

Parents' perceptions of their children participating in paediatric palliative treatment and care

P Mathe
23817968

Dissertation submitted in fulfillment of the requirements for the
degree *Magister* in Social Work at the Potchefstroom Campus
of the North-West University

Supervisor: Dr H Yates
Co-Supervisor: Dr M Van der Merwe

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DECLARATION

I, the undersigned, hereby declare that this study project is my own original work and that I have not previously in its entirety or in part submitted it at any other university in order to obtain a degree.

Penelope Mathe

Date:

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I would like to thank God for the strength and wisdom He has given me in the past two years. This has been a challenging journey and a learning experience for me. I will not exchange it for anything.

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ZINCANE IZIBONGO ZAMI LUKHULU UDUMO LWAKHE

(Thanks be to the Almighty God)

ABSTRACT

Children's participation is embodied in Article 12 of the United Nations Convention on the Rights of the Child (UNCRC, 2009). Children's participation is about the right of children who are capable of expressing their views to express them freely in all matters affecting them. In the context of paediatric palliative care children's participation is also about access to information regarding children's illnesses, treatment and care. Methods of communication, such as open communication and honesty are the main requirements in order for participation to be genuine. As a means to advance knowledge, this study explores parents' perceptions of their children participation in the context of paediatric palliative care. The study aims to formulate guidelines, which can be applied to promote children's participation in their treatment and care in the context of paediatric palliative care. The interpretive descriptive research design was used as the methodology that offers the perspective for analysing situations and enabling practical applicability. Data for this study was gathered by means of semi-structured interviews, a vignette and incomplete sentences. Participants were sampled through a purposive sampling to ensure that the participants are the holders of the needed data. The collected data was transcribed and analysed and the thematic analysis process was incorporated.

The findings of this study indicate the parents' stance towards children's participation in the paediatric palliative care context. Participants' perceptions indicate the fears they have with regard to children's autonomy. Participants' perceptions are in contrary to the literature on children's participation and the legislation on children's rights as their view is that children should not be involved in decision making processes regarding the children's treatment and care. Participants made reference to their concerns related to the right of their children to participate in decision making regarding their treatment and care. Reference was also made to the societal norms and culture that is part of their existence.

Findings suggest that the need exists for developing support systems which will assist the parents in facilitating their children's participation regarding their treatment and care in the context of paediatric palliative care.

Based on the findings of this study recommendation are made to health care systems, that is, the governmental bodies that are involved and responsible for the implementation of policies in health care, hospitals and hospices to focus on developing individualised support structures for parents with children who have life-limiting illnesses as the disease profiles vary and the

societal response differs towards these diseases. The support structures should be based on the parents' understanding of their circumstances and experiences regarding their children's participation in the paediatric palliative treatment and care.

OPSOMMING

Kinders se deelname word omvat in Artikel 12 van die Verenigde Nasies se Konvensie oor Kinderregte (UNCRC, 2009). Beskou vanuit 'n regte-perspektief, gaan kinders se deelname oor die reg van kinders wat daartoe in staat is om hulle standpunte uit te druk om daardie standpunte vrylik uit te spreek in alle sake wat hulle raak. Binne die konteks van pediatriese palliatiewe sorg behels kinders se deelname ook toegang tot inligting ten opsigte van hulle siektetoestande, behandeling en sorg. Om outentiek te wees, is kommunikasietodes soos oop gesprekke en eerlikheid die hoofvereistes vir deelname. As 'n manier om kennis te bevorder, ondersoek hierdie studie ouers se persepsies rakende hulle kinders se deelname binne die konteks van pediatriese palliatiewe sorg. Daar word beoog om riglyne te formuleer wat toegepas kan word om kinders se deelname te bevorder in hulle behandeling en sorg in die konteks van pediatriese palliatiewe sorg. Die verklarende beskrywende navorsingsmetode is as die metodologie aangewend wat die perspektief bied vir die analisering van situasies en wat die geleentheid bied vir praktiese toepassing. Data-insameling vir hierdie studie het geskied by wyse van semi-gestruktureerde onderhoude, 'n vinjet en onvoltooide sinne. Steekproefneming was doelgerig ten einde te verseker dat deelnemers die nodige data kon verskaf. Die ingesamelde data is getranskribeer en geanaliseer met 'n proses van tematiese analise. Die bevindings van hierdie studie dui op die ouers se standpunt ten opsigte van kinders se deelname binne die konteks van pediatriese palliatiewe sorg. Deelnemers se persepsies dui op die vrees wat hulle ervaar ten opsigte van kinders se outonomie. Deelnemers se persepsies is in teenstelling met die literatuur oor kinders se deelname en die wetgewing oor kinderregte, aangesien hulle siening is dat kinders nie betrokke behoort te wees in besluitnemingsprosesse rakende hulle (die kinders se) behandeling en sorg nie. Deelnemers het verwys na hulle bekommernisse wat verband hou met die reg van hulle kinders om deel te neem aan besluitneming ten opsigte van hulle behandeling en sorg. Daar is ook verwys na die gemeenskapsnorme en kultuur wat deel is van hulle bestaan.

Bevindings dui daarop dat daar 'n behoefte bestaan vir die ontwikkeling van ondersteuningstelsels wat ouers sal help om hulle kinders se deelname ten opsigte van hulle behandeling en sorg binne die konteks van pediatriese palliatiewe sorg te fasiliteer.

Gegronde op die bevindings van hierdie studie word aanbevelings gemaak aan gesondheidstelsels; dit wil sê die regeringsliggame wat betrokke is by en verantwoordelik is vir die implementering van beleide binne die konteks van gesondheidsorg, hospitale en

hospiese om te fokus op die ontwikkeling van geïndividualiseerde steunstelsels vir ouers met kinders met lewensbeperkende siektes, aangesien die profiel van die siektes varieer en die gemeenskapsreaksie op hierdie siektes ook verskil. Die steunstrukture behoort gegrond te wees op die ouers se begrip van hulle omstandighede en ervarings van hulle kinders se deelname aan die pediatriese palliatiewe behandeling en sorg.

Sleutelterm: deelname van kinders, kinderregte, pediatriese palliatiewe sorg

ISIFINGQO

Umthetho wezizwe ezihlangene (UNCRC,2009) wethula ilungelo lezingane lokuzibandakanya ekuthatheni iziqumo mayelana nokunakekelwa kwazo. Kuhlelo lokunakekela izingane ezibhekene futhi eziphila nezifo ezingalapheki, ukuzibandakanye kwezingane kumayelana nokuthi izingane zithole ulwazi eziludingayo mayelana nezifo, nokunakekelwa kanye nokulashwa kwazo. Ukugxumana okuvulelekile futhi okunokwethembeka kungezinye izimfanelo ezizokwenza ukubamba iqhaza kwezingane kube ngokweqiniso. Lesi sifundo sibhekene nokuphenya imibono yabazali mayelane nelungelo lezingane lokuzibandakanya ohlelweni lokunakekela izingane eziphila nezifo ezingalapheki. Lesisifundo sihlose ukuqala imigomo engaphumelelisa ukuzibandakanya kwezingane ohlelweni lokunakekelwa kanye nokuphathwa kwazo. Imininigwane ngalesisifundo iqoqwe futhi yahlelwa ngendlela ejulile imibuzo kanye nesinqamu sesithombe isetshenzisiwe ukuqinisekisa ukuthi labo abazibandakanye nalo bangabantu abafanelekile ukuthi babe yigxenye yalesisifundo.

Imiphumela yalesisifundo ibonisa indlela abazali balubona ngalo ilungelo lezingane lokuzibandakanya ohlelweni lwezingane ezibhekene nezifo ezingalapheki. Imibono yabazali ibonisa ukwesaba abanakho mayelana nelungelo lezingane lokuzimela. Imibono yabazali iphikisana nokulotshiwe emthethweni sisekelo ebhekene namalungelo ezingane. Abazali baphakamise imizwa yabo mayela namalungelo ezingane okuzibandakanya ohlelweni nokunakekelwa kanye nokulashwa kwazo. Abazali baphakamise nemizwa yabo mayelananamasiko abo abaphila ngaphansi kwawo.

Imiphumela yalesisifundo ibonisa isidingo sokuthuthukisa uhlelo oluzobhekana nokuqxasa abazali ukuze bakwazi ukusebenzisana nezingane zabo ohlelweni lwezingane eziphila nezifo ezingalapheki.

Ngokuya ngemiphumela yalesisifundo imibono engasiza ukwakha umthetho mgomo ongasiza zonke izinhlangano ezisebenza futhi ezibhekene nezinhlelo zezingane ukuthi zenze izinhlelo ezingabhekana nokuqxasa abazali bezingane eziphila nezifo ezingalapheki. Lolohlelo kumele lubheke ekwenzini imigomo encike ezimeni zabazali kanye nasendleleni abaqonda ngayo izimo zabo.

TABLE OF CONTENTS

DECLARATION	ii
ACKNOWLEDGEMENTS	iii
ABSTRACT	iv
OPSOMMING	vi
ISIFINGQO	viii
KEY TERMS	
CHAPTER 1 ORIENTATION AND PROBLEM STATEMENT	1
1.2 AIM OF THE STUDY	4
1.3 THEORETICAL STATEMENT	4
1.4 RESEARCH METHODOLOGY	4
1.4.1 Literature review	5
1.4.2 Research design	5
1.4.3 Research method	6
1.5 DATA COLLECTION	7
1.5.1 Method of data collection	7
1.5.2 Procedures	9
1.6 DATA ANALYSIS	10
1.7 ETHICAL ASPECTS	11
1.8 TRUSTWORTHINESS	12
1.8.1 Credibility	12
1.8.2 Dependability	13
1.8.3 Confirmability	13
1.8.4 Applicability	13
1.8.5 Authenticity	13
1.9 CHOICE OF STRUCTURE	14
1.10 CONCLUSION	14

CHAPTER 2 CHILDREN PARTICIPATING IN PAEDIATRIC	15
PALLIATIVE CARE: A THEORETICAL EXPLORATION	
2.1 INTRODUCTION	15
2.2 CHILDREN’S PARTICIPATION: A RIGHTS PERSPECTIVE	16
2.2.1 Defining participation	16
2.2.2 Children’s participation	16
2.3 PAEDIATRIC PALLIATIVE CARE	19
2.3.1 Historical perspective	19
2.3.2 The aim of paediatric palliative care	20
2.3.3 Children who benefit from palliative care	20
2.3.4 Ethical consideration	21
2.3.5 Psychosocial issues of children in paediatric palliative care	22
2.4 CHILDREN’S PARTICIPATION IN THE PAEDIATRIC	23
PALLIATIVE CARE CONTEXT	
2.4.1 Critical elements of child-friendly paediatric palliative care	23
2.4.2 Guiding principles of children’s participation	24
2.4.3 Partnership in paediatric palliative care	26
2.5 CHALLENGES THAT IMPEDE THE RIGHT OF CHILDREN	28
TO PARTICIPATE	
2.6 COLLABORATIVE COMMUNICATION IN PAEDIATRIC	30
PALLIATIVE CARE	
2.7 PARENTS AS FACILITATORS OF CHILD PARTICIPATION:	32

CHALLENGES AND OPPORTUNITIES	
2.8 CONCLUSION	33
CHAPTER 3 RESEARCH METHODOLOGY	34
3.1 INTRODUCTION	34
3.2 LITERATURE REVIEW	34
3.3 RESEARCH APPROACH AND DESIGN	34
3.3.1 Qualitative research approach	34
3.3.2 Interpretive descriptive design	35
3.4 RESEARCH METHOD	35
3.4.1 Pilot study	36
3.4.2 Sampling	37
3.4.3 Sampling method	38
3.5 PROCESS OF DATA GATHERING	39
3.5.1 Method of data gathering	39
3.6 DATA ANALYSIS	41
3.6.1 Preparation of data	41
3.6.2 Coding the data	41
3.6.3 Establishing themes	42
3.6.4 Interpreting data	42
3.7 ETHICAL CONSIDERATIONS	42
3.8 TRUSTWORTHINESS	44
3.9 CONCLUSION	46
CHAPTER 4 DATA PRESENTATION AND DISCUSSION OF	47
FINDINGS	
4.1 INTRODUCTION	47
4.2 RESEARCH FINDINGS	48
4.3 DISCUSSION	74
4.5 CONCLUSION	78

CHAPTER 5 SUMMARY AND CONCLUSION	79
5.1 INTRODUCTION	79
5.2 OVERVIEW OF THE RESEARCH	80
5.3 FINDINGS	82
5.4 GUIDELINES	83
5.5 RECOMMENDATIONS	86
5.6 LIMITATIONS	86
5.7 RECOMMENDATIONS FOR FURTHER RESEARCH	87
5.8 CONCLUSIONS	87
BIBLIOGRAPHY	89
ANNEXURE A: INFORMED CONSENT: PROSPECTIVE RESEARCH	
PARTICIPANTS	97
ANNEXURE B: CONSENT FROM HOPSICE ETHICS COMMITTEE	99
ANNEXURE C: CONSENT FROM HOSPICE TO MAKE USE OF CLIENT	100
SYSTEM	
ANNEXURE D: INTERVIEW SCHEDULE	101
ANNEXURE E: TRANSCRIPT	102
LIST OF TABLES	
Table 4.1: Category 1: Themes and sub-themes	48
Table 4.2: Category 2: Themes and sub-themes	65

KEY TERMS

Children's participation

Children's rights

Paediatric palliative care

CHAPTER 1

1.1 ORIENTATION AND PROBLEM STATEMENT

Children in paediatric palliative care daily encounter diverse challenges. Paediatric palliative care is the philosophy and the organised method for delivering competent, compassionate and consistent care to children with chronic and complex life-threatening conditions (Friebert, 2009:2). Paediatric palliative care has furthermore been described as the active total care of the child's body, mind and spirit in addition to providing care to the family (Campbell, 2011:6). The aim of the palliative care for children is to improve the quality of life of children facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by identification and faultless assessment and treatment of pain (Sepulveda, 2002:94). For Nieuwmeyer (2009:7) paediatric palliative care is based on the ethical principles of beneficence, nonmaleficence, autonomy and justice. One difference between paediatric and adult palliative care is that a variety of childhood conditions are rare and the length of illness can vary greatly from days to years (International Children's Palliative Care Network (hereafter ICPCN, 2009:3). Paediatric palliative care is thus an emerging sub-speciality that focuses on achieving the best possible quality of life for children with life-threatening conditions and their families (Liben *et al.*, 2008:852).

The ethical principles of paediatric palliative care, namely beneficence, non-maleficence, autonomy and justice have been developed as the response to an increased institutionalisation of children who are dying. However, there are serious concerns about whether these core principles are being followed and respected (Liben *et al.*, 2008:855). The guiding principles of ethics in paediatric palliative care as cited by Nieuweyer (2009:7) state that the principle of beneficence and non-maleficence asserts that the duty of health professionals is to do good to their patients and to protect them from undue harm. These principles are concerned with considering the best interest of the child. In paediatric palliative care parents are considered to be the decision makers on behalf of the child, whilst the health care workers are ethically and legally responsible for ensuring that the decision taken serves the best interest of the child. Within the ethical and legal framework health care workers are responsible for evaluating every paediatric patient's capacity to make decisions and for ensuring that the patient's best interest is being served (McConnell & Frager, 2004:8). However, conflicts and disagreements can occur as there is no universally agreed upon definition of "best interest".

Ascertaining the best interest of each child within the context of treatment in palliative care can be challenging due to the dynamics of paediatric diagnoses and prognoses. According to McConnell and Frager (2004:9) paediatric patients suffer from various life-limiting and threatening illnesses each of which has its own treatment options and decision-making points. Many illnesses are rare and are only encountered in paediatric practice. Children in paediatric palliative care can thus experience multidimensional pain, which is the interaction of cognitive, emotional, socio-environmental and physical pain (Sepulveda, 2002:91-96). In the absence of discussing treatment options with children, they can end up receiving more aggressive care compared to adults at the end of their lives (Liben *et al.*, 2008:855).

Aggressive care according to Pittman (2012:1), is life-prolonging care, such as chemotherapy and intensive care, which is aimed at keeping the patient alive, it is very expensive and may not improve the quality of life or comfort of the patient. Children's involvement in treatment may, however, alter the process and experience of their treatment and care. Dotinga (2012:1) is of the opinion that terminally ill people who are involved in discussions about the end-of-life care are less likely to undergo aggressive treatment when they talk to the professionals earlier on. In addition to the possibility that children's participation in their treatment may alter it for the better, the right of children to participate has been established. The right is borne from the notion that children with terminal illness deserve to be treated in accordance with human dignity. The General Medical Council (2007:7-14) identified the elements that constitute child participation in the health care context as: assessing the best interest of the child; open communication, that is, not talking about the child but talking to the child; involving the child in discussions about his or her treatment and care; informing the child in a child-friendly manner what is going on; purpose of the treatments and what they involve; risks, benefits and other social implications. Furthermore the right of children to participate has a profound impact on the interaction that takes place between the adults and children in the context of paediatric palliative care.

The right children have to participate extends beyond the parameters of palliative care. In a recent study that was undertaken by the Children's Institute of the University of Cape Town, the right of children to participate in social dialogue as protected in international and national law has been emphasised (Jamieson *et al.*, 2011:18). Professionals and parents have the responsibility to listen to children and to take their views seriously in order to make decisions that promote children's best interest. Instead of talking about children and making decisions on their behalf, professionals and parents are now obliged to include children in their

conversations and to inform children about their choices (Kruger & Coetzee, 2011:36). The participation of children in respect of their treatment may however require a fundamental shift in approach and practice for both parents and professionals. According to international and national children's rights instruments, legislation and the stated principles of paediatric palliative care, children are expected to openly voice their feelings, concerns and desires, whilst the responsibility to decide on behalf of the child is placed solely on the parent or the guardian, as children younger than eighteen years are not legally considered competent to make decisions that may irreversibly affect their lives (Liben *et al.*, 2008:854). From the above it is clear that the right of children to participate implies that children should be included in decision-making processes and that they should be provided with information about proposed treatments and outcomes even while the parents or legal guardians are to be acknowledged as full partners in all care and decisions involving the child.

A lack of active participation of children in matters pertinent to their lives has also been identified in professional practice in the field of paediatric palliative care. Anecdotal first-hand experience in the paediatric palliative care hospice in Gauteng is indicative of challenges in respect of children's participation and involvement in their treatment and care. Furthermore, first-hand interactions with parents at the hospice suggest that parents struggle with disclosure to children about the child's illness. It seems as if information regarding the children's diagnosis, prognosis and their right to make decisions is in most cases not communicated to the children. The reasons given by parents include that they are protecting their children from being upset and burdened by the knowledge that they are facing death. The reasons tie in with Bunn's (2012:2) research into attitudes of parents towards talking to children about life-limiting illnesses.

From the literature, as well as from professional experience it appears that, parents' perceptions of children's involvement and participation around decisions regarding treatment in the paediatric palliative care context requires more attention in research. Empirical data will be gathered from parents associated with a palliative care facility in a bid to address this gap.

Research exploring the perceptions of parents of their children's participation in paediatric palliative care will thus be undertaken during this study.

A challenge in the practice field of paediatric palliative care is to raise awareness and capacitate children and their duty-bearers about the right of children to participate as

stipulated in the Children's Act (2005). The possible contribution of this study will be to comprehend the children's right and ability to participate in the context of paediatric palliative care based on their parents' perception.

Based on the above, the research question guiding this study is: *What are the perceptions of parents with regard to their children's participation in paediatric palliative treatment and care?*

1.2 AIM OF THE STUDY

The aim of the study is to qualitatively explore and describe through the use of an interpretive descriptive approach parents' perceptions of their children's participation in paediatric palliative treatment and care. The study will be based at the paediatric palliative care hospice in South Africa. This hospice is accredited by the Hospice Palliative Care Association to render paediatric palliative care services. The area of focus will be Gauteng.

1.3 THEORETICAL STATEMENT

According to the South African Children's Act 38 of 2005, children have the right to participate in decision making regarding their lives. Parents' stance towards children's participation in decision-making in the context of paediatric palliative care could, however, undermine this right. To this end parent's perception regarding children's participation will be explored and described. If parents' perceptions of their children's participation in paediatric palliative care are understood better, recommendations can be formulated for the facilitation of children's participation in the context of paediatric palliative care.

