
5 years or more post school			

15. Are you employed?

Full time	Part time	
Not employed		

Part 2: About your abilities

16. Do you have any of the following difficulties (tick all that apply to you):

Difficulty concentrating, remembering or making decisions	Frequent worry, nervousness, or anxiety	Difficulty seeing	
Difficulty hearing	Difficulty speaking so people can understand you	Other (please specify)	

17. If you have difficulty seeing, what is your level of vision?

Low vision (significant difficulty seeing, even when using glasses)	Blind (without usable vision or completely blind)	Not applicable

18. If you have difficulty hearing, what is your level of hearing?

Hard of hearing (significant difficulty hearing, even when using hearing aids)	Deaf (no usable hearing)	Not applicable

19. What type of aac system do you use? (tick all that apply)

AAC low tech communication system (e.g. alphabet board)	Augmentative and Alternative communication (AAC) device or software	Cochlear implant
Crutches, cane or walker	Hearing aid	Screen magnifier
Screen reader	Sign language interpreter	Speech-to-text technology
Tele typewriter (TTY)	Telephone relay service or video relay service (including CapTel service)	Text-to-speech technology
Wheelchair	None of the above	Other (please specify other aid)

20. Have you been hospitalised during the past five years?

Yes			No	

If yes, please provide reason(s) for hospitalization as well as date

Reason	Date

SECTION B

Information about the pain-related communication board

	Based on your experience of using the pain-related communication board, what are your perceptions about the following?					
21.	I could find words and/or phrase for all the questions	Strongly disagree	Disagree	Agree	Strongly agree	
22.	I could easily find the words or phrases i was looking for	Strongly disagree	Disagree	Agree	Strongly agree	
23.	I found that the grouping of the same kinds of words/phrases grouped together made it easy for me to access my choice.	Strongly disagree	Disagree	Agree	Strongly agree	
24.	The colours on the communication board helped me to quickly access the words and/or phrases	Strongly disagree	Disagree	Agree	Strongly agree	
25.	Children with complex communication needs will find these words helpful to express their pain.	Strongly disagree	Disagree	Agree	Strongly agree	

26. Are there any new words/phrases that you think should be included on the pain communication board for children? If yes, please give examples ____

____

____

27. Are there any suggestions that you would like to make sure that the children with complex communication needs can use the words or phrases on this board? ______________________________

____

____

DECLARATION: By returning the completed questionnaire, I give permission that the information may be used for research purposes. I understand that all data will be treated confidentially.

Thank you for your participation and completion of this questionnaire.

Ensa johnson (ensa.johnson@up.ac.za / [redacted])
Centre for Augmentative and Alternative Communication, University Of Pretoria

APPENDIX W: Observation screening checklist for persons who use AAC (ObsAAC)

Name of person who uses AAC:
Age:
Date of observation:

Tick all the appropriate blocks

A: Communication/speech ability (if any)	
☐	Uses vocalisations
☐	Uses gestures
☐	Uses speech, but unintelligible
☐	Uses no speech
☐	
B: Information about the AAC system	
Type of system:	
☐	Low technology (give example)
☐	High technology (dedicated device):
☐	High technology (non-dedicated device):
☐	Language of speech generating device
☐	
C: Mobility	
☐	• Ambulatory
☐	• Uses wheelchair
☐	
D: Gross Motor Functional Classification System (GMFCS) (Palisano et al., 1997)	
☐	**GMFCS Level I**
☐	• Can walk and climb stairs without restrictions (e.g. using hands for support)
☐	• Has decreased speed, balance and coordination
☐	• Has limitations in more advanced gross motor skills
☐	**GMFCS Level II**
☐	• Can walk and climb stairs with a railing
☐	• Has difficulty with uneven surfaces, inclines or in crowds
☐	**GMFCS Level III**
☐	• Walks with assistive mobility devices on level surfaces
☐	• May have limitations walking outdoors or in community
☐	• May be able to climb stairs using a railing
☐	• May propel a manual wheelchair (sometimes with assistance - long distances or uneven surfaces).
☐	**GMFCS Level IV**
☐	• Walking ability severely limited even with assistive technology/devices
☐	• Uses wheelchairs most of the time and may use own power wheelchair
☐	• May participate in standing transfers.
☐	**GMFCS Level V**

	- Cannot walk independently.
	- May be able to use powered mobility.
	- Has physical impairments that restrict voluntary control of movement and the ability to maintain head and neck position against gravity
	- Is severely impaired
	- Cannot sit or stand independently, even with use of assistive technology/devices
E: Bimanual Fine Motor Function (BFMF) (Beckung & Hagberg, 2002)	
	BFMF Level I
	- Manipulates one hand without restrictions and the other hand with restrictions or limitations
	- Has limitations in more advanced fine motor skills
	BFMF Level II
	- Manipulates one hand without restrictions and the other hand has only the ability to grasp or hold OR
	- Limitations in more advanced fine motor skills in both hands
	BFMF Level III
	- Manipulates one hand without restrictions and the other hand has no functional ability OR
	- Limitations in more advanced fine motor skills in one hand; the other hand has only the ability to grasp or worse.
	BFMF Level IV
	- Both hands have only the ability to grasp
	- One hand has only ability to grasp; other hand has only ability to hold or worse
	BFMF Level V
	- Both hands have only ability to hold or worse
	- Difficulty using arms, hands or fingers

F: Accuracy of pointing (Indicate number correct out of possible 5)					
Correct	1/5	2/5	3/5	4/5	5/5
%	20%	40%	60%	80%	100%
Average time:					

Important disclaimer: This screening checklist Is not designed for diagnostic purposes and should not replace a qualified professional.