1.4 RESEARCH METHODOLOGY

A qualitative methodology will be applied to the exploration of parents' perception of children's participation in palliative care. In qualitative research the point of departure is to study the object within its unique and meaningful human situation or interactions (Collins, 2000:89). Qualitative research involves a holistic investigation in a natural setting. The

researcher focuses on understanding the subjective experiences of everyday life (Nieuwenhuis, 2010:47).

1.4.1 Literature review

The literature review for this study will be aimed at contributing to a clearer understanding of the problem that has been identified. The researcher will aim at broadening the context of the study and clarifying the gap that exists in relation to the existing research. Literature relevant to paediatric palliative care will be used by the researcher in order to identify gaps, which exist in current literature.

The following elements will form the bases of the literature review:

- Children's participation
- Children's right to participate
- Paediatric palliative care
- The role of parents in paediatric palliative care
- Challenges that impede the right of children to participate

Resources of literature that will be used are text books, electronic search engines and journal articles. The search engines will be those available through the North-West University library services: Google scholar, A-Z journal list, Sage Publications.

1.4.2 Research design

A qualitative interpretative description approach (Thorne, 2008) will be used to explore and describe parents' perceptions of children's participation in the paediatric palliative care context. Parents' perceptions could be better understood from how their social world is constructed. In this research, the meanings that the parents attach to children's participation will be explored. The data gathered will enable more detailed understanding about children's participation in paediatric palliative care as viewed by parents. The interpretive descriptive approach, according to Thorne *et al.*, (2004:5-7), attempts to understand the phenomena through the meanings that people assign to them in this study, the perceptions of parents about children's right to participate. This understanding will help to fill the gap that has been

identified in the literature and in practice. The strength of the interpretative description approach as stated by Nieuwenhuis (2000:60) is to offer a perspective and to analyse the situation under study. It is also to give an insight into how people perceive their situation. Within this study the researcher will not be satisfied with description alone. Meanings and explanations that may yield application implications will be explored (Thorne *et al.*, 2004:6).

1.4.3 Research method

For this study semi-structured interviews and a vignette will be used as data gathering methods. In this section the researcher will further explain the sampling of this investigation.

Purposive sampling will be used for the selection of participants. This means that the researcher will select participants based on the characteristics that make them the holders of the needed data. Purposive sampling in this study will be aimed at gaining insight into participation as it is regarded by the parents. The specific population of parents with children in paediatric palliative care is the target group. Strydom and Delport (2011:392) state that purposive sampling is based entirely on the judgement of the researcher, as the sample is composed of the elements that are characterised by attributes of the population that serve the purpose of the study.

The population from which the selection will be made is parents of children between the ages of 10 and 16 who are in paediatric palliative care in Gauteng but who are not in the final stage of the illness. In regard to this study the parents will be constituted of the biological parents and primary care givers in the case where both biological parents are deceased. Gauteng's hospice data base will be used in order to access parents of children who are under palliative care. Criteria for inclusion in the sample are:

- Age

The parents should have children who are in the age group of 10-16 years, the reason being that these children are able to understand and communicate their experiences and therefore parents can have an understanding of active child participation in decision-making processes related to palliative treatment and care.

- Demographic area

The sample will only be drawn from parents residing in Gauteng. Gauteng's hospice database will be used in order to access parents of children who are under palliative care.

- Language

The participants who are willing to be interviewed should be able to communicate in Zulu, Xhosa, Sotho, Setswana or English, as the researcher has command of these languages.

The existing clients of the researcher will not be included in this study as this may lead to role confusion and it would not be ethical practice.

Purposive sample sizes are often determined on the basis of data saturation. The researcher will sample continuously until no new information can be obtained (Mack *et al.*, 2005:5; Miles & Gilbert, 2005:151). Interpretive descriptive studies are often built upon relatively small samples (Thorne *et al.*, 2004:5).

1.5 DATA COLLECTION

In gathering data semi-structured interviews, a vignette, field notes in the form of sketchy notes, personal notes and inference notes will be used.

1.2.1 Method of data collection

- Vignettes

The vignette will be used in order to provide a less threatening way of exploring the topic. The study will explore sensitive topics on the perceptions of parents who have children suffering from life-limiting illnesses. Barter and Renold (1999:1) state that the vignette technique is a method that can elicit perceptions, opinions, beliefs and attitudes from responses or comments to stories depicting scenarios and situations. Within qualitative research vignettes are used as a complementary method with other data collection techniques. Vignettes are also described by Finch (1987:105) as the short stories about hypothetical characters in specified circumstances to which the participants are invited to respond.

- Semi-structured interviews

The interviews will enable the researcher to see the world as it is perceived by the participants. According to Greeff (2011:342), interviews are the predominant mode of data collection in qualitative research. Semi-structured interviews are suitable when the issue is controversial or personal (Greeff, 2011:352). In this study the sensitive issue of the participation of children with life-limiting illnesses and the perceptions of their parents will be explored, therefore semi-structured interviews will be appropriate for the study.

The interviews will be conducted on a one-on-one basis with the aim of exploring the participants' subjective experiences and perceptions with regard to the right of the child to participate. According to Du Plooy (2000: 176), the decision to use interviews depends on the researcher's knowledge of and familiarity with the topic, the purpose of the interview, the nature and sensitivity of the topic, the setting and the relation between the interviewer and the interviewee. The researcher is a social worker in the paediatric palliative care context. The empathic stance in interviewing will be followed in order to ensure more understanding and neutrality.

An interview schedule will finally be developed from particularly interesting topics that emerged from the literature study and participants' reflections on the vignette, which the researcher wants to explore further. After careful consideration, a set of questions will be developed (see Annexure D for a preliminary interview schedule).

Pilot interviews will be conducted by the researcher with the aim of ensuring that there are no flaws in the formulation of the questions that could lead to insufficient information that will be needed for the study. Pilot interviews will enable the researcher to become familiar with the process of interviewing.

To make participants feel more at ease during interviews, they will be given a typed format of the questions. The interviews will be tape recorded and transcribed. Consent will be sought from participants.

The participants will be debriefed after the interviews. Referrals will be made when necessary to the hospice's counselling department.

- Field notes

During interviews field notes will be made and they will be discussed at the end of the interview to ensure clarity and to deal with any misunderstanding that may occur during the interview with the participants. Firstly, sketchy notes will be taken as they will serve as memory joggers for more comprehensive notes. Personal notes which will be a reflective account by the researcher will also be taken. Lastly, inference notes will be taken as they contain the conclusions the researcher draws from the data and they contain new concepts that the researcher has developed and connections that the researcher has made between those concepts (Puttergill, 2000:240).

The data collection and fieldwork strategies that will be used by the researcher are that the researcher will have a direct contact with the participants under study. The researcher's personal experiences as a social worker working in such a context and insight in the field of palliative care are an important part of the inquiry and are critical to understanding participation in paediatric palliative care.

1.2.2 Procedures

The following aspects, which must be in place prior to obtaining access to data, will be considered:

- Prior to research being conducted, the researcher will need ethical approval from the Ethics Committee of the Faculty of Health Sciences of the North-West University.
- The researcher will seek permission from Hospice Wits Soweto before the research is to be undertaken.

The hospice data-base with the information of the children who are under paediatric palliative care will be used. The possible participants will be contacted telephonically and will be invited to participate in the study. If they are willing to participate, they will be asked to complete the informed consent documentation in written form.

- The researcher will ask permission to make use of the offices at the hospice which will be suitable for interview purposes.
- The researcher will clear the connection between the participants and researcher. The researcher is a social worker and there is a standing relationship of trust between the researcher and the parents of children in palliative care.

- Participants will be interviewed at a date and time that will be most convenient for the participants. Prospective participants will be informed in writing about the date and time of interviews.
- The researcher will ensure technical aspects of the research. This will be done by making use of a voice recorder to capture data during interviews, which will be transcribed verbatim and translated into English (if not in English). The researcher will take precautions to ensure that all data will be stored securely and that no unauthorised person will have access to the data.
- The hospice data-base with the information of the children who are under paediatric palliative care will be used. The possible participants will be contacted telephonically and an appointment will be made with them. The parents who cannot come to hospice will be visited at their homes. Those parents with children who are admitted in the paediatric ward will be seen at the office of the hospice.

1.6 DATA ANALYSIS

According to Babbie (2007:378) data analysis in a qualitative study is conducted with the aim of obtaining insight and knowledge about the patterns and meaning of relationships. Creswell (2007:81) states that in most qualitative studies data collection and analysis are not treated as two separate processes but are seen as cyclical and iterative. In this study the researcher will be guided by the saturation of data.

All interviews will be transcribed. Terre Blanche, Durrheim and Kelly (2006:322-326) mention that data analysis follows five steps, namely: familiarisation with and immersion in data involves the researcher's development of ideas and theories about the phenomenon being studied which in this study are the perceptions of parents regarding their children's participation in paediatric palliative treatment and care; developing themes which lead to logical conclusion based on evidence; coding which is the technique that is used for organising data or grouping segments of data together; and elaboration, which involves working out events in detail. The last steps are interpretation and checking. The transcribing and coding of the interviews will form the basis of data analysis in this study. All the similar incidences will be compared and organised into categories with the aim of identifying emerging themes and patterns.

1.7 ETHICAL ASPECTS

This research project falls within the approved ethics application of the Centre for Child, Youth and Family Studies. The ethics number of this project is NWU-00060-12-A1. The research theme is: Integrated relationship-focused support networks to enhance quality of life and wellbeing of children, youth and families.

Gauteng Hospice is accredited by the Hospice Palliative Care Association (HPCA). The researcher will seek permission from the Hospice Wits Soweto ethics committee before the research is undertaken.

In paediatric palliative care the ethical aspects of non-maleficence, beneficence, justice and autonomy are followed (Wassenaar, 2006:67-68). The researcher's personal experiences as the social worker working in such a context and insight in the field of palliative care are an important part of the inquiry and are critical to understanding participation in paediatric palliative care.

By following the principle of non-maleficence the researcher will ensure that no harm will be done to the participants. The principle of beneficence will oblige the researcher to maximise the benefits that the research will afford to the participants. The principle of justice requires the researcher to take responsibility, and to provide care and support for the participants who may be harmed by the research. Under the principle of autonomy the researcher will respect the participants and confidentiality will be discussed and not be breached.

The researcher will also adhere to the social workers' code of ethics (South African Council for Social Service Professions, 2007:4), which serves as the guideline to ensure that social workers conduct themselves ethically.

Application of the ethical aspects to this study will focus on the following:

- Obtaining consent

Participants will be informed about what the research will involve. Informed consent will be sought from the participants.

- Avoidance of harm

Participants will not be subjected to any form of physical discomfort, humiliation and embarrassment. Participants will be informed beforehand about the emotional impact that the study could have on them. Debriefing of the participants will be done after each interview as the study deals with the sensitive topic.

- Voluntary participation

The participants will not be forced or coerced to participate. The right of the participants to discontinue participation if they choose to do so will be respected.

- Honesty/Not misleading the participants

Participants will not be misled by giving them incorrect information about the purpose of the study.

- Confidentiality

It will be pointed out to the participants that confidentiality will be maintained throughout the research. The information will be coded and stored safely. The names of the participants will not be published or mentioned.

Annexure C contains the informed consent form.

1.8 TRUSTWORTHINESS

According to Nieuwenhuis (2007:80), the researcher in qualitative research is the data gathering instrument. Furthermore he refers to the seminal work of Lincoln and Guba (1985) who outlined the criteria for trustworthiness namely: dependability, confirmability, applicability, credibility and authenticity. Encompassing trustworthiness is crystallisation in that it provides the researcher with a complex and deeper understanding of the phenomenon (Nieuwenhuis, 2007:81) by using different ways of data collection and analysis.

1.8.1 Credibility

Credibility refers to the assurance that the conclusion stems from the data (Strydom & Delport, 2011:419). The researcher will use data obtained from the pilot study and semi-

structured interviews. The participants of the pilot study will sign the informed consent form. This will be aimed at ensuring that conclusions about perceptions of parents regarding children's participation in paediatric palliative care are truthful. The researcher will be able to demonstrate that the inquiry was conducted in such a manner as to ensure that the subject has been accurately identified and described.

1.8.2 Dependability

The researcher will ensure dependability by striving to eliminate any bias that might be brought to the study by constantly reflecting on the research process. To address the issue of dependability the researcher will rely on the objective coder from the North-West University who works with the researcher's supervisors. This will ensure that confidentiality is not compromised.

1.8.3 Confirmability

The researcher will provide evidence that corroborates the findings. In enhancing confirmability the researcher will document the procedures for checking and rechecking the data throughout the study. The study will confirm the gaps which have been identified. According to Strydom and Delport (2011:421) confirmability captures the concept of objectivity. Confirmability as stated by Trochim (2006) refers to the degree to which the results could be confirmed by others.

The researcher can actively search, examines the data collection and analysis procedures and makes judgements about the potential for bias and distortion.

1.8.4 Applicability

The study will apply to the health care situations whereby children have no voice in deciding how they need to be treated. The aim of this study is not to generalise findings but to begin with an exploration into an area about which little is known in order to start to inform practice regarding children's participation in paediatric palliative care.

1.8.5 Authenticity

In establishing the authenticity of the data, the researcher will ensure that the information is clear, concise and intelligible and that it is supported by other credible sources.

1.9 CHOICE OF STRUCTURE OF THE REPORT

This study will be in the form of a dissertation. The chapters will be set as follows:

Chapter 1: Orientation and problem statement

Chapter 2: Literature study

Chapter 3: Research methodology

Chapter 4: Data presentation and discussion of findings

Chapter 5: Summary and conclusion

1.10 CONCLUSION

This study is aimed at exploring the perceptions of the parents regarding their children's participation in their treatment and care in the context of paediatric palliative care. In order to achieve this aim, the next chapter will present a discussion of the literature that was reviewed in relation to the research topic.

CHAPTER 2

CHILDREN PARTICIPATING IN PAEDIATRIC PALLIATIVE CARE: A THEORETICAL EXPLORATION

2.1 INTRODUCTION

From a young age children have a sense of what makes them happy or unhappy. However, the context in which children find themselves determines to a great extent if they feel free to voice their feelings, needs and preferences. The dynamics at play when adults interact with children can either create an enabling environment for children to take ownership of what they think is in their best interest or it can limit the opportunity for children to act as partners in making decisions pertinent to their lives (Mannion, 2007:405-406).

Over the past years children's rights developed as minimum standards and guiding principles to ensure that children survive, grow and develop within a stable and healthy environment. One of the pillars and a guiding principle of the UNCRC is the participation of children as reflected in Article 12, which states that it is the right of children to participate in decisions affecting them and to express their views in this regard (UNCRC, 2009).

This study will attempt to contribute to the children's participation discourse by exploring how children's participation in the context of paediatric palliative care is perceived by parents. In the first section of this chapter the concepts of children's participation, the right of children to participate, children as partners in decision-making processes, parent-child interactions and paediatric palliative care are defined, hereafter the literature on children's participation specifically within the context of paediatric palliative care are discussed. The ethical considerations of paediatric palliative care as well as the psychosocial and cultural dynamics and conditions present in this context are emphasised in this chapter.

The gap that was identified in this study was to explore parents' perceptions of their children's participation in paediatric treatment and care. The lack of literature about children's participation in paediatric palliative care in South Africa emphasised the need to review literature about the rights of children to participate in decision-making regarding their treatment and care. Studies, which have been done in the context of paediatric palliative care

were reviewed with the aim of pointing out the strengths and limitations of children's participation in this context.

The possible contribution of this study to social work will be to provide an in-depth description of parents' perceptions of their children participating in the context of paediatric palliative care. The data on the perceptions of parents can be used to formulate guidelines for supporting parents in facilitating children's participation in the paediatric palliative care context. Social work has since its beginning, been focused on meeting human needs and developing human potential (IFSW, 2008: 2). The value base of social work, working from a rights perspective, is that all people, children included, should be respected and valued as complete human beings. The role of social workers in promoting full compliance of children's rights is that through their day-to-day contact with people they are able to accumulate vital information about the impact of laws and wider policies and practice on people (UNICEF, 2002:11). Furthermore, a focus on the way parents perceive children's participation can assist in understanding what support parents need in facilitating their children's participation in the context of paediatric palliative care.

2.2 CHILDREN'S PARTICIPATION: A RIGHTS PERSPECTIVE

2.2.1 Defining participation

The term participation is used to describe processes such as dialogue and information-sharing between children and adults based on mutual respect. Participation suggests some degree of involvement and for participation to occur transparency is needed (Jamieson, 2011:22-28). Davey (2010:6) described participation as the process through which someone influences decisions about his/her life. Participatory decision making can take place along any realm of human social activity. Participation is often legally mandated as it enables individuals to influence agency decisions in a representational manner. Participation cannot be genuine if no opportunity is given to understand the consequences and the impact of the opinions of the individual.

2.2.2 Children's participation

The child who is capable of forming a view is granted a right by Article 12 of the United Nations Convention on the Rights of the Child (hereafter: UNCRC, 2009) to express that view freely in all matters affecting him/her. The child's views are given due weight in

accordance with the child's age and maturity (UNCRC, 2009). Lansdown (2001:2) describes Article 12 as a substantive right, stating that children are entitled to be actors in their own lives and to participate in decision making. As with adults, democratic participation is not an end in itself but it is the means through which to achieve justice, to influence outcomes and to expose abuses of power. The principle of participation recognises the potential of children to enrich decision-making processes, to share perspectives and to participate as citizens and actors of change.

In order for children to participate, Lansdown's (2001:2) is of the opinion that adults should create the opportunities for children to do so, as Article 12 imposes an obligation on adults to ensure that children are enabled and encouraged to contribute their views on all relevant matters. Lansdown (2001:15) also noted that because children are rarely heard in adult arenas, there is sometimes a tendency to exaggerate their contribution and the other view was that when they do participate in the adult forum it is not acceptable to challenge or disagree with them.

The children's right to participate is embedded in human rights provisions across a range of international treaties and domestic legislation. In South Africa the Children's Act 38 of 2005 has the most substantive provisions for children's participation. Children's right to participate is linked to society's perception of children as participating members and to adult-child power relations (Viviers & Lombard, 2012:9).

Cashmore and Parkinson (2002:837-839) suggest "a shift of children's participation from a paternalistic approach to one where children are seen as stakeholders in decisions with a right to have the same input rather than being merely the object of concern". There were many reasons to include children as active partners in their own health care, however, this rarely happened. It was attributed to the shortage of tools to clarify children's conceptualisation of health and illness, to assess their capacity for decision making, to actively share information with children and to assess the outcome of shared decision making on the child patient (Levetown, 2008: e1442).

The study conducted by Wiener (2013:715) indicated that in many cases, parents mistakenly thought that not informing the child was best. Some professionals argued that paternalistic decisions to withhold "harmful" information from the child could be justified. Crompton (1990:27) talks about the "cost of concealment" when children are kept "officially ignorant". As early as the 1990's, Crompton advocated that children should be informed about issues,

stating also that adults often hide their own fear behind concern to protect children from distress.

One of the most striking landmark studies of terminally ill children conducted by Bluebond-Langner (2010:332) indicated that from the early age children were often aware of their diagnosis and their prognosis. She found that “adult avoidance of disclosure and denial of difficult information led the child to feel abandoned and unloved”. At the same time, the child’s response was often to protect the “unaware” adults, despite great personal cost; this situation was called mutual pretence and it had a negative impact on both parties.

Children’s lack of understanding does not give sufficient reason for not being involved in discussion regarding decision-making about their treatment and care. Children will try to understand their situation by using whatever information they have. Adults tend to assume that children often have no understanding of what is happening in their lives. Children can through increased experience and information construct and figure-out complicated pieces of information. Children need to be asked about their opinions, to be given choices and usable information, even when their decision will not be determinative (Bluebond-Langner, 2010:335-340).

Wiener (2013:715-718) argued that enhanced understanding in children provide a sense of control, which in turn lessen fear, reducing the harm associated with illness. Moreover, “if the child was asking about the condition, he or she often already knew something was wrong and checking to see who to trust. Children who do not ask should be given the opportunity to receive information, but if they refuse it, information should never be forced on them”.

In the study conducted by Lyon (2013:5) the findings suggest that adolescents with life limiting conditions indicated that they were capable of participating in and understanding the consequences of their decisions. They also valued autonomous decision making without excluding the parents.

According to Jamieson *et al.*, (2011:23) participation is not just the right, it is also a responsibility. Whilst learning to take responsibility for their well-being children rely on parents and other care-givers to fulfil their rights and to make decisions on their behalf.

The research context in which children’s participation for the purpose of this study is further explored is paediatric palliative care. Paediatric palliative care is a suitable context for exploring and describing children’s participation because for both adults and children

participation is a challenging learning process and cannot be reduced to a simple formality. In paediatric palliative care the unit of care is the patient and the family. Within this context the way children participate in the treatment and care plan will thus be influenced by the parent-child relationship and interactions. Paediatric palliative care as the research context for this study will be explained in more detail.

2.3 PAEDIATRIC PALLIATIVE CARE

2.3.1 Historical perspective

Palliative care was developed from the modern hospice initiated by Dame Cecily Saunders in 1965 in England at St Christopher's Hospice. The first children's hospice was Helen House in Oxford. It was started by Sister Frances Dominica in 1987 in memory of a little girl she has cared for (Ganca, 2009:13).

There are now twenty-five children's hospices in the United States, Poland has sixteen children's hospice programmes and there are many other programmes in Europe. South Africa has four specialist programmes registered with the Hospice Palliative Care Association (Ganca, 2009:13).

The World Health Organisation (WHO, 1998a) describes paediatric palliative care as the clinical speciality concerned with the management of the physical, emotional, social and spiritual pain amongst the children living with life-limiting illnesses. It is provided from the point of diagnosis, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological and social distress. Effective palliative care is delivered by a multidisciplinary team. It can be successfully implemented even if resources are limited. It can be provided in community health centres and even in children's homes. Paediatric palliative care is focused on ensuring the best possible quality of life for children whose illness makes it likely that they will not live to become adults.

The Canadian Hospice Palliative Care Association (2006:7) describes paediatric palliative care as the organised method for delivering compassionate and consistent care to children with life-limiting conditions and their families. Paediatric palliative care focuses on minimising suffering and enhancing the quality of life. It is also a child and family approach to care that is based on shared decision-making and sensitivity to the family's cultural and spiritual values, beliefs and practices.

Ganca (2009:8) is of the opinion that if applied earlier paediatric palliative care can enhance the quality of life and positively influence the course of illness. Children with life-limiting conditions have very specific palliative care needs, which are often different from those of adults.

2.3.2 The aim of paediatric palliative care

The aim of paediatric palliative care is to achieve quality of life. Quality of life relates to an individual's subjective satisfaction with life. The quality of life assessment in paediatric palliative care looks at four domains namely: the physical, emotional, social and spiritual. All children with palliative care needs require individualised care provided in a planned, coordinated, timely and flexible manner as directed by the need. The unit of care is the patient and the family. The family's views are important but should not supersede the patient's wishes (Liben *et al.*, 2008:852). Solomon *et al.* (2002:2) stated that the aim of paediatric palliative care is to maximise family involvement in decision making and care planning in the ways and to the degree that the individual family finds comfortable.

2.3.3 Children who benefit from paediatric palliative care

According to Solomon *et al* (2002:1) there are three distinct populations of children who stand to benefit from paediatric palliative care. They are children born without an expectation of survival to adulthood who may live a long time with substantial suffering, children who acquire illnesses such as cancer and those who suffer relatively sudden death due to trauma. The International Children Network Palliative Care (2009:1) classified children with life-limiting illnesses into four groups namely:

- Life-limiting illnesses for which curative treatment may be possible but can fail. Examples are irreversible organ failures of liver, heart and kidney and also cancer.
- Life-threatening conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, for example cystic fibrosis.
- Progressive conditions, which may extend over many years without curative treatment options, where treatment is exclusively palliative. Examples are HIV/AIDS, muscular dystrophy and Batten's disease.

- Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and the likelihood of premature death. Examples are cerebral palsy, brain and spinal injury.

2.3.4 Ethical considerations

The Hospice Palliative Care Association (HPCA, 2009) regarded ethics as the integral part of the foundation of hospice which has a distinguished history of concern for the welfare of people with life-limiting illnesses. In caring for patients with life-limiting illnesses, there are often complex decisions to be made and it is helpful to have a good understanding of the application of ethics principles to assist in decision making.

The following are the ethical guiding principles in paediatric palliative care.

- Respect for Autonomy

For children to be considered autonomous, they should participate in decision-making processes and have the developmental capacity to think, decide and act on the basis of such thought, free from pressure or coercion (Drake *et al.*, 2008:6). In order for the child to be able to participate and make informed choices he/she needs to have an understanding of the illness as well as the risks and benefits of treatment and non-treatment. According to Drake *et al.* (2008:7), the ability of the child to participate competently can be categorised into one of four areas namely: being informed, being consulted, having views taken into account in decision-making and being respected as the main decision maker.

Respect for autonomy underpins the concept of informed consent. The person with autonomy is considered to be the person who is well informed about the risks and benefits of the treatment and is able to make informed decisions. It is the duty of the health professional to disclose all the available information to the individual (Nieuwmeyer, 2009:7).

The right to information, which is enshrined in both South African and regional human rights conventions (HPCA, 2012:21) plays a central role in health care. Only when an individual is properly informed is he/she able to give informed consent to start or to continue to receive treatment. The Hospice Palliative Care Association Code of Ethics (HPCA, 2012:22) recognises that the fundamental principle underlying all care practices is respect for the worth, dignity and human rights of every individual.

- Beneficence and non-maleficence

These principles are often considered together as they are about the balancing of risk and benefit. The principle of beneficence recognises the duty of health professionals to do good for their patients and to protect the individual from undue harm. For the majority of children in paediatric palliative care, substitute decision makers are required and parents are usually the best people to fulfil this role. Parents are expected to make decisions that are in the best interest of the child and health professionals play a role in helping the parents and children with the task and decisions to be made through collaboration and consensus-building.

The principle of non-maleficence recognises the duty of health professionals not to harm their patients. Treatment can only be justified if there is benefit to the patient (HPCA, 2012:29).

- Justice

Health professionals have the duty to treat patients equally and fairly. All patients with active, progressive and far advanced disease and short life expectancy for whom the focus of care is relief and prevention of suffering and the quality of life should have access to palliative care. In paediatric palliative care health professionals are expected to ensure access to needed information and resources and to participate with people in improving the quality of their lives (Nieuwmeyer, 2009:7).

2.3.5 Psychological issues of children in paediatric palliative care

Children in palliative care, according to Muckaden *et al.* (2011:7) “have needs that are quite different from those of adults who are receiving similar care. The age-dependant cognitive abilities of children affect their perception of their illness, dying and control of the situation. A young child up to two years of age does not have any concept of death, and treatment must be aimed at providing physical comfort. Children from two to seven years may see death as a reversible process; it is important to minimise separation anxiety and to deal with guilt feelings. A child between seven and twelve years of age is likely to understand the permanence of death, and may suffer from guilt, abandonment and fears of body mutilation”. The adolescent faces a struggle between a need to be independent and possibly worsening physical symptoms and lack of control.

2.4 CHILDREN'S PARTICIPATION IN THE PAEDIATRIC PALLIATIVE CARE CONTEXT

2.4.1 Critical elements of child-friendly paediatric palliative care

Muckaden *et al* (2011:7) stated that up to 1970, it was believed that children need to be informed about their illness but a closed protective approach was recommended, whereby the information considered to be harmful would be withheld from the ill child. The work of Bluebond-Langner (2010: 332-334) radically changed this view. She found that children with a fatal illness had extremely high levels of generalised anxiety even when the prognosis was not directly revealed to them. These children were also likely to depict loneliness, separation and death in their fantasy stories. A marked discrepancy between what the children actually knew and what their parents perceived they knew was also noted. Very few children discussed death concerns with their parents.

In another study which was conducted by Drake *et al.* (2008:19) it was noted that older children are able to choose or influence their management and care whereas the infant is disadvantaged in having no opportunity to express views concerning his/her care. Levetown's (2008:e1445) opinion is that the child health decision making is family centred decision making and the pre-existing parent-child relationship should be understood. Parents and children were more satisfied and adherence to treatment was enhanced when the child was addressed in information gathering. However, parents wanted to be involved in the decision regarding how their children were informed about their health conditions. She further noted that research demonstrated improved adherence to the plan and resultant health outcomes when the child was treated as a partner. Liebert (2006:173) is also of the opinion that the process of decision making should be negotiated between the child and the family and in complex cases, consultation with an institutional ethics committee may be necessary.

In their study called "Allowing adolescents and young adults to plan their end-of-life care", Wiener *et al.* (2012:6) state that adolescents found the avoidance of conversation about impending death by adults around them creating a sense of isolation, fear and anxiety. Ultimately this placed the adolescents at risk of dying in emotional isolation. The findings of Wiener's (2012:8) study suggest that adolescents appreciated open and honest discussion and that they described a need for more specific information and clarity pertaining to life support and possible choices in the case of an acute event.

In the study conducted by Hsiao (2007:363), the findings illustrated that children displayed a diverse profile of communication preferences. According to that study, some children expressed a desire for more direct communication with the health professional and others preferred that their parents should speak for them.

A task force was convened by the Midwest Bioethics Centre in 1991 to consider the implications of the Patient Self-determination Act for the health care of minors. In this process the focus was to expand health care treatment decision making for minors. The primary focus was on the ethical issues relating to the participation of children in decision making regarding their health care. Most rights statements reviewed by the task force were actually written for parents rather than for minor patients. The effort of the task force was to provide a statement of rights directed to and understandable by children coupled with information for parents.

2.4.2 Guiding principles of children's participation

The right of children to participate has been emphasised by international and national legislation such as the South African Children's Act 38 of 2005. Section 10 of this Act provides a legal obligation to ensure child participation and it states:

Every child that is of such age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration.

The guiding principles in realising children's rights which are also applicable to the context of paediatric palliative care include evolving capacities of children, best interest of the child and responsibilities of parents.

i) Evolving capacities of children

The model developed by the task force (Bartholome *et al.*, 2007:1-12) which reflected three categories of minors with respect to their capacity to participate in treatment decision making was formulated namely:

- Minors without the capacity to participate in decision making in any meaningful way, e.g. infants, toddlers and minors with cognitive impairments. The task force suggested that since these minors have limited capacity to participate directly in decision making parents are primarily responsible for the health and well-being of their child.

- Minors with a developing capacity to participate in decision making e.g. elementary school-aged children. The task force suggested that these children should participate in treatment decision making to the fullest extent of their capacity and the assent of the child should be solicited prior to any health care intervention.
- Minors, who have achieved the capacity to make most health care decisions, e.g. mature minors, emancipated minors and most senior high school-aged young adults. According to the task force, the role of the minors with decisional capacity is to make treatment decisions including refusal of treatment, authorisation of do not resuscitate orders and decisions to withhold or withdraw life support. They should be respected as people responsible for their own health and well-being.

The three fundamental aspects the task force proposed acknowledged and attempted to honour children's capacity to make decisions regarding their treatment and care in the paediatric palliative care context (Bartholome *et al.*, 2007:1-2).

The first and most innovative component of the model was child assent. The task force believed strongly that a model for health care decision making involving minors must include the recognition of the developing capacity of minors for rationality, autonomy, and participation in decision making. Assent is the free expression of a child's willingness to undergo a specific health care treatment based on the child's knowledge and understanding (Bartholome *et al.*, 2007:1).

The task force also proposed that the health care providers are ethically obliged to solicit the assent of their minor patients who are capable of participating in treatment decision making but have not yet fully developed decisional capacity. In addition health care providers treating minors with evolving capacity are also obliged to obtain informed parental/guardian permission for health care treatment for their children. Although the law in most jurisdictions recognises a parental right to consent to the health care treatment of their children, the task force believed that the concept of parental consent raises serious ethical problems. In lieu of parental consent, the task force proposed the adoption of the concept of informed parental/guardian permission (Bartholome *et al.*, 2007:11).

Lansdown (2001:2) is of the opinion that in accordance with the children's age and maturity the weight that must be given to children's views needs to reflect their level of understanding

of issues involved. She argued that competence does not develop uniformly according to rigid developmental stages. The social context, the nature of the decision, the particular life experience of the child and the level of adult support will all affect the capacity of a child to understand the issues affecting him/her.

ii)

Best interest of the child

The law required that anyone taking a decision that affects a child has to make sure that the best interests of the child are a key consideration. According to Jamieson (2011:23) child's best interests are influenced by many factors such as the child's experiences, opinions and wishes. Section 7 and 9 of the Children's Act 38 of 2005 reinforce the constitutional principle that the best interest of the child is important. The Act is concerned about the legal welfare of the child and it needs people who are responsible for the care of the child to take the best interest of the child into consideration (HPCA, 2012:110). Whereas Hammarburg (2008:2) is of the opinion that the best interest of the child is a concept which has proven difficult to define and measure and cannot normally be the only consideration but should be amongst the first aspects to be considered and be given considerable weight in all decisions affecting children.

iii) Responsibility of the parents

Parents have legal and physical responsibilities and duties in respect of their children. Parents have important roles which entail providing a home for the child, maintaining and protecting the child. Children have a right to live in an environment that is safe both physically and mentally. Parents have their own cultural norms and these norms influence the expectations which are placed on the family life and the respective roles of parents.

2.4.3 Partnership in paediatric palliative care

Effective paediatric palliative care according to Vadwa and Marston (2012:65), depends upon a multiplicity of partnerships, but most importantly the one with the child. Building partnerships with children in their care is important and often neglected. Parents are seen as the main decision makers when it comes to their children's treatment and care.

The Children's Act No. 38 of 2005 provides the legal framework and endorses the right of children to participate in decision-making. Specific provisions include conditions under which a child may consent to his/her medical treatment. Partnering with children involves

facilitating child participation in the health care context and according to this Act it can be done in the following ways:

- Not only talking about children but also talking with children.
- Not only making decisions on their behalf but also including children in conversations.
- Informing children in a child-friendly manner what is going on, the benefits, risks, and social and other implications of the treatment.
- Informing them more about their choices.

The right of children to participate has certain implications for how children with a terminal illness deserve to be treated in accordance with their human dignity. Furthermore, it has a profound impact on the interaction that takes place between adults and children in the context of paediatric palliative care (HPCA, 2012:12).

The children's right approach is the bases of effective paediatric palliative care programming. The important requirements of childhood are described in the rights of children to health care, a healthy environment, parental and family care, access to information, education and participation.

In a child rights survey which was conducted by Viviers, Clacherty and Maker (2011:59) children highlighted the importance of participation by ranking it second on the list of rights most often violated. Children who participated in this survey valued the direct and honest discussion about what was important in their daily lives. They expected a participation experience that would respect their individuality, knowledge and their capacity to make their views known. They also wanted participation which is authentic and genuinely useful and trust between them and the adults who are facilitating their participation.

The study about children's participation which was conducted in the Children's Hospital in KwaZulu-Natal, indicated that children were concerned that there were no formal channels through which they could easily voice their needs and grievances. Children's recommendation on their personal autonomy was that they would like to talk for themselves (Kruger & Chalwa, 2012:53).

2.5 CHALLENGES THAT IMPEDE THE RIGHT OF CHILDREN TO PARTICIPATE

There are still significant barriers that impede the right of children to participate in the context of paediatric palliative care. In determining the way forward and ensuring that the barriers are dealt with the following challenges needs to be addressed:

- The dynamics of paediatric demographics

Mc Connell and Frager (2004:9) state that healthcare decisions for children with life-limiting illnesses presented a wide range of challenges. Paediatric patients suffer from a large number of life-threatening illnesses and disorders, each with its own unique trajectory, treatment options and decision-making points. The duration, type and intensity of care required vary tremendously between patients as well as within the same patient at different times during the illness. This makes it difficult to raise the issue of palliative care options and decision making about these options.

- Societal perspective on the seriously ill child

The death of a child is considered much less natural than that of an adult and ranks amongst the worst losses a family can experience. Due to the inherent need to do everything possible for the child any intervention is to be considered simply because it is available and confers hope of continued life. Mc Connell and Frager (2004:9) are of the opinion that the wish to protect terminally ill children has prevented research initiatives from which they could have benefited and it was also difficult to collect and apply quality of life and outcome data about children's varied and rare illnesses.

- Culture

Culture is described as the learned pattern of behaviours, beliefs and values shared by individuals in a particular social group. It provides human beings with both their identity and framework for understanding experience. Culture is dynamic and not fixed. Although there are guidelines for what is culturally competent none describe any individual family (Ganca, 2009:9).

The important principles of paediatric palliative care include honesty and open disclosure. These principles encourage independence of patients through participation in decision making and open expression of feelings and concerns. However, in some cultures children are not included in discussions of disease diagnosis and death. Honesty about dying is regarded as threatening to the cultural roles and functions of the parents. Open discussions with children are regarded as the threat and invasion that takes away the protection around children and make them children vulnerable. The lack of disclosure in these cultures does not necessarily imply lack of communication. Findings by Liben *et al* (2008:856) suggested that the “ill child and family members engage in behaviours, practices and rituals that indirectly acknowledge the threat of death but avoid directly addressing topics which are considered taboo”. Children adapt to their environment and they function within the values and rules that govern interactions.

Elements of culturally sensitive care involve developing increased sensitivity to the influence of culture on health care, beliefs and practices. Cultural sensitivity requires respect for the patient and his/her individuality. It underlines the fact that good and respectful communication is the foundation of quality palliative care. Association with a particular cultural, ethnic or religious group may influence patients receiving palliative care in respect of their expression and meaning of pain and suffering, beliefs about the cause and meaning of illness and attitudes towards disclosure and awareness (Kari *et al.* 2011:39-43).

- Spirituality

According to McSherry *et al* (2007:625) integral to providing comprehensive paediatric palliative care is an understanding of a family’s spiritual needs. Spirituality becomes a lens through which individual’s families try to understand themselves, their relationships and their beliefs influence the decisions they make. The need to incorporate religion and spirituality into the medical care of children is important, as most families consider themselves to be religious or spiritual. In the context of caring for seriously ill children it is important that the definition of spirituality remain broad and include an individual’s views on life, search for meaning and purpose and self-awareness.

Spiritual issues are valued and central to the family’s experiences. Health professionals need to ask children and parents about their spirituality and religious background. This will enable the health professionals to respond adequately to the vast cultural and spiritual variation in disclosure. Liben *et al.* (2008:857) suggest that a “culturally sensitive approach requires

fundamental changes on tackling institutional discrimination in the provision of palliative care, incorporating cultural issues in the medical curricula and embracing complexity and developing a richer appreciation of how minority communities achieve a dignified end of life”.

- Confidentiality in paediatrics

According to the General Medical Council (2007:18) respecting patients’ confidentiality is an essential part of good care and this applies even if the patient is a child. Without the trust that confidentiality brings, children might not give all the facts needed to provide good care. Children should be informed about the possible use of their information, including how it could be used to provide their care and for clinical audit. Sharing information with the consent of the child with the right people can help to protect children from harm and ensure that they get the help they need. It can also reduce the number of times they are asked the same questions by different professionals. By asking for children’s consent to share relevant information, the health professional is showing them respect and involving them in decisions about their care.

2.6 COLLABORATIVE COMMUNICATION IN PAEDIATRIC PALLIATIVE CARE

The foundation of decision-making communication between the children with life-threatening illnesses and their parents requires the involvement of the professionals. Collaborative communication entails the exchange of information and relationships between the people who are communicating. Feudtner (2007:1) states that collaborative communication in paediatric palliative care consists of establishing a common goal and exhibiting mutual respect and compassion for each other and assuring maximum clarity and correctness of what is communicated. It assures that medical treatment is in accordance to with the child’s and parent’s wishes and enhances the child’s and parent’s ability to make good decisions.

According to Mack and Wolfe (2006:13), improved communication is noted as one of the most important factors in enhancing end-of-life care in a paediatric setting. Among the few studies that have examined quality of health care provider communication in paediatric palliative care, parents have emphasised the importance of having a continuous caring relationship with staff. Although these studies revealed many important findings about the

quality of communication that parents seek in a health care provider during palliative care, the child's perspective on this topic is absent. Parents and children may have different ideas about the child's communication needs therefore gaining the child's perspective is critical if there is to be a cohesive relationship among all members of the paediatric triad namely: the child, the parents and the service provider (Hsiao *et al*, 2007:356).

According to Hinds *et al*. (2005:72) parents' perceptions of insufficient delivery of information to them by health care professionals have been associated with lingering regret and emotional distress. Parents can maintain a sense of hope for their child's survival even after being told that their child's death is certain. Parents who feel that the medical team is giving up may be resistant to engaging in important treatment discussions related to end-of-life care.