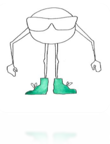
References

Beckung, E. & Hagberg,G. (2002). Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 44(5), 309-316

Cerebral palsy alliance (2015). Gross motor classification system. Retrieved online: https://www.cerebralpalsy.org.au/what-is-cerebral-palsy/severity-of-cerebral-palsy/gross-motor-function-classification-system/

Palisano, R. J., Rosenbaum, P., Walter, S., Russell, D. J., Wood, E., & Galuppi, B. E. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology*, *39*(4), 214-223.

APPENDIX X: Scripted interview guide for HPPS-S

<table>
<tr><td rowspan="5">Welcome</td><td>• Set participant at ease</td><td colspan="3">✓ <i>Thank you that you are willing to participate in this study.</i></td></tr>
<tr><td>• Introduce yourself.</td><td colspan="3">✓ <i>Hello, my name is Ensa. I am a PhD student at the Centre for AAC, University of Pretoria.</i></td></tr>
<tr><td>• Get informed consent</td><td colspan="3">✓ <i>Thank you for completing the consent form. Do you perhaps have any questions you would like to ask me about the study?</i></td></tr>
<tr><td>• To discuss the pain-related communication board as well as alphabet board</td><td colspan="3">✓ <i>Now we will quickly talk about the communication board layout, to help you to answer the questions. I trust that you had some time to look at the board? The board consists of all the words and/or phrases that children, parents and teachers suggested and which were used 10 times or more by them. You will see that there are colours on the board. Please note that these colours have randomly been selected just to indicate the different types of words. The pink coloured words are all those words that describe pain. (Researcher reads the words and/or phrases to the participant while pointing at it.) The blue words are words that tell other people what to do when you are in pain. (Researcher reads the words and/or phrases to the participant while pointing at it.) The orange words tell you more where the pain is and how the injury looks like. (Researcher reads the words and/or phrases to the participant while pointing at it.) Green words are words about causes of pain – either internally or externally. (Researcher reads the words and/or phrases to the participant while pointing at it.) The yellow words that you can use to cope with pain. (Researcher reads the words and/or phrases to the participant while pointing at it.) Purple words are words that you use to reflect on how you could have prevented the pain. (Researcher reads the words and/or phrases to the participant while pointing at it.) The brown words are words you can use to indicate the consequences of the pain and how it influenced your participation. (Researcher reads the words and/or phrases to the participant while pointing at it.)</i></td></tr>
<tr><td>• To introduce the character in the vignettes of the set of hypothetical physical pain scenarios</td><td></td><td colspan="2"><i>This is Ziggi. This is the character that children themselves chose and named. I will now share three stories with you that I’ve shared with the children in order to get the words and/phrases that you see on this communication board. Then I will have to answer three of the same questions that the children had to answer by using the communication board. If you can’t find a suitable answer on this pain-related board, you can use the alphabet board (or your device) to answer the questions. Okay, let’s begin.</i></td></tr>
<tr><td>Discussion</td><td colspan="4">The researcher will follow the script of the vignettes in the set of hypothetical physical pain-scenarios while showing the illustrations on the iPad.</td></tr>
<tr><td></td><td>Story grammar structure</td><td colspan="2">Story</td><td>Illustration on iPad</td></tr>
<tr><td rowspan="4"></td><td>Title</td><td colspan="2">Scenario 5 (Ziggi had an operation)</td><td rowspan="4"></td></tr>
<tr><td>Setting (Where and when)</td><td colspan="2">Ziggi wakes up in his/her hospital bed.</td></tr>
<tr><td>Initiating event</td><td colspan="2">The doctor removed his/her tonsils.</td></tr>
<tr><td>Problem</td><td colspan="2">He/she doesn’t feel well.</td></tr>
<tr><td></td><td>Plan or attempts</td><td colspan="2">He/She struggles to speak to his/her mommy.</td><td></td></tr>
</table>

	Questions	11. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) 12. What would Ziggi say to her mommy about her hurt? 13. What would Ziggi say or do to make it better?	
	Title	**Scenario 7** (Ziggi has a headache - bodily pain)	
	Setting (Where and when)	Ziggi struggles to do his work in class. He/she is really not feeling well	
	Initiating event	His/her teacher wants him/her to work in his/her books. He/she just can't.	
	Problem	He/she has a headache, He/she wants to vomit.	
	Plan or attempts	He/she walks to the teacher.	
	Questions	11. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) 12. What would Ziggi say to her mommy about her hurt? 13. What would Ziggi say or do to make it better?	
	Title	**Scenario 10** (Ziggi gets a drip)	
	Setting (Where and when)	Ziggi is very sick in hospital.	
	Initiating event	Ziggi needs medicine to make him/her better. The medicine is given to him/her through a drip – They have to put a thin needle in his/her arm to get the medicine in his/her body.	
	Problem	The nurse tries to puts a drip in Ziggi's arm. She keeps missing the vein where sha has to put the needle in.	
	Plan or attempts	She has to try again and again.	
	Questions	11. What would Ziggi say about his/her hurt? (Prompting questions: How does the hurt feel? Tell me more.) 12. What would Ziggi say to her mommy about her hurt? 13. What would Ziggi say or do to make it better?	
Completion of social validation questionnaire	Participant completes the social validation questionnaire either by using his/her AAC system which is recorded by a second person or his/she personally writes the answers in. Suggestions for improvement should also be provided.		
Closing the session	Thank you very much for helping me with the social validation of the words and/or phrases and providing good suggestions for improvement of the communication board.		