Communication about prognosis the end-of-life issues are complicated further when disclosure to the terminally ill child is considered. Clinicians generally agree that children should be informed about their prognosis and will benefit from open communication about their impending death. Such recommendations according to Hsiao *et al*. (2007:356) are about disclosure, which is based on clinical experience and not on controlled clinical trials involving children with life-threatening illnesses. Most initial disclosures to the child about prognosis come from the parents. Some parents, in an effort to protect their child and themselves from reality, will resist disclosing to a dying child.

Hinds *et al*. (2005:73) state that in the study which was conducted on parents with children with life-limiting illnesses "27% of parents who did not have end-of-life discussions with their terminally ill child reported regret, whereas all parents who did have such discussions denied having regrets. Without data to inform appropriate, effective communication procedures, it remains unclear when discussions should be initiated, what type of information should be provided, and how information should be delivered to dying children. Children differ in respect of the amount of diagnostic and prognostic information that they desire. Some children find it helpful to know detailed information about disease and treatment, whereas others find that same level of information distressing". In the end-of-life care, decision-making can be perceived by some parents as tiring if the responsibility for choosing care options is placed on the parents at a time in when they are losing their child.

Therefore, the role and participation of the health care team is crucial in imparting knowledge, information, making recommendations and working collaboratively to reach

consensus on what is in the best interest of the child (CHPCA, 2006:11). Several studies conducted on the perceptions of children on participation indicated that they are capable of participating in and understanding the consequences of their decisions and want to participate in shared decision making (Lyon *et al.*, 2013:5).

In paediatric palliative care the unit of care is the family. The family provides psychological, physical, spiritual and social comfort to the child (HPCA: 2012:2). All aspects of care are provided in a manner that is sensitive to the child's and family's personal, cultural and spiritual values, beliefs and practices and their developmental stage. The child has the right to age-appropriate information about his/her illness, potential treatments and outcomes. The family and service provider have the right to be informed about the illness, potential treatments and outcomes. Effective supportive paediatric palliative care depends on the ability of the family, the child and the palliative care team to communicate.

2.7 PARENTS AS FACILITATORS OF CHILD PARTICIPATION: CHALLENGES AND OPPORTUNITIES

Extensive research has been done on the impact of the ill child on the parents and families. In the study, which was conducted by Aoun (2004:26) in Australia, it was highlighted that parents caring for a child with a terminal illness suffer from issues which involve family disruptions, social isolation, physical and emotional distress. The parents of the ill child experience high levels of depression, an impaired social life, set within a family environment with low support and high levels of conflict. McGrath (2001c) reports that parents have a strong need for practical assistance and emotional support to be able to cope with the challenges of caring for their child during the long invasive treatment. Some concerns are about how to cope with terminal illness, imminent death, social stigma and discussing fears.

To parents of children with life-limiting illnesses, the illness of the child becomes the context that defines what it means to be a parent as their identity is forged in and through this experience. In the study, which was conducted in the US and Britain on parents with children with cancer where standard therapy had failed and cure was not likely, it was found that for parents, their task and responsibility, as they perceived and enacted them, was to leave no stone unturned to help their children. Parents did not take into consideration the child's choice of withdrawing the treatment (Bluebond-Langner 2010:334).

The review of literature on children's participation made it clear that parents are key role players in facilitating the process of communication between themselves, their child and the health care professionals. Parents will to a great extent determine the way in which their children participate in influencing their palliative treatment and care plan. In order for social workers to offer support to parents whose children are in palliative care, an in depth understanding is needed of how parents perceive the participation of their children in palliative treatment and care. This again leads to the research question of this study namely: *What are the perceptions of parents with regard to their children's participation in paediatric palliative treatment and care?*

2.8 CONCLUSION

Previous research in general paediatric consultations has shown a marginalisation of children's roles, especially with regard to discussions about treatment and care. Most of the studies, which were done on paediatric palliative care, are based mainly in First World communities which can afford expensive medical interventions.

In the South African context it is evident that children receiving palliative care have psychosocial needs that are not fully addressed. Research and the training of staff dealing with such children are of paramount importance. According to McSherry *et al.* (2007:612), experiences of psychosocial distress in children are rarely understood in a way that defines treatment. Children receiving palliative care most often report distress that is linked to various illness-related factors, namely: the family's ability to tolerate the child's discomfort, complex communication channels within the family, financial status, living conditions and social support. Currently there is no validated psychosocial assessment tool available to assess these domains. Assessment depends on the establishment of a respectful relationship between the health professional, the parents and the child.

Recommendations from previous research prove that there is a gap in research regarding the way parents perceive their children's participation in the treatment and care their children receive in the context of paediatric palliative care in South Africa.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

The purpose of this chapter is to give a detailed description of the research processes and the application of the methodology in the empirical investigation of this study. This chapter will explain the research approach and design which were used, the selection of the sample, the methods of data collection and the data analysis for this study. The ethical considerations which were observed and adhered to during this study and the assurance of trustworthiness will also be addressed in this chapter.

3.2 LITERATURE REVIEW

The literature review in Chapter 2 gave an overview of the existing literature related to children's participation in the paediatric palliative care context and other factors related to this topic with the aim of broadening the context of the study and clarifying the gap that exists in relation to the existing research. The researcher undertook an extensive search into and reading of the resources relating to this topic. The material from these literature sources was then structured by the researcher with the aim of ensuring that the reader will understand how the idea of this study came about. The context of this topic was also described in detail with the aim of outlining the nature and meaning of the problem.

The main topics which were reviewed in Chapter 2 were children's participation, children's right to participate, paediatric palliative care, challenges that impede the right of children to participate and collaborative communication in paediatric palliative care. The researcher identified the gaps in research which serve as the reason for conducting this study.

3.3 RESEARCH APPROACH AND DESIGN

3.3.1 Qualitative research approach

The researcher decided on a qualitative methodology with the aim of exploring parents' perceptions of children's participation in paediatric palliative care and to answer the question

about the parents' perceptions of children's participation. A qualitative methodology gave the researcher the opportunity to study the parents within their unique and meaningful human situation and interactions (Collins *et al.*, 2000:89).

The features of a qualitative methodology, namely the focus on natural settings, the interest in meanings and perspectives and understandings, the emphasis on the process and the inductive analysis and grounded theory (Woods, 2006:1) provided the descriptions of how parents perceive the children's participation within the context of paediatric palliative care. The objective of the study which was to explore the parents' perceptions of their children's participation in the treatment and care within the paediatric palliative care context was thus addressed.

3.3.2 Interpretive descriptive design

The literature review suggested that there are few resources addressing children's participation in paediatric palliative care in South African. The researcher used the interpretive descriptive design with the aim of exploring parents' perceptions about children's participation. According to Thorne *et al.* (2004:5-7), the interpretive descriptive design attempts to understand the phenomena through meanings that people assign to them. In this study the researcher also aimed at seeking meanings and explanations that the parents assign to their social context. The strength of the interpretive descriptive design is to create the ways of understanding, to offer the perspective and to analyse the situation under study (Thorne *et al.*, 2004: 1).

In this study, the interpretive descriptive design is an inductive analytic approach, aimed at understanding the parents' perceptions about their children's participation in their treatment and care. In this way it will be possible for the findings to further improve children's participation within the context of paediatric palliative care. By exploring the perceptions of the parents, the researcher aimed at immersion in the details and specifics of the data to discover important patterns and themes (Johnson & Christensen, 2004:362).

3.4 RESEARCH METHOD

The protocol for this study was approved by two NWU research panels and this study falls within the approved ethics application of the Centre for Child, Youth and Family Studies at

the North-West University as stated in Chapter 1. The researcher also adhered to the Course of Ethics and Code of Conduct regulating Social Workers.

After receiving ethical approval for this study, the hospice's database, which contained all the information about the parents with children living with the life-limiting illnesses in Gauteng, was obtained. The population from which the selection was made was parents of children between the ages of 10 and 16 who are under paediatric palliative care but are not in the final stages of the illness. Sixteen parents were contacted telephonically with the aim of asking for their permission to participate in the study. Only 12 parents agreed to participate in the study.

3.4.1 Pilot study

The researcher conducted the pilot study with the aim of testing the tools of data collection, namely semi-structured interviews, a vignette and incomplete sentences. This was done with the aim of ensuring that there were no flaws in the formulation of the questions that could lead to insufficient information that would be needed for the study. The researcher also needed to gain confidence in conducting research interviews.

Three parents of children who were admitted to the paediatric ward for respite care at the hospice were approached and were informed about the researcher and the proposed study. The researcher explained the aims of conducting the pilot study and what the pilot study was all about. According to Strydom and Delport (2011:394), it is important to conduct the pilot study, as it determines whether the relevant data can be obtained from the participants. The emphasis is on obtaining participants possessing the same characteristics as those of the main investigation of the study.

During the pilot study it became clear that the vignette was causing trauma to the participants. All the participants indicated that they would not wish for other parents to see the vignette, which was used. The participants were then referred for further counselling with the psychologist based at the hospice.

Based on the pilot study, the vignette was then changed and the vignette which was obtained from Jill Kruger of the Phila Impilo campaign (2012) was then used. The vignette was about the voices of children and their right to participate in their treatment and care. The same parents who were involved in the first pilot study were then requested to view the second vignette. They all agreed that the second vignette was not traumatising and it could be used for the actual research.

3.4.2 Sampling

- Purposive sampling

The researcher used purposive sampling with the aim of getting insight into participation as perceived by the parents. The participants were selected based on the characteristics, which made them the holders of the needed data. The researcher used her judgement in selecting the participants. Strydom and Delport (2011:392) state that purposive sampling is based on the judgement of the researcher, as the sample is composed of the elements that are characterised by attributes of the population that serve the purpose of the study.

- Population

The selection was made from the population of parents with children who are under paediatric palliative care.

- Age

The researcher decided on participants with children who are between the ages of 10 and 16 because, children of that age are capable of making informed decisions. These children are able to understand and communicate their experiences and therefore parents can have an understanding of active child participation in decision-making processes related to palliative treatment and care. The researcher also decided to select the participants whose children were not in the final stages of the illness.

- Demographic area

The sample was drawn from parents residing in Gauteng as the largest paediatric palliative care hospice is based in Gauteng and high number of children who are under paediatric palliative care reside in Gauteng. The researcher also noted that families with children needing paediatric palliative care from the other provinces in South Africa often move to Gauteng so that they are able to be nearer to the places where they are able to access palliative care services.

- Language

Two of the participants who gave consent to be interviewed were Sotho-speaking and the other ten were Zulu-speaking. The researcher has a good command of both these languages

and English was also used minimally, therefore so the interviews were conducted in both Sotho and Zulu.

3.4.3 Sampling method

- Step 1: Making contact

The names of the parents with children under paediatric palliative care but who were not in the final stages of the illness were obtained from the database. The database had 35 parents with children who are under long-term palliative care. There were 25 parents with children between the ages of 10 and 16. Sixteen parents were contacted telephonically by the researcher because they reside in areas where the researcher will have access to them. The information about the researcher and the proposed research was provided to them. They were allowed to ask questions. Only twelve parents agreed to be interviewed. The researcher requested a visit to the homes of the participants to have the consent forms signed and to conduct the interviews.

- Step 2: Signing of the consent forms and interviews

After setting dates and times with the willing participants, the researcher visited them at their homes. The information about the researcher and the proposed study was repeated to the participants. Annexure A was read to the participants in the language they could understand. They were then requested to sign the consent form. For those parents who wished to have a copy of Annexure A, copies were made and delivered by the researcher at their homes.

- Step 3: Follow up

The researcher proposed to share the results of the study with the participants telephonically. The participants indicated that they would appreciate to receive feedback about this study.

- Sample size

Though 12 participants consented to be interviewed, it was apparent during the eighth interview that data saturation had been reached. Interpretive descriptive studies are often built upon a relatively small sample (Thorne *et al.*, 2004:5).

3.5 PROCESS OF DATA GATHERING

Eleven of the interviews took place at the participants' homes and one interview took place at the hospice's office. All the participants indicated that they would not want to be interviewed in the presence of their children and other family members. All the participants who were interviewed in the comfort of their own homes ensured that their family members were not at home during the times of the interviews. One interview was conducted in the researcher's car as the participant's friends and other family members were in the house. The participants' confidentiality was completely protected. Babbie (2010:67) stated that confidentiality in a research project is when the participants and their responses are known to the researcher, but the researcher ensures not to make any identifiable details public.

3.5.1 Method of data gathering

The researcher used the vignette, incomplete sentences, semi-structured interviews and field notes in gathering data. According to Fouchè and Delport (2011:65), multiple forms of data collection should ideally be used in qualitative research in order to also add to crystallisation (Nieuwenhuis, 2007:81) and to enhance the trustworthiness of the research. Kelly (2006:287) states that qualitative researchers want to make sense of feelings, experiences and social situations as they occur in the real world and the central axiom of qualitative research is to work with data in context. In this study the researcher aimed at articulating the perceptions of the parents whose children are under paediatric palliative treatment and care.

The data was gathered by interviewing the participants. Kelly (2006:287) is of the opinion that qualitative interpretive researchers should not unsettle the context, but attempt to become a natural part of the context. This could be achieved by entering the research setting with the necessary care and engaging with the participants in an open and empathic manner. The researcher is the social worker employed in the palliative care context. The researcher is familiar with the psychosocial issues experienced by parents and families of patients who are under palliative care. The skills and knowledge that the researcher has in the field of social work are employable in the research context. The interviewer in this research is, according to Creswell *et al.* (2007:88), is expected to be a good listener, never to be judgemental, never to criticise, to be able to observe the participants' non-verbal communication, to maintain eye contact and to keep an upright posture. These aspects were adhered to by the researcher during the interviews.

- Semi-structured interviews

The researcher started the interview with general question. This was done with the aim of firstly, obtaining general information about the participants and secondly, helping the participants to relax and to be at ease. The semi-structured interviews were then conducted with the aim of enabling the researcher to see the world as perceived by the participants. Greeff (2011:352) states that semi-structured interviews are suitable when the issue is controversial or personal. As this study is addressing the sensitive issue of participation of children with life-limiting illnesses and the exploration of the perceptions of their parents, semi-structured interviews were appropriate as the method of data collection. The researcher informed the participants beforehand that they were not under any obligation to answer questions which they felt they did not want to answer. The interviews differed in terms of duration based on the participants' willingness to share their experiences. On average they took more or less 40 minutes.

- Vignette

After the semi-structured interviews, the three-minute vignette, based on the medical treatment in hospitals by Jill Kruger (2012) was introduced to the participants. The vignette was about children's participation and their need to have their voices heard in hospitals. After watching the vignette the participants were allowed to give their general overview of the vignette. Exploration about the specific segments of the vignette was also done. During the first two interviews the researcher sensed that the participants were irritated by the incomplete sentences. The researcher then decided to ask one incomplete sentence, which resulted in the participants sharing more information about their perceptions about children's participation in the context of paediatric palliative care.

The researcher conducted the interviews according to the interview schedule. Probing was done with the aim of exploring and clarifying the information given by the participants.

Field notes

Field notes were taken during the interviews and clarity was sought from the participants at the end of the interviews. This was done with the aim of dealing with any misunderstanding that occurred during the interviews. Personal notes which were the reflective account of the researcher's experiences were also taken. (Collins *et al.*, 2000:245).

3.6 DATA ANALYSIS

Due to the fact that the interviews were conducted in Sotho and Zulu the researcher could not find transcribers with a good command of these languages. The researcher was faced with the task of transcribing and translating the data into English. This task was beneficial in the sense that the researcher became more familiar with the data. Terre Blanche *et al.* (2006:322-326) state that data analysis follows five steps which include, familiarisation with and immersion in data involves the researcher's development of ideas and theories about the phenomena being studied. Through the process of transcribing the researcher became familiar with the data and was able to develop themes, which emerged during the interviews. Braun and Clarke (2006:87-93) emphasised six phases that need to be followed when analysing data, which are, familiarising with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and lastly producing the report. The researcher implemented the above mentioned phases and the objective coder assisted in coding as mentioned in Chapter 1.

3.6.1 Preparation of data

Voice recordings were translated and transcribed. The researcher made use of the four-column format. The first column contained the interview's questions. The second column contained the participants' responses. The third column was used for coding. The last column was used for the notes. Nieuwenhuis (2007:89) states that the recording of the interview data should be done in a meticulous manner and the transcript of what was said should be kept for the purpose of data analysis. Kelly (2006:302) is of the opinion that transcribing the interview is important as it is easier to refer back and forth to different parts of the interview if it is on paper and it is of value to annotate the text with notes on non-linguistic expressions, such as sighs, laughs and silences, which the researcher might miss in the transcription. After the transcription of the data, the researcher re-read the text a number of times with the aim of understanding the data better.

3.6.2 Coding the data

After the data was coded and transcribed it was divided into meaningful units, which were analytical. Key words were written to code the data, which was perceived to be important. Nieuwenhuis (2007:105) describes coding as the marking of the segments of data with symbols, descriptive words or unique identifiable names. The master list, which has all the

codes and explanations that were used in the study, was kept by the researcher. The coding process enabled the researcher to collect together all the text and data that was associated with some thematic ideas (Nieuwenhuis, 2007:105). The codes were developed by the researcher whilst coding the data.

3.6.3 Establishing themes

During this phase codes were organised into themes, and because this was a challenging process, adjustments were made on numerous occasions. According to Nieuwenhuis (2007:109), when the researcher works with emergent categories, identified codes should be read through and themes that recur in the data should be found as they become the researcher's categories. Schurink *et al.* (2011:415) is of the opinion that a part of the themes-developing phase is evaluating the data for its usefulness and centrality. The researcher should determine how useful the data is in illuminating the research question being explored and how central they are to the story that is unfolding about the social phenomena being studied. Themes, which emerged will be discussed in greater depth in Chapter 4.

3.6.4 Interpreting data

After data analysis was done the researcher had summaries of what the parents said about participation and the researcher had to make sense of the data. Schurink *et al.* (2011:416) state that the researcher interprets data by finding out how people being studied see the world, how they define the situation and what it means to them. Nieuwenhuis (2007:113) state that in interpreting data, the ultimate aim is to come to findings and draw conclusions and each conclusion must be based on substantiated findings from the data that was reported in relation to what is already known so as to reveal possible new insights or corroboration of existing knowledge. The detailed and comprehensive description of data will be presented in Chapter 4.

3.7 ETHICAL CONSIDERATIONS

The researcher ensured that the research was conducted in an ethically sound way. The following was ensured during the research:

- Informed consent

Each participant was provided with the letter which contained detailed information regarding this study (Annexure A). The participants who took part in the study signed the consent form

and the researcher has the copies of all the consent forms. The purpose of informed consent was to ensure that the participants understood that they were not forced to participate in the research and they could refrain from answering questions which they did not want to answer (Wassenaar, 2011:72).

- Avoidance of harm

The participants were informed beforehand about the emotional impact that the study might have on them. Participants were not subjected to any form of physical discomfort, humiliation and embarrassment. Strydom (2011:115) states that it is often assumed that harm in participants in the social sciences can be of emotional nature but physical injury might occur. At some point during the interviews the participants were allowed to talk about ill children in general not specifically their own children. As far as the researcher is concerned none of the participants showed signs of being emotionally distressed by participating in the study during and after the interviews. When the researcher realised in the pilot study that the vignette causes discomfort and emotional reactions, these participants were referred for counselling and the vignette was changed in order to not evoke such intense emotional reaction.

- Voluntary participation

The participants were informed in advance that they had the right to discontinue with participation if they wished to do so and their decision would be respected. The participants were not forced or coerced to participate. Voluntary participation according to Paul *et al.*, (2003:35) is the third requirement for informed consent where the participants should not be improperly pressured.

- Honesty/Not misleading the participants

The participants were given honest information about the study and the reason why the study was conducted. According to Strydom (2011:119) deception should be avoided at all times on the participants if it happens it should be rectified immediately.

- Confidentiality

It was pointed out to the participants that confidentiality would be maintained throughout the study and under no circumstances would their identifiable details be made public or published. The researcher also informed the participants that precautionary action would be

taken in storing the data. According to Smith (2003:56) confidentiality relates to the protection of individuals, institutes and the data collected.

3.8 TRUSTWORTHINESS

The researcher considered five criteria of trustworthiness in conducting this study namely, credibility, dependability, confirmability, applicability and authenticity. The purpose of trustworthiness in qualitative research is to establish the truth value of the research project (Schurink *et al.*, 2011:419).

- Credibility

According to Schurink *et al.* (2011:419) credibility refers to the assurance that the conclusions stem from the data. Shenton (2004:73) suggested that the following strategies should be applied by the researchers in ensuring the credibility of the study:

- Appropriate, well-recognised research methods

The research methods which were used in this study were well researched and chosen as the most appropriate methods for this study. The data was collected through the use of semi-structured interviews, a vignette and an incomplete sentence.

- Debriefing sessions between researcher and supervisors

There was a schedule set for the sessions between the researcher, supervisor and co-supervisor. This also served as the debriefing sessions and the guidance for the researcher regarding the process of this research study.

- The background, qualifications and experience of the researcher

The researcher has a degree in Social Work from the University of South Africa. After graduating the researcher worked at a centre for children with disabilities and afterwards at the hospice as the paediatric palliative care social worker. That is when the researcher became interested in researching the topic on children's participation.

- Member checks of data collected and interpretations

After the interviews were completed, the researcher summed up the interviews with the participants by also reflecting back on what was said by the participants during the interviews

➤ Thick description of phenomenon under scrutiny

This study was qualitative in nature therefore it allowed thick descriptions regarding the topic of the perceptions of parents regarding their children's participation in the context of paediatric palliative treatment and care.

➤ Examination of previous research to frame the findings

A literature review was done to frame the findings of this study.

- Dependability

As far as the researcher is concerned in this study the processes used were described in detail. If this study were to be repeated in the same context with the same participants using the same methods, the results would be more or less the same (Shenton, 2004:71). According to Sinkovics *et al.* (2008:699) dependability is concerned with stability of the results over time.

- Confirmability

According to Schurink *et al.* (2011:421) confirmability captures the concept of objectivity. The researcher ensured that the findings were the result of the perceptions of the parents. During data analysis the researcher ensured that the data and interpretations of the study were grounded in events not the researcher views (Lincoln & Guba, 1985:323).

- Applicability

The researcher ensured that the findings would be applicable to the health care situations where children have no voice in deciding how they need to be treated. Applicability is the extent in which findings of the study can be applied to other contexts (Krefting, 1991:214).

- Authenticity

The researcher has ensured that the data is authentic, that the information is clear, concise, and intelligible and that it is supported by other credible sources. Authenticity was proved

through the data collection methods which depicted the range of different realities (Tobin & Begley, 2004:392).

3.9 CONCLUSION

This research was conducted in the qualitative approach and the interpretive descriptive design was used. The methods, which were followed in this study, were explained in detail in this chapter. The strategies, which form part of qualitative research, were followed. Data collection was done through the use of multiple methods. The criteria for trustworthiness, which were used during this study, were also explained. The data was analysed in the manner that portrayed the perceptions of parents about the children's participation within the context of paediatric palliative care. Ethical aspects of the research were taken into consideration during this study. The research findings will be discussed and presented in the following chapter.

CHAPTER 4

DATA PRESENTATION AND DISCUSSION OF FINDINGS

4.1 INTRODUCTION

The literature review in Chapter 2 indicated the importance and value of children participating in their paediatric palliative care. The guiding principles of participation as a children's right were discussed. It was evident in the literature that decision making in relation to the treatment and care of children can be considered as a family-centred decision making and pre-existing parent-child relationships should be understood (Levetown, 2008:e1445). The importance of parents as facilitators of child participation was therefore explored as a theme in the children's participation discourse. The review of literature assisted in the identification of the gap in the current body of knowledge about children's participation. It was found that the kind of support parents with children in paediatric palliative care need in facilitating their children's participation in the treatment and care was not well explained in national research. To address this gap, information on how parents perceive their children participating in the context of paediatric palliative care was needed. In accordance with the identified gap and the need for this study, the aim of this research project was to interpretively describe parents' perceptions of their children's participation in paediatric palliative treatment and care. Based on the exploration and description of parents' perceptions of their children's participation, guidelines can be formulated for the support of parents in their role as facilitators.

The purpose of this chapter is to report on the empirical research findings of this study. The data for this study was obtained through the qualitative interpretive descriptive research design, which has an actual practice goal as explained in Chapter 3. Semi-structured interviews, a vignette and an incomplete sentence were used by the researcher to collect data. The data that was obtained through the individual interviews was transcribed verbatim. Through the application of thematic data analysis, broad categories and themes that emerged from the data could be identified. The findings of the study will be presented by means of the identified categories, themes and sub-themes and will be confirmed and supported by direct quotations of participants. The research findings of this study will be discussed and controlled against existing literature in the field of children's participation in order to indicate if the data obtained concur with or differ from or are unique in the light of the existing body of literature.

4.2 RESEARCH FINDINGS

Chapter 3 presented the profile of the participants who took part in this study. Chapter 3 explained the data analysis methods. The researcher focused on presenting an in-depth description of how the parents perceived children's participation in paediatric palliative treatment and care. Kreuger and Neuman (2006:161) are of the opinion that the researcher interprets the data by finding out how people being studied see the world and how they define their situation. In the presentation of the findings the researcher's objective is to give a description of the parents' perception of their children's participation in paediatric palliative care.

Categories, which link with the aim of this study, were developed. Parents' perceptions related firstly to their children's participation in paediatric palliative treatment and care and secondly to their role as parents in their children's participation and could be identified as categories and are presented below.

CATEGORY 1: CHILDREN'S PARTICIPATION IN PAEDIATRIC PALLIATIVE CARE

Children's participation in paediatric palliative care refers to the extent to which parents allow the children to participate in decision making regarding their treatment and care. The table below illustrate the main themes and sub-themes that emerged from transcribed data in relation to this category.

Table 4.1: Category 1: Themes and sub-themes

CATEGORY 1:CHILDREN'S PARTICIPATION IN PAEDIATRIC PALLIATIVE CARE		
Themes		Sub-themes
Theme 1 Access to information	1.1	Diagnosis
	1.2	Admission to hospice
Theme 2	2.1	Taking of medication

Children's participation in care and treatment plan	2.2	Parents' fears and uncertainties
	2.3	Deciding what is in the best interest of the child
Theme 3 Power shifting	3.1	Authority
	3.2	Powerlessness
Theme 4 Possible limitations to participation	4.1	Communication and honesty
	4.2	Age
	4.3	Children's questions
	4.4	Societal norms and culture

THEME 1: ACCESS TO INFORMATION

Access to information as a theme refers to how parents view children's access to information about their diagnosis, admission to hospice and in general the treatment and care options in the health care context. Articles 17 and 13 of the UN Convention on the Rights of the Child protect children's right to information (UNCRC, 2009).

Sub-theme 1.1: Diagnosis

It emerged during the interviews that all the participants' children were born with the human immunodeficiency virus (HIV). Participants' knowledge about their children's diagnosis and their unwillingness to share the diagnosis with the children indicate the fears that the parents have about being diagnosed as HIV positive and this determines the extent to which children are provided with information in the context of paediatric palliative care. Evident from participants' perceptions was the limited access that children have to information in relation to their diagnosis.

The child was 2 years old when I found out he was sick. When he is asking me about the medication he is taking I tell him that he is taking the medication in order to be big and strong. He does not know that he is under hospice care. He just sees these nurses who are visiting him here at home but does not know where they are coming from. We do not talk about that disease here at home. (Participant 1)

I found out in the year 2011 that the child was sick. He was tested at the clinic and I was told about his diagnosis. The child was not told about his diagnosis. He does not know what type of medication he is taking. He is very young (10 years). For now he thinks he is taking flu medication. (Participant 2)

It was in 2003 when we first knew about the child's diagnosis. Currently the child does not know that he has the disease. Fortunately enough for me he does not ask any questions. (Participant 3)

The child was born with the disease. The child suspects that something is wrong. I constantly lie to the child. Right now I am not ready to tell the child about the diagnosis. (Participant 6)

We found out about the child's sickness around the year 2000. He does not understand what is wrong with him. (Participant 7)

The child was born with the disease. We haven't told her about the diagnosis, we will cross that bridge when she starts asking questions. (Participant 9)

The child does not know about his diagnosis what if we tell him and he tries to commit suicide? (Participant 11)

Participants indicated that the children were not informed about the diagnosis because according to the parents, their children are still too young to comprehend what is happening to them. Children are not always present when the physician first tells the parents the results of diagnostic procedures or when options for further care and treatment are first discussed (Bluebond-Langner, 2012:335). According to the Child's Right International Network (CRIN, 2006:1) it should be ensured that children have access to information especially the information aimed at promoting the wellbeing, physical and mental health of the children. As mentioned in this study disclosing the diagnosis to a child is a controversial and emotionally charged issue for parents and children (Wiener, 2007:1). There are different psychosocial aspects of HIV/AIDS that influence the reaction of parents towards informing their children

about their diagnosis. The risk and fear of discrimination and stigmatisation associated with HIV may cause parents to say:

“Right now I am not ready to tell the child about the diagnosis”.

Parents’ decision not to disclose the diagnosis to the children is often influenced by fear that children might not keep the diagnosis a secret (Madiba, 2012:49). HIV diagnosis disclosure involves communication about a potentially life-threatening illness. It was clear from participants’ comments that not informing the child about the diagnosis is the only way they know how to deal with the situation. The findings of this sub-theme differ from what literature and specifically rights perspective stipulate in terms of what ought to happen for children to participate. It is evident here that dynamics in the social environment, such as HIV determine how participation is facilitated by parents. The gap between what the theory of participation as a children’s right stipulates and what happens in reality in health care practice in terms of decision making needs the understanding of contextual dynamics and how they influence parent-child relations and perceptions of children’s participation.

Sub-theme 1.2: Admission at hospice

Participants indicated that there is a stigma attached to and myths about hospice care in the communities. To some people hospice care means giving up hope. This was evident from the participants’ responses when they were asked whether their children knew that they were under hospice care.

He does not know what hospice care means. He is only happy when he sees the nurses come to visit him. He only knows that his mother died of AIDS. (Participant 1)

No, when he was admitted at hospice we told him that he was in the private children’s hospital. (Participant 7)

I was not given information about hospice and palliative care I only learned more about hospice when my child was already admitted. I regarded hospice as the place of death I still do. That is why it is not easy for me to discuss hospice and palliative care with my child. (Participant 3)

I am not sure if she knows; but I think just a little. I went with her to visit her grandfather who is my ex-husband. He is HIV positive. When we came back from hospice she asked me

what was wrong with her grandfather. I told her that her grandfather is HIV positive. (Participant 4)

No he does not know. The time he was admitted there we told him that he was in the beautiful hospital where they were helping him to gain some weight. (Participant 6)

No, he does not know. The hospice nurses are always visiting him. You know how it is we all know that nurses are from clinics and hospital so there is no difference between the hospice nurse and hospital nurses. (Participants 9)

The doctors at the hospital told me that they were referring the child to the hospice so that the child would get better care than in the hospital. The child was not part of that decision making. (Participant 10)

Participants in this study did, in many ways, acknowledge that they feared the stigma attached to the diagnosis and hospice care. Michelson and Steinhom (2007:212) describe paediatric palliative care as the end-of-life care, which has achieved national status as an important health care goal. Palliative care aims at improving the quality of life of children and their families facing problems associated with life-limiting illnesses. Hospices are known as places of death. Many hospices are known to be treating people who have less than three months to live. The parents' views about not informing the children about being under hospice care are associated with the stigma attached to hospice and the diagnosis of both the parents and the children. The literature on palliative care supports participants' perceptions about the fears they have about hospice care. Hospice Palliative Care Association (HPCA, 2012: 6) mentions that there are barriers to the provision of palliative care, which need to be addressed by raising awareness of the benefits of palliative care within communities.

THEME 2: CHILDREN'S PARTICIPATION IN TREATMENT AND CARE

Parents pointed out that children's participation in treatment and care is related to the taking of medication, the fears and uncertainties of the parents and deciding what is in the best interest of the child.

Sub-theme 2.1: Taking of medication

It was interesting that parents' perceived the taking of or refusal of taking the medication as the primary way in which children will participate in their care and treatment.

It is not right for a child to decide about the treatment and care. What if he makes a wrong decision? It might happen that he does not know that he has the disease because he is not sexually active. It depends on how a child thinks. If a child takes his medication there is no problem but if the child does not want to take medication, he does not have the a say in the matter, he must be forced to take medication. (Participant 5)

I can talk to the child but I must have the last word. If you allow children to have a say in serious matters such as their treatment then you are controlled by the child. (Participant 6)

I do not have a problem in discussing medication with the child as long as the child knows that the decisions lie with me. (Participant 7)

Yes, can you really imagine the child is sick and is also expected to make decisions about the treatment that is not going to work. (Participant 9)

It is my responsibility as the parent to ensure that my child receives the best medical care. I do not see how the child fits in. For me children's rights in the health care context are a complete no. (Participant 12)

Parents indicated that it is their responsibility as parents to ensure that children get the best medical treatment. Once again HIV provides the context from which the responses of the participants need to be understood and interpreted. Antiretroviral drugs are to be taken for life. Once a child defaults on the medication, the body develops resistance and that leads to other opportunistic infections and eventually death. The importance for the children to take the medication was emphasised. Children's rights were viewed as the tool that interferes with the parents' role, whereas the literature emphasises the importance of autonomy for children which thus sets out that the child could refuse treatment (Johnston, 2009:487).

Sub-theme 2.2: Parents' fears and uncertainties

Participants seem to fear that if children are given an opportunity to have a voice regarding their treatment and care the children according to the parents could make decisions which could be detrimental to their health.

It is not right for a child to decide about the treatment and care what if he makes wrong decision. (Participant 5)

What if you give the child the opportunity to have an opinion about the treatment and the child decides not to take medication, how I am going to handle that? (Participant 12)

If I involve the child in discussions about his treatment and he decides not to continue with the treatment, I will be killing the child and it's me who must bury the child. (Participant 11)

Participants indicated that they feared that when children are given the opportunity to decide they will decide what is not right and not in their best interest. Research suggests that children are not included in decision related to their treatment and care due to fears on the part of those who consider themselves responsible for making decisions (Bunn, 2012:2). Participants were reluctant to talk to children because of their own fears regarding the child's response towards news of his/her child illness. Perhaps because of this fear Von Lutzau *et al.* (2012:278) state that children find themselves being offered care based on the assumptions of adults. Cashmore and Parkinson (2008:95) are of the opinion that information based on research that has listened to children about their experiences and wishes could be utilised in helping parents and children to put their situation into a wider context. The impact of defaulting on medication has been mentioned in sub-theme 1.

Sub-theme 2.3: Deciding what is in the best interest of the child

Participants indicated that they knew what is best for their children and regarded themselves as the main decision makers when it came to their children's treatment and care. The responses below are an indication of the participants' perceptions on determining what is in the best interest of the child. Participants' perceptions are primarily related to the view of children who are only supposed to be seen and not heard. In relation to the question that was posed to participants on what would be the participant's response should the child ask how

he/she contracted the virus and how the participant would handle the situation should the child decide to stop taking the medication, one participant responded:

As a parent I know what is best for my child. I do allow him to have a say in other things not about his health condition. I am the one who takes decisions... He is the child; he would not dare ask me that question. Children have no business discussing such issues with parents. (Participant 1)

My role is to decide what is best for him and to take care of him...I will not allow him to have a say regarding his treatment and care...Children are children and they should remain children. (Participant 2)

In the health care situation I do not see how the children's rights fit in. If the child is sick he/she has no right to decide how she/he needs to be treated. Let the experts in the field and the parent decide what needs to be done. (Participant 3)

I remember after we told the child about her diagnosis and she started defaulting on her medication, without her permission the child was then admitted at hospice. As the parent I was doing what I knew was best for her. (Participant 4)

There is no way that children could be involved in decision making. Children must do what we parents tell them to do. There is no such thing as listening to children...I will not give the child a choice the child will do what I as the parent think is right. (Participant 6)

The child must know that a parent has the final say. (Participant 8)

I am a parent; I know what is best for him. (Participant 10)

As the possible consequence of children not knowing about their diagnosis and about their admission to hospice, it seems as if parents want to protect their children from making decisions that are not in their best interest. According to the International Federation of Social Workers (IFSW, 2002:25), in all actions concerning children the best interests of the child shall be a primary consideration. There seems to be a division between what is in the best interest of the child as a human being and what is in the best interest of one aspect of being human, that is, their health. Parents know the diagnosis and children do not know. As a result of parents' access to information with regard to the child's diagnosis parents know the benefits of the treatment and care plan and children do not. In the light of what parents know and the children do not know, it makes sense that parents feel responsible for making the

decisions with regard to the treatment and care of their children. Participants indicated that children have to obey what the parents tell them because they know what is best for their children based on the information available to them. It is evident that parents have responsibilities and duties towards ensuring better care for their children but the above seem to be in contrast to what the principle of the best interest of the child entails. The United Nations High Commissioner for Refugees (UNHRC, 2008:14) described the best interest of the child as the well-being of the child which is determined by the child's level of maturity, age and experiences. Simply put, the best interest of the child means listening to and considering the views of the child and taking that into account in decision-making processes. Bluebond-Langner *et al.* (2010:334) indicated that parents of ill children see themselves not only as decision makers but also as protectors and advocates of their children. Based on the participants' responses, it seems that from the position of the child in the parent-child relationship that the best interest of the child does not necessarily imply that parents listen to and consider the opinion of their children when decisions are made by parents in the context of paediatric palliative care.

THEME 3: POWER SHIFTING

Parents perceive their authority as challenged by children's rights which are seen as a government tool to indirectly assault the parents' authority over their children. It seems as if parents believe that they and people of the older generation have the right to dominate the younger generation. They as the parents have given birth to the child and with this, comes responsibilities. For parents the courts hold parents responsible for the care and protection of their children and these responsibilities are, for parents, related to having the control and power over their children.

Sub-theme 3.1: Authority

Parents' understanding of their authority over their children determines the extent to which children will be allowed to participate in decision-making processes in the context of paediatric palliative care. The participants' responses indicated the importance of care and protection that they need to offer to their children.

When I am ready to disclose his diagnosis to him, I will tell him. My role is to decide what is best for him and to take care of him. Children are children and they should remain children. (Participant 2)

My role is to take care of my child and to ensure that he takes his treatment. The parents decide what needs to be done. (Participant 3)

My role is to ensure that the child gets the best treatment. If a child takes his medication there is no problem but if the child does not want to take medication, he does not have a say in the matter he must be forced to take medication. (Participant 5)

Children must do what we parents tell them to do. There is no such thing as listening to children. I can talk to the child but I must have the last word. The children will do what we as parents tell them to do. I will not give my child a choice. I agree and disagree with the children's rights when it comes to the child's health and treatment I will not give the child a choice the child will do what I as the parent think is right. (Participant 6)

Right now he does not have a say. I do not have a problem in discussing medication with the child as long as the child knows that the decisions lie with me. (Participant 7)

The child was not part of decision making there was no need to talk to the child. The child must know that a parent has the final say. Where have you ever heard children engaging in matters that only concern their parents? My role is to care for the child and help the child to receive the best care. If we are going to allow children to tell us they do not want to take medication, it is then that we are going to bury them. (Participant 8)

My role is to take him for treatment and to ensure that he is comfortable at all times. No, children should not make any decisions about such issues. What do they know? (Participant 9)

My role is to make sure that the child gets treatment and he must attend all his appointments. I am a parent; I know what is best for him. In our culture the child has no say; children only need to listen to the elders. (Participant 10)

Parents want to protect their children in terms of the emotional effect the diagnosis can have on the child and probably the shame and stigmatisation that goes with HIV diagnosis.

The child was not informed. I do not want my child to have the same experience as mine when I was told about his diagnosis. It is my responsibility as the parent to ensure that my child receives the best medical care I do not see how the child fits in. For me children's rights in the health care context are a complete no. (Participant 12)

If the authority of parents is not acknowledged, parents can feel robbed of their dignity, as one parent explained:

I am the one who take decisions even though at the hospital they will tell you something and then pretend they want your opinion... They take away our dignity as parents. (Participant 1)

Parents are of the opinion that the core responsibility of making decisions lies with them. In his lecture Makarenko (2010:1) supports the parents' opinions. He mentioned that the very idea of authority is an attribute of older people, which is taken for granted. Children are aware of this and they accept this authority of parents over them. In the research which was conducted by Mack (2011:2085) about parents' roles in decision making for children with life-limiting illnesses, nearly two thirds of the parents indicated that they held the roles they wanted in decision making regarding their children's end-of-life care. Legally it is the parents' responsibility to care for the child and if the courts will punish a parent for not taking care of the child, the law by extension has acknowledged parental authority. Morally the parents must exercise authority over their children as they need constant supervision. Given the weight of parents' responsibilities authority obviously cuts both ways. Children have rights to the provision of care, protection and participation. From the participants' responses in this study, it seems as if parents feel their responsibility can be associated mainly with protection and care. In the UNCRC (2009) it is made clear that children's rights must always be understood and interpreted in relation to the principles of parental guidance and the evolving capacities of the child. These principles support the very important role of parents in matters pertinent to children's well-being and make provision for parents to take responsibility in accordance with the age and maturity of their children.

Sub-theme 3.2: Powerlessness

The responses from the participants indicated that they are in a powerless position in a context where their children have been diagnosed with HIV and even more powerless when keeping in mind that they have infected their children as the children are born with HIV. Parents infected with HIV are in a powerless position themselves. There are social risks, such

as stigmatisation, discrimination and feelings of shame they may already have experienced associated with disclosing the diagnosis to children. The lack of choice for parents at the health care institutions can furthermore contribute to the feelings of powerlessness.

No options were given to me I was just told that he will be given the ARVs. I will disclose the diagnosis to him when I am ready to do so. Even though at the hospital they will tell you something and then pretend they want your opinion. We are afraid that they might be stigmatised and if other children can know about them, they will be affected at school. (Participant 1)

The child was not told about his diagnosis. He does not know what type of medication he is taking. I will be forced to tell him that he is taking medication for HIV/AIDS just like me, his mother. (Participant 2)

Currently the child does not know that he has the disease. Fortunately enough for me he does not ask any questions. I was not given any options. (Participant 3)

All we have to do as the community is to support each other and stop stigmatising the disease. The problem that I have now is that since she is going to high school she will meet new children. There are those who will support her and those who will stigmatise her. I encouraged her that she must not change and stop taking the medication. (Participant 4)

He did not have a say whether he want to go to hospice or not because he had previously defaulted on his medication many times. At the hospital due to his history of defaulting they just wanted to chase him away and not give him medication. I pleaded with them to give him a last chance; maybe he will be better. They referred him to hospice to stay for a week in order for his medication to be administered. (Participant 5)

I will tell her not to tell her friends about our clinic visits. It must remain between the two of us. I was advised by the social worker that if she reaches the adolescent stage she must be told about the disease before she can sleep with boys. (Participant 6)

Participants highlighted their powerless position as parents and what they perceived as the social risks when disclosing the diagnosis to their children. The literature on HIV/AIDS differentiates between three categories of stigma, which are the reflection of fear and apprehension that is associated with any deadly transmissible illness, the use of HIV/AIDS to express attitudes towards people perceived to be associated with the disease and lastly, the

stigmatisation of people living with HIV (Schweitzer *et al.*, 2007: 334-349). Participants feared being identified and labelled as being different and deviant from the social ideal (Rand Health, 2009:3). Parents are responsible for the HIV transmission to their children and may experience feelings of guilt and shame that can even let them feel more powerless in the situation where the child may experience that there is something wrong with him/her.

THEME 4: POSSIBLE LIMITATIONS TO PARTICIPATION

This theme focuses on the reasons why children are not allowed inclusion or participation in decision making. The participants reported on communication and societal norms and culture as limiting children's involvement and participation in their treatment and care in the context of paediatric palliative care.

Sub-theme 4.1: Communication and honesty

Communication is relevant to the way in which children's participation is facilitated or not facilitated. It seems as if the hospital staff encourage parents to communicate with their children but parents are finding it difficult to talk to their children. They also find it difficult to be honest with their children regarding the children's health condition. Parents revealed that they did not agree that the child be told the bad news when it was suggested at the hospital.

The child suspects that something is wrong. I constantly lie to the child. Right now I am not ready to tell the child about the diagnosis. (Participant 5)

She asked me why she is always taking the blood test with me. I lied to her. I told her that I am sick and told her that since we have been sharing the same bed since she was a baby and also I used to breastfeed her they have to check to see if she is not sick. I could see that she suspects that something is wrong. (Participant 6)

They suggested that the child should be sent to a support group at the hospital and I refused as I did not want my child to know about his diagnosis in that manner. I will disclose it to him when I am ready to do so. (Participant 1)

I do not want my child to have the same experience as I had when I was told about his diagnosis. Whenever we go for hospital appointments, I first indicate to the nurse who is

attending to the child that the child is not aware of his diagnosis. I do not want any surprises
(Participant 12)

They did ask me at the hospital whether I have disclosed the diagnosis to the child. I told them that I was afraid. (Participant 2)

The counsellor insisted that the child should know what is happening with his health.
(Participant 5)

This sub-theme indicates that to a large extent the decision to disclose the diagnosis and involve the children in participation rests with parents. It seems from the participants' responses that the proper support structure available to parents is limited. The clinical staff seemed to be inadequately trained or not adequately involved in facilitating the communication processes between the parents and children. These results also confirm what has already been found in research as discussed in Chapter 2 (refer to Chapter 2, section 2.4.1). According to Crompton (1990:27), adults often hide the fear of their own feelings behind concern to protect the child. The reasons given by the parents in this study of not informing the children about the diagnosis signify the power relation between parents and their children. The lack of support structures for the parents with terminally ill children and this case HIV infected children, could also have an impact on how parents then decide to handle child participation. Levetown (2008:e1443-e1446) found that there is a need for clinical staff to be trained and the lack of resources within paediatric hospitals seem to be one of the major problems associated with the way communication is carried out between the clinical staff, parents and children.

The participants' need to tell lies to the children is based on the need of the parents to protect the child from knowing about impending death and from being discriminated against by the society due to the nature of the diagnosis. Parents seem to be using secrecy to manage stigma as outlined by Letteney and LaPorte (2004:7). The view of Wiener (2013:715) is in line with participants' responses as she mentioned that parents' dishonesty with children is based on the parents' avoidance of talking about end-of-life with their children.

Sub-theme 4.2: Age and evolving capacity

Participants' perceptions reveal their understanding of children's capabilities to participate in relation to their age, their level of understanding and the maturity of the children.

The right age to tell her is fourteen years (the child is currently 13 years old). (Participant 6)

He does not understand what is happening to him. He is still a child (15 years old). (Participant 6)

He is very young (10 years). For now he thinks he is taking flu medication (Participant 2)

Children are children and they should remain children (Participant 3)

The parents seem to be unaware of the evolving capacity of children to contribute to decision-making processes and to make decisions. According to Lansdown (2001:2), the weight that must be given to children's views needs to reflect their level of understanding of the issues involved. The social context, the nature of the decision, the particular life experience of the child and the level of adult support will all affect the capacity of a child to understand the issues affecting him/her. The study conducted by Coad and Shaw (2008:324) indicated that children's evolving capacity is often based on age-related qualities and less on the child's abilities, such as decision-making abilities, self-expression and interaction with others. There appears to be a contrast between parents' perceptions about evolving capacity of children and what the literature has reported. The literature about the evolving capacity emphasises that recognition of the developing capacity of children should be based on rationality, autonomy and participation in decision making. (Bartholome *et al.*, 2007:11).

Sub-theme 4.3: Children's questions

Participants indicated that the children are not asking questions and are not supposed to ask questions, especially when it concerns the treatment and care. When asked how they would respond to the children when the child asks about why he/she is taking medication and how he/she acquired the HIV, the participants gave the following responses:

He is the child; he would not dare ask me that question. (Participants 1)

I will not allow him to have a say regarding his treatment and care. I know that as time passes he will realise that he is not getting better and he is taking the medication non-stop. I will be forced to tell him that he is taking medication for HIV/AIDS just like me, his mother. Children are children and they should remain children. I do allow him to have a say in other things but not about his health condition; but to those things he needs to say only the right things. (Participant 2)

Fortunately enough for me he does not ask any questions. I believe the child must have the necessary knowledge but the child must make the right choices. For now he is okay, taking his medication and he is not questioning anything...He will not ask me that sort of question because I am his parent. (Participant 3)

Where have you ever heard of children engaging in matters that only concern their parents? The child must know that the parent has the final say. What is so difficult for them about listening to listen to us? The child will never control us in this house. (Participant 8)

We will cross that bridge when she starts asking questions. No, children should not make any decisions about such issues. What do they know? No, because I am afraid that he will ask questions, which I am not prepared to answer. (Participant 9)

The participants' responses also indicate that children do try to initiate participation as they have desire to know what is happening to them.

He grew up and started to ask why he was taking medication and had to go for treatment, whilst other children he was playing with are not taking any medication. (Participant 1)

Participants perceived children not asking questions as a reason for not disclosing and to providing information for the children. Furthermore, it seems as if parents viewed children as being unable to reason and figure out what exactly was happening to them. At the same time the complex realities of being infected with HIV/AIDS results in hopelessness and fear and according to the participants' opinion it seems as if children need to be protected from this. The literature on HIV/AIDS suggests that the health community should begin to use more creative interventions such as focused information dissemination in order to address and combat the stigma (Visser, 2007:2-3).

Sub-theme 4.4: Societal norms and culture

Social norms have an effect on how children and their participation is viewed by parents. Culture suggests that parents are often guided by their beliefs, values and the way of life, which they have been socialised into by the generation before them. Some of the cultural beliefs that the parents uphold were revealed. Participants revealed that some cultural beliefs could not be changed as they help to build and maintain the moral fibre in the society, as well as in their homes. Participants have reported that they were brought up to understand that there should be clear boundaries between children and parents.

According to the way in which I was brought up parents should not discuss some issues with children especially this one concerning the child's life and death. (Participant 1)

If you allow children to have a say in serious matters such as their treatment then you are controlled by the child. Our belief system is that mothers and fathers need to be honoured; that's how children learn respect. (Participant 6)

This sickness must be kept a secret. We learned when we were growing up that some information about the members of the family should be kept a secret. That is why I have not told him about his diagnosis. (Participant10)

By telling the child that he has a terminal illness means that you are telling the child that he is dying. I was raised not to talk about death with children. (Participant 2)

In our culture the child has no say, children only need to listen to the elders. (Participant 10)

Where have you ever heard of children engaging in matters that only concern their parents? (Participant 8)

The participant who indicated that she does discuss the disease with her child revealed her reasons for doing so.

What if I die now and the child does not know about the diagnosis? They will stop taking medication and they will die too. My child knows that there is no cure for his disease but the treatment will keep him alive for much longer. (Participant 4)

The result of this sub-theme indicates that children's participation depends on the societal norms and values that the families share. Societal norms and culture pose a major challenge as they are inherent in how parents and health professionals treat children who are ill (Kruger & Coetzee, 2011:38). Cultural beliefs and dominant discourses around death and dying may further influence the thinking and behaviour of parents concerning the right of the child to participate (Ganca, 2009:14). In some cultures children are not included in discussions of disease diagnosis and death thus the concept of autonomy may compete with local ethical systems (Liben *et al.*, 2008:855).

The literature states that there is a moral and ethical obligation to discuss health and illness with the child and this is supported by laws and policies, such as the Children's Act of 38 of 2005. These laws indicate an expectation that children will be active participants in their care

(Levetown, 2008:e1145). The response of the participants indicated that children are not considered as partners in decision making in the matters of medical care and treatment. Children are socialised to respect the role of parents and other adults as the authorities. Societal norms are often meant to represent a solution to the problem of attaining and maintaining social order. Norms are assumed to elicit conformity, and that there is a strong correlation between people's normative beliefs and their behaviour.

This study is an indication that the common values of parents regarding children's participation are embodied in norms that when conformed to determine the attitude that the parents have about the children's right to participate. Participants mentioned that they could not change the way they are functioning within their homes however the laws that claim to protect children with regard to their opinion overlook the authority of parents and their cultural beliefs.

CATEGORY 2: PARENTS' ROLE IN THEIR CHILDREN'S PARTICIPATION

The table below illustrate the main themes and sub-themes that emerged from transcribed data in relation to this category.

Table 4.2: Category 2: Theme and sub-themes

CATEGORY 2: PARENTS' ROLE IN THEIR CHILDREN'S PARTICIPATION		
Themes		Sub-themes
Theme 5 Parents' perceptions of the concept "children's participation"	5.1	Parents' perceptions of children's rights
Theme 6	6.1	Communication with parents

Support to parents	6.2	Counselling
	6.3	Hospital environment
Theme 7	7.1	Parents' experiences and emotions
Disclosure and non-disclosure	7.2	Informing children and choices

THEME 5: PARENTS' PERCEPTIONS OF THE CONCEPT "CHILDREN'S PARTICIPATION" AND POWER SHIFTING

Parents' perception of the concept "children's participation" indicate how parents understand and give meaning to children's participation, the parents' perceptions of children's rights, communication with parents, counselling, hospital environment, parents' experiences and emotions and informing children and choices.

Sub-theme 5.1: Parents' perceptions of children's rights

Parents' perceptions of children rights indicate the extent to which parents view children's participation as the children's right and how they feel about the fact that children have rights holders. The participants revealed that they do not attach any importance to children's rights as they cause confusion between them and their children, whilst the government is perceived as the entity, which interferes with the way parents raise their children.

I feel bad about these children's rights. They take away our dignity as parents. Moreover now when the right of the child to participate in decision making regarding their treatment and care is mentioned, that has nothing to do with children. I do not see any reason to involve the child in anything especially when the child is sick. (Participant 1)

In the health care situation I do not see how the children's rights fit in. If the child is sick he/she has no right to decide how she/he needs to be treated. Let the experts in the field and the parent decide what needs to be done. (Participant 3)

I agree and disagree with the children's rights when it comes to the child's health and treatment. I will not give the child a choice. The child will do what I as the parent think is right. (Participant 6)

I do not see any use for children's rights. The child must know that the parent has a final say. The child cannot control me in my house. As for me the right of the child to decide in health care context makes me feel sad. (Participant 8)

Participants appeared more comfortable with rights associated with care and protection of children and not that much with participation.

Some children's rights are good and some are unfair, for example children should be protected from abuse and neglect but allowing the child to participate in his treatment and care is not good. (Participant 7)

I do not have a problem with the rights that protect the child from abuse but I disagree with the rights that allow children to have a say especially in the health care context. The parent must decide. No parent wants to see her child die. By giving children the platform to be heard means they could also decide to do whatever they please. (Participant 9)

I do not like the subject of children's rights if we are going to allow children to tell us how they would like to be treated. The next thing they will tell us is that they do not want to take medication. That is when we are going to bury them. As the parent I know that my child's life depends on medication. (Participant 10)

It seems as if it is difficult for the parents to appreciate the value of children's participation in health care and it appears as if there is no education on what children's rights imply even though these rights are visible on the hospice's notice boards.

At the hospice I have seen the rights of the children all over the walls but for me as the parent they do not mean anything. (Participant 11)

I am not in favour of children's right, especially in the hospitals. Children are there to be helped, not for them to have a say about treatment. What difference would their participation make? As the parent I need to take responsibility for any decisions that need to be made anyway at the hospital. The doctors will tell you that they are going to do this and that. We do not even decide as much as parents never mind the child. For me children's rights in the health care context are a complete no. (Participate 12)

When asked to complete the sentence on the importance of children's rights the parents gave the following responses:

I said before children's rights are not good. They interfere with the way we raise our children. These are our children not the government's children. (Participant 1)

I am not in favour of children's rights. (Participant 2)

Children's right are important I do agree with the law that says the child must have full knowledge of his situation. I also want to know if it is right to tell him about his condition now. (Participant 3)

Children's rights are not good because these children then think they are superior to us the parents. I wish the government could take all these children and stay with them. (Participant 5)

Children's rights are not important. What about our rights as parents? It seems as if the government want us to be controlled by children. What about our culture? What saddens me is that whenever you try to discipline the child/your child, they cry abuse. (Participant 6)

Children's rights are not important; they work against our culture. I am totally against children's rights. (Participant 7)

These are not government children, they are our children but we are always being told what to do or what not to do with our children. I do not see any use for children's rights. The child must know that the parent has the final say. What is so difficult for them about listening to us? The child will never control us in this house. (Participant 8)

They are not important. I do not understand what they are trying to do. Children's rights are everywhere but you don't get to see parents' rights. I think they are taking this too far, especially with this one you were asking me about. (Participant 9)

I think children's rights are in conflict with our culture. We grew up knowing that parents and all the elders need to be respected. Imagine now the sick child with rights. (Participant 11)

The results of the study strongly indicated that participants perceive children's right as the threat to their authority as parents and inappropriate in the context of paediatric palliative care. There is a clear difference in this perception of parents and what the UNCRC (2009), for example stipulates in Article 5 concerning children's rights that need to be understood and realised within the context of parental guidance. Despite what the literature reports about the

rights of children in the context of paediatric palliative care parents seem to have different views. Parents seem to be unsure of children's rights and the children's abilities to make correct choices. It seems as if children's subordinate position in culture and society may affect the thinking about participation as a children's right. Maybe an emphasis on children's status in society in terms of the minimum standards they are entitled to in relation to quality of life may be a possible reason for why parents want to defend their rights against the rights of children. There was a clear polarity in terms of legislation and the Constitution governing children's rights and the culturally embedded views of the participants regarding the rights of their children.

The next theme emphasises the importance of support to parents. Aoun (2004:26) and (McGrath, 2001c) indicated that parents of children facing life-limiting illness often have high levels of depression and they have a strong need for practical assistance and emotional support.

THEME 6: SUPPORT TO PARENTS

Support to parents as a theme focuses on the way in which parents receive the necessary support from the health care providers considering the HIV/AIDS diagnosis, treatment and care. Eleven of the twelve participants shared the same experiences regarding support in the health care context. Communication patterns with parents and counselling services within the hospitals form part of support to parents.

Sub-theme 6.1: Communication with parents

Communication with the parents indicates the extent to which hospitals give information to the parents. According to the participants hospitals do not have sufficient communication channels.

No options were given to me I was just told that he will be given the ARVs. (Participant 1)

I was not given information about hospice and palliative care. I only learned more about hospice when my child was already admitted. I regarded hospice as the place of death I still do. That is why it is not easy for me to discuss hospice and palliative care with my child. (Participant 3)

No options were given. I did not feel supported by the hospital staff. To them what they were telling me about my child's diagnosis was normal. They did not consider how I felt at that moment. (Participant 5)

At the hospital due to his history of defaulting they just wanted to chase him away and not give him medication. I pleaded with them to give him a last chance; maybe he will be better. (Participant 7)

Participants mentioned that no options and information was given to them regarding what they needed to do next in terms of caring for their children who were diagnosed as HIV positive. The study conducted by Meert (2008:5-6) supports what participants reported as it revealed that parents often felt that physician withheld information about the child's prognosis while some parents expressed stress and frustration with receiving contradictory information from different physicians caring for their child. Lack of proper systems and shortage of staff in the hospitals could be linked to poor communication channels. Levetown (2008:e1446) indicates that the most frequent criticisms of the health care practice concerns relationships with practitioners. These relationships have an effect on parental satisfaction. When parents perceive that they have not been treated with respect it will impact on their perceptions about hospitals, hospice care and the treatment and care provided.

Sub-theme 6.2: Counselling

Three out of twelve participants indicated that they received counselling regarding their children's illness. Yet eleven participants indicated that they chose to keep the diagnosis from their children.

They sent me to Bara for treatment. I received counselling, not the child. (Participant 1)

When they are telling you bad news they just give it as it is. There is no time for proper counselling. (Participant 3)

Participants indicated that parents do not always get support from the hospitals. Goldstein and Rimer (2013:200) affirm that parents do not always get the support from health care professionals, and that the role articulated in the hospitals' policies for supporting parents is not routinely exercised. Participants considered the busyness of hospitals as a barrier to involvement. Follow-ups are not done and people are not referred to other agencies which might render proper counselling.

Sub-theme 6.3: Hospital environment

Responses of the participants indicate that service at the hospitals differs. Other participants received good advice and care whilst others have bad experiences.

At the hospital I was given all the information I needed about the child's disease. They suggested that the child should be sent to a support group at the hospital and I refused as I did not want my child to know about his diagnosis in that manner. I will disclose it to him when I am ready to do so, even though at the hospital they will tell you something and then pretend they want your opinion. (Participant 1)

I think the workers at the hospitals are inhumane. They quickly tell you the bad news and they do not care how you feel afterwards. They did ask me though at the hospital whether I had disclosed to the child; I told them that I was afraid. (Participant 2)

Hospitals are busy places. Workers there have no time to spend on one person. When they are telling you bad news they just give it as it is. There is no time for proper counselling. (Participant 3)

At Harriet Shezi they always advise us that when the child is sick, we should let the doctor know about the HIV status of the child so that a child can be given the correct medication. (Participant 4)

I did not feel supported by the hospital staff. To them what they were telling me about my child's diagnosis was normal. They did not consider how I felt at that moment. (Participant 5)

I used to attend Cotlands support group where they told us that we should disclose to children before they hear it from outside. (Participant 8)

I have been to hospitals since he was born I don't remember being given options about his treatment and care. They always tell me the dos and the don'ts. (Participant 10)

No options were given. They just informed me what they will do for the child. At times we are afraid to ask questions, especially in the public hospitals. Doctors and nurses there have no time. The doctors told me that hospice will offer my child better care than in the hospital and indeed the child is well taken care of. Hospice nurses visit the child here at home all the time. (Participant 11)

The doctors decided, I was only told that the child will get better care and he will be visited at home as well. (Participant 12)

The results of this sub-theme indicate the difference in services that are rendered by health care services. The study conducted by Goldstein and Rimer (2013:201) supports the participants' perceptions about health care services. Their findings indicate that parental accounts suggested that health care professionals play a supportive and appreciated role, yet they as parents had limited involvement in decision making regarding the care for their children. The study conducted by Hinds (2012: 916) indicated that parents have reported needing positive feedback from the physician and the physician's reactions to parents' preferences can influence parental trust of the physician and the perceptions about the hospital.

THEME 3: DISCLOSURE AND NON-DISCLOSURE

To disclose or not to disclose as the theme, focuses on the issues surrounding the parents' willingness or unwillingness to share the information about the diagnosis with the children. Participants' responses to the vignette will be integrated under the sub-theme of parents' experiences and emotions.

Sub-theme 3.1: Parents' experiences and emotions

Participants reported their emotions and experiences concerning their children's diagnosis and their involvement with the health care system. The vignette on the medical treatment evoked emotions in the parents. The DVD used was obtained from Jill Kruger of the Phila Impilo campaign (2012). The vignette was about the voices of children and their right to participate in their treatment and care. The following responses were given regarding the vignette.

Seeing the video clip makes me feel sad yet it is good. The sad part is seeing the sick child who is unable to do anything. Generally, when the person is sick and the body is full of pain you end up not knowing what to do. This sickness is very painful, especially for the children (Participant 4)

After watching the video clip my thoughts are that you should talk to your child. You see the children in the clip, they know that they are sick. I think once my child knows about his

diagnosis, it will be easier for me to talk to him and allow him to participate. If my child should decide to stop taking the medication I will be disappointed because this is his life. I will tell him that if he does not want to take medication that means he does not want to live. (Participant 2)

The DVD also teaches me that I should sit down and talk with the child and teach him about the treatment. You must show him love and try to make a child understand. (Participant 5)

Watching this video clip is painful but I agree with the child who is talking about the treatment. I do agree in giving a child a biscuit in order for him to take medication. Even at the clinic they give them sweets when they are drawing blood from them. This teaches me to talk with the child; I should tell a child even though I will have the last word. I want to leave this knowing that I have done my work as a parent. I do not agree with letting a child to decide. (Participant 6)

It is always sad to see sick children but I believe that even if the child is sick they should be treated the same as other children. They should not be given any special treatment. As parents we need to talk to children and show them love but not spoil them. (Participant 11)

Participants reported the feeling of sadness, yet they still maintain their positions as the main decision makers concerning their children's treatment and care. The research by Bluebond-Langer (2010:334) supports the participants' perceptions about their role as decision makers, as her study indicated that the illness of the child becomes the context that defines what it means to be a parent. The findings of Hinds (2012:916) support the participants' views as it indicated that parents of children with incurable illnesses report that achieving their internal definition of being a good parent to the ill child helps them to emotionally survive and making decisions on the child's behalf gives them a sense of competence.

Sub-theme 3.2: Informing children and choices

The participants' responses reveal their understanding about informing the child and allowing children to have choices in a health care context.

I believe in talking to children about the things that matter but I will not allow the child to make a wrong decision. (Participant 1)

The times have changed, so there is nothing wrong about informing the child about the issues of life. I believe the child must have the necessary knowledge but the child must make right choices. (Participant 3)

I do talk to the child about problems and I do allow the child to talk to me. (Participant 2)

I do agree with the law that says the child must be informed because children must have knowledge. (Participant 4)

I do not have a problem in discussing medication with the child, as long as the child knows that the decisions lie with me. (Participant 7)

The results of this sub-theme indicate the challenges the parents encounter to allow their children to have choices, especially regarding the children's treatment and care. The study by Coad and Shaw (2008:318) affirms the view that children are not offered choices about their personal health care. These authors argue that choices for children are perceived as a positive development in health care. A study carried out at the Tata Memorial Hospital in 2007 highlighted the attitudes of parents towards giving information and support provided to the paediatric patient. Thirty-one parents were interviewed, three of whom felt that the child was already aware of his/her illness without being told directly. Two were open to discussing the disease with the child, but felt that it would be difficult to talk about dying. The majority did not wish to discuss the disease or dying with the child, citing anticipated distress or young age as reasons for non-disclosure. In this study, parental anxiety and collusion were the major barriers to informing and allowing children to have choices (Muckaden *et al.*, 2011:7). Creative models were developed to engage children in participation, yet the participation of children is not evident in the health care. Article 13 (UNCRC, 2009) stipulates that children have the right to the freedom of expression and this is linked to children having choices and expressing those choices.

DISCUSSION

The two categories, which were identified in this study, namely children's participation in paediatric palliative care and parents' role in their children's participation described how parents perceive children's participation in the treatment and care within the context of paediatric palliative care.

It emerged during the interviews that all the participants' children were diagnosed with HIV/AIDS. Through the discussions on the first category it seems as though the nature of the diagnosis of the children who are HIV positive appears to have an impact on how parents perceive children's participation and their role as parents in the treatment and care in paediatric palliative care. Although the systems theory was not included in the literature review, it became evident from the findings that it is necessary to discuss the findings of this study based on this theory. The systems theory serves as a theoretical framework in understanding the dynamics in which parents with children who are faced with life-limiting illnesses find themselves.

Systems theory (Visser, 2012:25) suggests that individuals cannot be understood in isolation from one another and from their environment. It models complex entities created by the multiple interactions of components and concentrates on the dynamics that define the characteristics functions and relationships that are internal or external to the system. Understanding psychosocial aspects of HIV involve understanding the interrelations between the individual's subsystem, which in this study is the relationship between the child and the parent. The perceptions of the parents regarding children's participation forms part of the subsystem as those perceptions impact on the extent to which children could be allowed participation in their treatment and care. In order for the parents to exercise their authority over their children, boundaries, which differentiate them from other systems, are required. Parents' perceptions indicate that they exercise the boundary of a closed system in relation to their children, as they are unwilling to disclose the information about the diagnosis to the children. Societal norms and culture also contribute to the features of a closed system as indicated in the themes where parents said that children should not have the right to participate regarding their medical care. The internal system refers to the parents' internal processes and experiences, which determine their perceptions towards children's participation. The external relationship is formed by the hospitals, government and legislation regulating children's rights. The suprasystem (Visser, 2012:25), in this case, is the government that formulates laws and legislation that support children's rights and participation. Parents' perceptions regarding the children's participation are influenced by complex dynamics of human psychological, biological, social and cultural issues and they need to be understood within the context of culture and each individual's life situation. Parents indicated the fear of talking to their children about death and dying, which relates to the impact of societal and cultural interactions.

The discussion of these categories indicated how parents perceive their role in relation to their children. Participants consistently indicated that in their parental role they have authority over their children. The evolving capacities of children seem not to be considered by parents in relation to children's participation in their treatment and care. Parents and children's relationships are determined to a large extent by the social norms and culture. Parents reported that their culture does not allow for sharing of power and sharing control with children in decision-making processes. This is an indication that the common values of parents regarding children's position in the families are embodied in the social norms and culture. Parents mentioned that they would not change their way of life based on the laws that claim to protect children yet at the same time overlook the parents and their cultural beliefs. Whereas decision making for children who are under paediatric palliative care is guided by law and in medical ethics by the principle of autonomy, there is little concordance for this principle, as children are not allowed participation in their treatment and care. When consensus about what is in the best interest of the child cannot be reached despite efforts to do so, the wishes of the parents prevail. This suggests that children's participation is fundamentally about child-parent relations. Children's rights instruments acknowledge the importance of the role of parents. In this regard, Article 5 of the UNCRC (2009) stipulates that the rights and duties of parents to give direction and guidance to the child should be respected by States parties.

Parents reported that they were informed about their children's diagnosis and it was their choice to withhold the information from the children. This is an indication that the children are excluded in discussions regarding their treatment and care. Communication regarding children's treatment and care only takes place between the parents and the clinical staff. It is clear from this study that the parents are responsible for the exclusion of children from any form of discussions regarding their children's treatment and care. The fact that the parents withhold the information from the children suggests that children's participation has deficiencies and reframing of participation is needed in the context of paediatric palliative care. Clarke and Percy-Smith (2006:2) reported that the powerful adult agendas make it difficult to achieve effective and meaningful participation for children. In the context of paediatric palliative care it is important to understand why parents have the need to feel in control and responsible for determining what is in the best interest of the child.

On the other hand, there seem to be various reasons why parents would choose not to allow children to participate in decision making. Parents' needs to protect their children and

parents' fear about the reaction of the children when they discover that they are dying were cited as some of the reasons for not disclosing to children. It is of concern that children remain uninformed about such an illness which potentially affects their whole functioning. In addition, if they do not know about their status, they may inadvertently expose others to HIV, for instance if they injure themselves at school and expose others to blood and also if they become sexually active. Parents reported their dissatisfaction about children's rights especially the right of the children to participate. Parents had minimal understanding of what participation entailed. The explanation and description given to parents about participation had a minimal impact on the way parents perceived children's rights. Parents expressed their disappointment regarding the government's actions to implement children's rights without consultation with the parents. The fact that children's rights are universal did not find favour with the parents. The parents viewed children's rights as interfering with their own ways of raising their children. Added to their concern that there was no consultation done with them in terms of the laws, which have to do with their children, they mentioned that their culture was not considered and there was no platform where they could voice their concerns. These problematic interpretations of and experiences related to children's rights may be of importance in exploring possible limitations of the rights discourse. In the complex context of paediatric care, a one-sided focus on the rights of children can possibly cause stress and fragmentation in the context of relationships where more of an emphasis on partnerships is needed.

The question is how to strike a balance between the needs of children and parents to be heard. Constitutionally the rights of children are protected, however, those rights are not protected to the same degree as the adults' rights. There are three reasons why children do not have the same constitutional rights as adults: children's limited decision-making capacity, the vulnerability of children and the important role parents play in making decisions for their children (Maradiegue, 2003:2).

This concurs with the literature that states that research on children's participation needs to move towards the model where these tensions and cultural problems associated with the rights-based approach are more reflexively addressed. Mannion (2007:408,419) argues that children's participation research can become more relationally sensitive and participation initiatives should acknowledge the critical part adults play in the dialogical processes. The role of parents in their children's participation could be read as the backdrop for setting up guidelines regarding the support of parents with children under paediatric palliative care.

CONCLUSION

The findings of this study afforded greater understanding of parents' perceptions regarding their children's participation in the context of paediatric palliative care. Parents' perceptions could be seen from the systems theory whereby their role as parents is embedded in and impacted on by the internal, external as well as the suprasystem, in this case the government legislation that emphasises the rights of children to participate in decision making regarding the treatment and care in the context of paediatric palliative care. According to the systems theory, the less the interaction between the systems of parents, children and the government, the greater the degree of deterioration and disintegration of the system (Visser, 2012:26). The need for formulating guidelines for support mechanism for parents regarding children's right to participate has been indicated. The next chapter will make recommendations on how to achieve this goal.

CHAPTER 5

SUMMARY AND CONCLUSIONS

5.1 INTRODUCTION

The point of departure of this study was to explore and describe the perceptions of parents of their children's participation in paediatric palliative care. The findings of this study show that there are many complex aspects that seem to hinder children's participation in paediatric palliative care. One of the elements is that parents do not feel supported by the health care system in facilitating their children's participation within this context.

The dynamics within the social environment that can influence how parents perceive their children's participation was well illustrated as another element in this study (Kasper, 2012:1-2). For example, the fact that the children of the participating parents are diagnosed with HIV/AIDS has an impact on how parents think about their children participating in the treatment and care they receive in paediatric palliative care. The stigma attached to HIV/AIDS made it more difficult for parents to disclose their children's status to the children. Furthermore, it was clear that parents seemed to disagree with the right of the child to participate in decision making regarding treatment and care within this context.

Parents' misconceptions of children's rights also had an impact on children's participation, as parents seem to think that children's rights are there to challenge their authority as parents and primary care givers of the children. It can be argued that the perceptions of parents regarding the right of their children to participate could impact on the implementation of these rights in the context of paediatric palliative care. The findings of both the literature review as presented in Chapters 1 and 2 and the empirical study emphasised the dynamic interaction between the context, parent-child relation and child participation outcomes. Based on the literature review related to this topic, the researcher argued that in order for participation rights of children to be considered and facilitated by parents in the context of paediatric palliative care, it would be necessary to comprehend parents' perceptions about their children participating in the treatment and care that paediatric palliative care offers. The nature of the diagnosis of the children should also be taken into consideration, as it has an impact on how the parents view children's participation in the context of paediatric palliative care. It would be necessary to educate and inform the parents regarding children's rights.

The researcher's decision to explore the perceptions of parents regarding the children's participation was driven by the fact that when the parents have limited understanding and ownership regarding children's right to participate, then it would be futile for social workers and other professionals to try and enforce or implement these rights in the context of paediatric palliative care. The input of parents is thus viewed as an important database in ensuring that parents are supported in their understanding and facilitation of children's participation from the time of diagnosis throughout the progression of the disease.

The findings of this study will be used in this chapter to formulate recommendations in the form of guidelines for supporting parents with children who have life-limiting illnesses in the context of paediatric palliative care. The study will be evaluated against the research question and aim that was set out in Chapter 1. Possible limitations of the study will be indicated. The recommendations for future research on this topic will be made at the end of this chapter.

5.2 OVERVIEW OF THE RESEARCH

Chapter 1 of the study served as the planning document and proposal for implementation. As set out in Chapter 1, the research question guiding this study was: What are the perceptions of parents with regard to their children's participation in paediatric palliative treatment and care? The aim of this study was to qualitatively explore and describe through the use of an interpretive descriptive approach parents' perceptions of their children's participation in paediatric palliative treatment and care. The researcher is of the opinion that this study met the aim that was set out in Chapter 1. The researcher was able to explore and give a description of the parents' perceptions of their children participating in paediatric palliative treatment and care.

The literature review in Chapter 2 focused on developing the theoretical grounding of this study. The understanding of participation from a rights perspective, all the different aspects that constitute paediatric palliative care and the role of parents in relation to children's participation were highlighted in Chapter 2. The gap that was identified in this study was to explore parents' perceptions of their children's participation in paediatric palliative treatment and care. Paediatric palliative care constitutes the research context in which the meaning of the construct children's participation was explored in depth. Having a deeper understanding of children's participation in the context of paediatric palliative care and with specific

reference to parents' role in facilitating children's participation, guidelines for supporting parents in their role can be provided. Parents' perceptions were the empirical data that the researcher used in understanding better how parents perceive their children's participating in the treatment and care within paediatric palliative care context. The theoretical framework on children's participation in paediatric palliative care that was developed in Chapter 2 guided the researcher's interpretation and discussion of data in Chapter 4.

Chapter 3 reflected on the methodological procedures which the researcher used in the implementation of this study. The aim of this study was reached through the utilisation of the qualitative methodology and interpretive descriptive design. Purposive sampling was used to identify the participants. The interview schedule with open-ended and narrative questions, a vignette and incomplete sentences was used with the aim of exploring the participants' perception regarding children's participation. The interviews were voice recorded and transcribed. The process of data analysis assisted the researcher in gaining an understanding from the participants' views of children's participation. The data analysis was done with the assistance of an objective coder, thus the themes in the data were identified free from the researcher's personal perspective. Trustworthiness was ensured amongst other things by the supervision of two supervisors (Nieuwenhuis, 2007:80).

Chapter 4 reported on the participants' perceptions regarding children's participation. It was evident that the parents perceive that they are not supported by the health care system when it comes to dealing with social aspects, such as stigma, discrimination, fear of disclosure and taking care of the children with life-limiting illnesses. Due to all the dynamics associated with being HIV positive, parents find themselves compelled not to disclose the diagnosis to their children. The access to information for the participants was reported to be a challenge. The sense of powerlessness and the fears and uncertainties of parents were reported. Parents indicated that their authority, norms and culture were threatened by children's rights. Participants argued that it was their duty to make decisions on behalf of their children, primarily to take responsibility for the care and protection of their children. According to their opinion, this duty and responsibility should not be interfered with.

5.3 FINDINGS

Category 1: The children's participation in paediatric palliative care was confirmed by four themes, namely access to information, children's participation in the care and treatment plan, power shifting and possible limitations to participation. Category 2: The parents' role in their children's participation was informed by three themes namely parents' perceptions of the concept "children's participation", support to parents and disclosure or non-disclosure.

It was found that the participants' reasons for not informing the children about their diagnosis was that children were still too young to know what was happening to them. It was evident that the participants seemingly did not consider the evolving capacities of their children. It was also found that the nature of the diagnosis namely HIV/AIDS, may have an impact on the participants' decision not to inform their children about their diagnosis. In Chapter 2 a historical perspective about hospices and palliative care was outlined. During the empirical study it was found that participants were not given information about paediatric palliative care and their perception regarding hospice was that it is the place of death. Once again there is stigma attached to hospice care. This indicated the necessity of giving the necessary information to the parents with children who have life limiting-illnesses.

It was found that participants perceive the taking of medication or the refusal to take medication as the primary way in which children will participate in their treatment and care plan. The parents thus feared that should children be given a voice in their treatment and care, children could make decisions, which might be detrimental to their health. Literature review indicated that children with fatal illnesses had high levels of generalised anxiety even when the prognosis was not directly revealed to them and children could maintain the system of mutual pretence with their parents (Bluebond-Langner, 2010:335). The literature review on the best interest of the child highlighted what the law required from parents and anyone taking care of children. The empirical investigation of this study indicated that participants perceive it as their responsibility to decide what is in the best interest of their children.

Furthermore, the findings indicated that parents perceive authority and powerlessness as aggravated by the social risk associated with the stigma of being HIV positive. The lack of information given to parents by the health care personnel results in parents feeling powerless and having limited authority in the way they need to deal with their children's illness. In Chapter 2 a theoretical perspective was explored to describe partnership in paediatric palliative care. It was found that parents often feel that they have authority to decide on

behalf of the child regardless of the child's age of maturity. Parental anxiety was found to be a major barrier to open communication with children.

The findings of the empirical study pointed out that there is a need for support structures for parents with children living with life-limiting illnesses. Health care workers were also reported as having limited skills in facilitating communication between children and parents. Lack of access to information for parents about palliative care was found to be problematic as it had an impact on the treatment and care plan for the children. The empirical investigation of this study contributed to the understanding of how societal norms and culture impact on the children's participation.

In Category 2 it was found that the parents regard children's rights as a threat to their authority as parents. This emphasises the need for educating parents and children about children's rights in the context of paediatric palliative care.

It was reported that parents are not supported by the health care system. Lack of proper systems and shortage of staff in the hospitals could be linked to poor communication channels.

Despite the emotions of sadness that the parents have regarding their children's illness, participating parents were adamant in maintaining their position as core decision makers when it comes to their children's treatment and care. It was also revealed that parents find it difficult to allow the children who have life-limiting illnesses choices regarding their treatment and care.

5.4 GUIDELINES

The following guidelines for supporting parents with children who are suffering from life-limiting illnesses can be considered by health care professionals and social workers in the context of paediatric palliative care.

- The researcher created a warm and emphatic environment for the participants during the interviews. The participants were assured of confidentiality. Despite the fact that the participants' children were diagnosed with HIV/AIDS participants were willing to share their perceptions and experiences with the researcher. The implementation of this study is the proof thereof that the participants were willing to participate in this

study. Parents welcomed the space in which to talk about their perceptions and related experiences. Open and free spaces need to be created for parents to talk about their perceptions and experiences related to their children having a life-limiting disease and place in paediatric palliative care.

- In order to create support mechanisms for the parents with children who have life-limiting illnesses, an understanding of the disease and the impact it has on the psychosocial aspects of the parents is needed. Social and psychological factors influence the ability to cope with the disease. The stigma and discrimination attached to the disease usually lead to powerlessness. It is recommended that the social dynamics that impact on parents' perceptions regarding children's participation are incorporated in the training and practice of the health care professionals.
- Participating parents have expressed the need to be more involved in health care decision making for their children. Parents did not always feel informed, included and engaged in clinical decision making. Parents mentioned that they were referred to hospice by the doctors without proper consultation with them. For the parents to be more involved in decision making regarding their children they must become active partners in interdisciplinary decision making and care as they can make important contributions towards the care decisions. It is recommended that collaborative decision making should be facilitated in the practice of paediatric palliative care as it will assist the parents to have more realistic expectations and have more understanding regarding their children's treatment and care. A framework for involving children in decision making process in the context of paediatric palliative care should recognise the reality of children not always agreeing with the decisions that are made on their behalf. If parents have positive experiences of being part of decision making it may encourage parents to involve and partner with their children in relation to the treatment and care provided within this context.

- Parents' culture and societal norms need to be respected and addressed while introducing alternative and new perspective in relation to children's participation. Cultural beliefs could seriously violate human dignity and the rights of children. In this study the vignette was used and it has challenged and stimulated awareness of parents' patterns of thinking and alternatives in dealing with the issue of children's participation. Among the factors that may affect the way parents receive information in the health care system are parents' cultural beliefs. Parents may reject instructions issued by the health care providers because of the parents' belief systems. End-of-life planning and decision making might be interpreted negatively by parents. It is therefore recommended that ethical principles applied within paediatric palliative care context, such as autonomy, non-maleficence, beneficence and justice should accommodate varying cultural perspectives, as some parents consider it detrimental to tell their children the truth about their diagnosis. Creative mediums such as art-based activities can be explored and utilised in the context of paediatric palliative care to assist parents in becoming aware of thinking patterns and in generating alternative ways of thinking about children and their participation from within.
- It seemed pertinent that the parents be educated on the nature and content of the children's rights and the guiding principles of children's participation, such as evolving capacities of children, the best interest of the child principle and parental guidance. Parents' perceived misconceptions about children's rights are an indication that more knowledge is needed by parents on the topic of children's rights. A perspective of children enjoying their rights while parents and other adults enjoy theirs should be stressed to address the one-sided promotion of children's rights. It is recommended that children's rights education should be grounded in an understanding of the importance of the human dignity of each individual person, children included, and the value of partnerships in decision-making processes in the context of paediatric palliative care.
- Parent-child relationships should be recognised, respected and supported within the training of health professionals and in paediatric palliative care when it comes to assisting parents with regard to talking about topics, such as life and death with their

children, listening to children, positive contact-making skills with children and facilitating children's participation.

5.5 RECOMMENDATIONS

The following are the recommendations directed at health professionals and social workers in the context of paediatric palliative care:

- Parents should receive education on children's rights in general and the children's right to participate in decision making.
- It was revealed in this study that culture plays an important role in the lives of parents with children facing life-limiting illnesses; therefore it is recommended that the health care workers receive education concerning how to provide cultural competent care and training on how to assess parents' anxiety and stress levels.
- Fundamental changes should be made to tackle institutional discrimination in the provision of palliative care, incorporating cultural issues and developing a richer appreciation of how parents should achieve dignified service.
- It is also important that the parents receive sufficient information about paediatric palliative care and hospice care.
- The support to parents should be provided by the interdisciplinary team, including social workers, doctors, nursing staff and parent support groups.
- A validated psychosocial assessment tool should be developed to assess the domains related to illness factors such as complex communication channels within the family, social support and living conditions.

5.6 LIMITATIONS

- Language

The participants were Sotho and Zulu-speaking people. The interview schedule had to be translated from English into SeSotho and IsiZulu. Words such as participation in Zulu and Sotho proved problematic to translate as they become a sentence which needed to be clearly defined to the participants.

- Demographic area

This study included participants speaking SeSotho and IsiZulu residing in Gauteng. The study acknowledges that it would not necessarily be possible to generalise the findings of this study. In qualitative research the aim is not to generalise.

- Nature of diagnosis

When data was collected, the aim was not to interview the participants with children who are HIV positive it was to interview parents with children who have any life-limiting illnesses. When obtaining data source from the hospice the researcher was only given the names and contact details of the participants the diagnosis of the children was not included. It only emerged during the interviews that all the children were diagnosed with HIV/AIDS and the study cannot therefore be generalised to other life limiting illnesses, such as cancer or motor neuron disease.

5.7 RECOMMENDATIONS FOR FURTHER RESEARCH

Based on the findings of this study, recommendations for further research might include:

- Exploring children's perceptions about their right to participate in decision making in the context of paediatric palliative care.
- Further research could be aimed at exploring health care workers' perceptions about the right of children to participate in decision making regarding the children's treatment and care.
- Conducting similar research in other paediatric palliative care settings.

5.8 CONCLUSIONS

The aim of this study was to qualitatively explore and describe, through an interpretive descriptive design, the parents' perceptions of their children's participation in paediatric palliative treatment and care. In order to achieve this aim it was important for the researcher to understand theoretical perspectives on children's participation in the paediatric palliative care context. The theoretical framework assisted the researcher in understanding and interpreting the gathered data. The participants of this study shared valuable insights on the topic. The guidelines and recommendations made in this study were based on the participants' perceptions about children's participation in paediatric palliative care.

This study revealed the challenges that face children's participation in decision making regarding their children's treatment and care and the stance of the parents towards the right of the children to participate. The findings of the study indicated the need to educate parents about children's rights as stipulated in the Constitution. The findings of this study also revealed that under the best interest standard, children who are under paediatric care and who have some ability to understand their condition are not given an opportunity to have their voices heard, as parents often decide on behalf of the child. The need for supportive interventions for the parents with children living with life-limiting illnesses was identified and addressed in the formulation of the guidelines.

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ANNEXURE A

INFORMED CONSENT: PROSPECTIVE RESEARCH PARTICIPANTS

Participation in research study for M (Social Work) by Penelope Mathe, student at the North-West University

PARENTS' PERCEPTIONS OF THEIR CHILDREN PARTICIPATING IN PAEDIATRIC PALLIATIVE TREATMENT AND CARE

Purpose of the study

The aim of the study is to enhance the right to participate in decision making for children who are under palliative care. The aim is also to explore of children, parents and professionals perceptions regarding the right of the child to participate in decision making in this regarding palliative care.

The research is aimed at the children who are under palliative care between the ages of 10 to 16 years, their parents and professionals who are working with them. The area of focus is Gauteng province.

The reason for this study is to enhance awareness of the children's rights to participate in decision making and to explore children's, parent's and professional's perceptions regarding the rights of children to participate. The results may be used in future to create awareness on the part of parents and the professionals about the significance of the right of children to participate in decision making regarding their lives in the palliative care context.

Participation and risks

- Participation in the study is voluntary. Participants may withdraw from the study at any stage if they wish to do so.
- Emotional risk may be involved in this study as the participants are the children and parents whose children have terminal illness. The researcher will be sensitive in and try to reduce the risks by listening and being non judgemental to the participants.

Information gathering and confidentiality

- Information will be gathered by means of the interviews and it will be tape recorded. The recordings could only be listened to by the research team. It will not be made public at any stage.
- The information will be handled with confidentiality and will not be made public. The identifying information will not be used in the research report.

Feedback

The written feedback will be given after the completion of the study.

General

You are welcome to contact researcher at any stage for the duration of the study on her cell number 076 308 3120.

Conclusion

By signing below, you are indicating that you read the information above and it was explained to you by the researcher and that you agree to participate in this research study.

I, _____ hereby declare that I have read and understood the above mentioned information. I agree to take part in the research study,

Parent's/Guardian's signature

Date

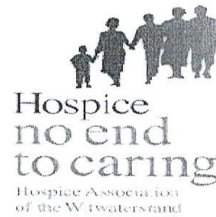
Researcher's signature

Date

ANNEXURE B:

INFORMED CONSENT FROM HOSPICE ETHICS COMMITTEE

SOWETO HOSPICE
15984/5 Eben Cuyler Drive
Zone 3 Diepkloof
Tel: (011)983-7400
Fax: (011)983-7401



Date: 31 July 2013

TO WHOM IT MAY CONCERN

This is to certify that Penelope Mathe was granted permission by the Hospice Wits Soweto Ethical Committee to conduct the research for the purpose of the Masters Degree in Social Work under the North-West University.

Name and surname: SUSAN MOKOTO
Position: Home care supervisor
Signature: [Signature]

Name and surname: DR. P. O. MASHELE
Position: Medical Doctor
Signature: [Signature]

Name and surname: RACHEL MABENA
Position: IPH UNIT MANAGER
Signature: [Signature]

SOWETO HOSPICE
TEL: 011 983 7400
FAX: 011 983 7401

ANNEXURE C:

INFORMED CONSENT FROM HOSPICE TO MAKE USE OF THE CLIENT
SYSTEM

PO Box 87600 Houghton 2041
50 Second Avenue Houghton Johannesburg
Tel: +27 (0)11 483 9100 Fax: +27 (0)11 728 3104
Email: offices@hospicewitwatersrand.org.za



PRIVATE AND CONFIDENTIAL

October 2013

TO WHOM IT MAY CONCERN

I, Jacqueline Kaye, Human Resource & Training Manager for the Hospice Association of the Witwatersrand (HospiceWits), at address P.O. Box 87600, Houghton, 2041 OR 50 2nd Avenue, Houghton, 2198, declare that Penelope Mathe is currently employed by the Hospice Association of the Witwatersrand (HospiceWits) on a permanent basis in her capacity as our Social Worker for the In Patient Unit and the Homecare nursing in Soweto.

HospiceWits is hereby granting Penelope Mathe the permission to conduct interviews with the parents of the children who are under the HospiceWits Palliative care programme, and/or who were once admitted in our paediatric ward.

Please contact the writer at the telephone number provided should you wish to confirm this employment or the permission granted, as stated herein.

Yours sincerely

Jacqueline Kaye
Human Resource & Training Manager

011 483 9100

ANNEXURE D: INTERVIEW SCHEDULE

Interview questions for parents

The following are three different types of questions which will be asked namely: Leading questions, free narration questions and probing questions.

- When did you discover about your child's illness?
- What options were you given regarding the child's treatment and care?
- Tell me more about the support given to you by your family and clinical staff regarding the decisions that you made about the child?
- Tell me more about how your child was informed about his/her diagnosis?
- How was the decision made for your child to be admitted at hospice for palliative care?
- In what way was your child part of the decision making?
- Tell me more about the role your child fulfil in his/her paediatric palliative treatment and care.
- In general what can you describe as the role of the parent in terms of the child's treatment and care?
- What is your opinion about children's participation in decision making regarding their treatment and care?
- What stance do you hold about children's rights?
- What are your suggestions on facilitating your child's participation in decision making regarding his/her life?

ANNEXURE E: TRANSCRIPT

PARTICIPANT 1

Q: When did you discover about your child's illness?

He was born with this disease. When he was two years old he was hospitalised at Bara and was operated on. His mother did not care so I took him to stay with me. His mother passed away last year in June. He grew up and started to ask why they he was taking medication and have to go for treatments whist other children he was playing with are not taking any medication. I told him that he was taking medication in order to grow well.

Q: What options were you given regarding the child's treatment and care?

P1: No options were given to me I was just told that he will be given the ARVs.

Q: Tell me more about the support you were given by your family and clinical staff regarding the decisions that you made about the child.

P1: At the hospital I was given all the information I needed about the child's disease. They suggested that the child should be sent to a support group at the hospital and I refused as I did not want my child to know about his diagnosis in that manner. I will disclose to him when I am ready to do so.

Q: What I am hearing is that the child does not know about the diagnosis.

P1: Yes, but at Harriet Shezi they have asked me if I have already told the child about what is wrong with him. I told them I was afraid to tell him. They said I should attend disclosure classes but I am not ready not now.

Q: Does the child know that he is under hospice care?

P1: He only knew yesterday. He does not know what hospice care means. He is only happy when he sees the nurses come to visit him. He only knows that his mother died of AIDS.

Q: In general what can you describe as the role of the parent in terms of the child's treatment and care?

P1: I am the one who take decisions even though at the hospital they will tell you something and then pretend they want your opinion.

Q: Could you please tell me what you understand about children participation

P1: I don't know anything about children's participation

Q: Do you perhaps know about children's right to participate in decision making about their treatment and care?

P1: I feel bad about these children's rights. They take away our dignity as parents moreover now when the right of the child to participate in decision making regarding their treatment and care is mentioned, that has nothing to do with children. I do not see any reason to involve the child in anything especially when the child is sick. According to the way in which I was brought up parents should not discuss some issues with children especially this one concerning the child's life and death.

Q: What if the child already knows something and decides to ask you why are you hiding the information from him?

P1: He is the child he would not dare ask me that question. Children have no business discussing such issues with parents (ANGRY)

Q: Would you perhaps consider listening to the child and talking with the child.

P1: I do not know where we are going with this, even considering that we should listen to children whilst they are sick and in need of help puzzles me.

Q: I am sensing that my questions annoys you

P1: I believe in talking to children about the things that matters but I will not allow the child to make wrong decision. I do allow him to have the say in other things not about his health condition but to those things he needs to say only the right things. Here at home we do not talk about HIV/AIDS (DISCREPANCY) We are afraid that they might be stigmatised and if other children can know about they will be affected at school.

Q: What is your opinion about children's right?

P1: I feel bad about the children's rights because these children fall pregnant at the young age and they could abort, you cannot even discipline the child by giving him hiding. You cannot even send the child somewhere. These rights take our dignity as mothers because we do not have a say in our children's lives. They have taken our ubuntu as black people.

INTRODUCING THE VIGNETTE

Q: What is your general view about the video clip?

P1: I wish this video clip could be seen by all children who are sick so that they could see the importance of taking the medication. I do not agree that the child should be given the biscuit as the way of showing that what was done to him was painful. It is not right it means that every time the child gets medication he must be given a "bribe". What will happen the day you do not have the biscuit.

INCOMPLETE SENTENCES

Q: I have four incomplete sentences that I would like you to complete for me they are based on the video clip we have just seen.

1. This video taught me that....
2. I am aware of....
3. Participation is...
4. Children's rights are important or not important because....

P1: You see I will not answer the other question (irritated) I will only answer the last one. As I said before children's rights are not good they interfere with the way we raise our children. These are our children not the government's children.

PARTICIPANT: 2

Q: When did you discover about your child's illness?

P2: I found out in the year 2011 that the child was sick. He was tested at the clinic and I was told about his diagnosis. The child was not told about his diagnosis. He does not know what type of medication he is taking. He is very young (10 years). For now he thinks he is taking flu medication.

Q: What options were you given regarding the child's treatment and care?

P2: The nurse advised me to have the child tested. He was tested at the clinic that's where I found out he was sick. They sent me to Bara for treatment. I received counselling not the child.

Q: I am hearing that the child does not know his status

P2: *He does not know what medication he is taking and he does not know his status. For now he thinks he is taking flu medication. When I am ready to disclose to him I will tell him.*

Q: In general what can you describe as the role of the parent in terms of the child's treatment and care?

P2: *My role is to decide what is best for him and to take care of him*

Q: *Tell me what do you understand about children's participation and children's rights*

P2: *Participation in what?*

Q: In decision making regarding his treatment and care

P2: *I will not allow him to have a say regarding his treatment and care. I know that when the time goes on he will realise that he is not getting better and he is taking the medication non-stop. I will be forced to tell him that he is taking medication for HIV/AIDS just like me his mother.*

Q: What is your opinion about talking with children about their treatment and care?

P2: *By telling the child that he has terminal illness means that you are telling the child that he is dying. I was raised not to talk about death with children.*

Q: Was there any support given to you by the hospital?

P2: *I think the workers at the hospitals are inhumane, they quickly tell you the bad news and they do not care how you feel like afterwards. They did ask me though at the hospital whether I have disclosed to the child I told them that I was afraid.*

Q: What is your opinion on decision making by children?

P2: *Children are children and they should remain children*

INTRODUCING THE VIGNETTE

Q: What is your general view about the video clip?

P2: *After watching the video clip my thoughts are that you should talk to your child. You see the children in the clip they know that they are sick. I think when my child about his diagnosis*

it will be easier for me to talk to him and allow him to participate. If my child could decide to stop taking the medication I will be disappointed because this is his life. I will tell him that if he does not want to take medication that means he does not want to live.

INCOMPLETE SENTENCES

Q: I have four incomplete sentences that I would like you to complete for me they are based on the video clip we have just seen.

1. This video taught me that....
2. I am aware of....
3. Participation is...
4. Children's rights are important or not important because....

P2: (Looking very exhausted) This video has taught me that it is important to talk to children. I am not in favour of children's rights. I cannot answer the other questions

PARTICIPANT 3

Q: When did you discover about your child's illness?

P3: It was in 2003 when we first knew about the child's diagnosis. Currently the child does not know that he has the disease. Fortunately enough for me he does not ask any questions.

Q: What options were you given regarding the child's treatment and care?

P3: I was not given any options

Q: Tell me more about the support given to you by your family and clinical staff

P3: I was not given information about hospice and palliative care I only learned more about hospice when my child was already admitted. I regarded hospice as the place of death I still do that is why it is not easy for me to discuss hospice and palliative care with my child. Hospitals are busy places workers there have no time to spend on one person. When they are telling you bad news they just give it as it is. There is no time for proper counselling.

Q: In general what can you describe as the role of the parent in terms of the child's treatment and care?

P3: My role is to take care of my child and ensure that he takes his treatment.

Q: What is your opinion about children's participation in decision making regarding their treatment and care?

P3: In the health care situation I do not see how the children's rights fit in. If the child is sick he/she has no right to decide what she/he needs to be treated let the experts in the field and the parent decide what needs to be done. I agree that the times have changed so there is nothing wrong about informing the child about the issues of life. I believe the child must have the necessary knowledge but the child must make right choices.

Q: I am wondering what will happen should he decide to stop taking the medication.

P3: When the time comes that he decides to stop taking medication and complains then we will do something then. For now he is okay, taking his medication and he is not questioning anything, but if I have to tell him I don't have a problem I will tell him.

Q: What is your opinion regarding the right of children to participate in decision making regarding their treatment and care.

P3: I do allow the child to sit down with me and to talk to me about the problem. I do also sit with my older children and share my problems with them. If I'm wrong I do accept my fault, but at the end it depends on a person. As for me I was taught not to keep secrets, maybe that is why I do not have a problem I have the knowledge.

INTRODUCING THE VIGNETTE

Q: What is your general view about the video clip?

P3: I like what this child in the video clip is saying. It is important to have knowledge about the things that happening around us. I like what the child is saying about the TB treatment that it should be taken even though sometimes you might not feel like it. I also like the part about the drip and how it works, and also the part that the woman is saying that it is by grace that we do what we do. It is important to have knowledge about the things that are happening around you. If I see that the child is not feeling well maybe he has flu, at least I can tell the child to wear a jersey and shoes because I know about his sickness. I do not want him to be sick. He takes his medication on time and eats his food on time.

INCOMPLETE SENTENCE

Q: I have the incomplete sentence that I would like you to complete for me it is based on the video clip we have just seen.

1. Children's rights are important or not important because....

P3: Children's right are important I do agree with the law that says the child must have full knowledge of his situation. I also want to know if it is right to tell him about his condition now?

Q: What do you think?

P3: Yes we are not the same we must accept the situation but I don't agree with parents who says we not tell them when we are suppose to tell them, because you will find that the child really does not know about the disease. For example, when your child has a friend who has the same disease and the friend knows about it because at his home they are talking about it. Your child who does not know through his conversation with his friend will figure out what is wrong with him. It is not right not to tell your child.
