Experiences of the recipients of Reach For A Dream Foundation projects

Debra Anne Myburgh

23289236

Dissertation submitted in fulfilment of the requirements for the degree *Magister Artium* in Psychology at the Potchefstroom Campus of the North-West University

Supervisor: Ms. J. Avenant

Co-supervisor: Prof. A.C. Bouwer

November 2014

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

It all starts here ™

ACKNOWLEDGEMENTS

FOREWORD

This dissertation is presented in article format in accordance with the guidelines set out in the *Manual for Postgraduate Studies, 2008, of the North-West University*. The technical editing was done according to the guidelines and requirements set out in Chapter Two of the Manual.

The article will be submitted to the *African Journal of Primary Health Care & Family Medicine*. The guidelines for the submission to this journal are attached in Appendix 1.

DECLARATION

I, Debra Anne Myburgh, herewith declare that the dissertation entitled:

Experiences of the recipients of Reach For A Dream Foundation projects, which I
herewith submit to the North-West University: Potchefstroom Campus, is my own work
and that all references used or quoted were indicated and acknowledged.

Signature:_____ Date: 01/11/2014

Mrs D.A. Myburgh

English language editor credentials: Lyn Voigt Literary Services Lyn Voigt: B. Mus. (Eng
Hons) [Wits] H.Dip Ed. [JCE]. Writer [study guides]; Re-writer [plain language practitioner];
Editor [educational and literary]; Member: Professional Editors' Group and English Academy
of Southern Africa.

Signature:_____Date: 1ˢᵗ October 2014

Mrs L. Voigt

ynvoigt@intrepid.co.za

Afrikaans language editor credentials: Corrie Geldenhuys; MA (Linguistics) *cum laude*, MA
(Musicology), HED, PGLS (Postgraduate Diploma in Library Science), UTLM (University
Teacher's Licentiate in Music) Accredited member of the South African Translators Institute
(A/E and E/A), Member of the Professional Editors Group of South Africa.

Signature: ____ C.Ge_____ _ Date: 1ˢᵗ October 2014

Corrie Geldenhuys
corrieg@mweb.co.za

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOM CAMPUS

Post Graduate Studies and Organisation

SOLEMN DECLARATION AND PERMISSION TO SUBMIT

1. Solemn declaration by student

I, DEBRA ANNE Myburgh

declare herewith that the thesis/dissertation/mini-dissertation/article entitled (exactly as registered/approved title),

EXPERIENCES OF THE RECIPIENTS OF REACH FOR A DREAM FOUNDATION PROJECTS

which I herewith submit to the North-West University, Potchefstroom Campus, in compliance / partial compliance with the requirements set for the **Masters Psychology** degree, is my own work, has been language edited and has not already been submitted to any other university.

I understand and accept that the copies that are submitted for examination are the property of the University.

Signature of student _____   University number **23287236**

Signed at **Fourways** this **24** day of **february** 20**14**

Declared before me on this **24** day of **february** 20 ....

Signature _____ BLANTINA RAISEBE LEDWABA

Stamp of Commissioner of Oaths is required here

24/00/2015

Commissioner of Oaths _____

PLEASE NOTE: If a thesis/dissertation/mini-dissertation/article of a student is submitted after the deadline for submission, the period available for examination is limited. No guarantee can therefore be given that (should the examiners' reports be positive) the degree will be conferred at the next applicable graduation ceremony. It may also imply that the student would have to re-register for the following academic year.

2. Solemn declaration and permission to submit by supervisor

The undersigned declares

- The student is hereby granted permission to submit his/her mini-dissertation/dissertation or thesis YES/NO

- That the student's work has been submitted to Turnitin and a satisfactory report has been obtained YES/NO

Signature/Supervisor/Promoter: _____   Date: 16/11/2014

SUMMARY

KEY TERMS: life-threatening illness; **hope**; **positive thought**; **psychosocial intervention programmes**; **experience**; **'dream' projects**

In children, life-threatening illnesses (LTIs) present with both physical and psychosocial side effects, which seem to contribute to the perpetuation of hopelessness and fear among the children and their families. Children with LTIs often experience regular and painful treatment routines. A LTI not only impacts on the child but also on the family. LTIs put families in a critical and vulnerable situation, evoking emotions such as shock, disbelief and fear. Hope and coping strategies appear to be crucial for both children and their families when facing the effects of a LTI on a child. While medical intervention strategies are used to alleviate physical side effects, psychosocial intervention strategies (as referred to in this research study) that are focused on improving the well-being of the child and family, appear to be limited. Psychosocial interventions are defined as any intervention that emphasizes psychological or social factors, rather than biological factors. Psychosocial intervention strategies, such as 'dream-come-true' projects, appear to ameliorate distress, offer respite, decrease isolation, empower individuals, increase self-confidence and give the children unique opportunities to connect with their families in a positive, normal way. Such a psychosocial intervention strategy is offered by the Reach For A Dream Foundation (RFAD) in South Africa. The experiences of the recipients of RFAD 'dream-come-true' projects were the focus of this study. The goal of this research study was to study the 'dream-come-true' psychosocial experiences of children/adolescents and their families, by means of a narrative enquiry design. This design allowed participants to tell their stories truthfully, giving the researcher the opportunity to immerse herself in the personal experience of each participant.

Participants were purposively, and then randomly, selected from an RFAD client list. A total of six children/adolescents, between the ages of 8 and 18 years, were randomly selected from Johannesburg and the surrounding areas. The children/adolescents and both parents were interviewed, except for one father who was not present (17 participants in total). Child/adolescent interviews included the use of fun, tactile emotive cushions to assist the participants to recognize emotions they had felt 'pre-dream', during the 'dream', and 'post-dream'. Semi-structured, individual in-depth interviews were used to interview parent participants. The parent's story was not interrupted, thereby providing the opportunity for a

fluid narrative. In addition to interviews, the researcher made field notes of the participant's reactions, body language and emotions after each interview. All interviews were recorded and transcribed. Tesch's (1990) approach was used to identify, analyse and report patterns within the data. The findings of this study suggest that intervention strategies improve emotional health and overall wellness in participants. 'Pre-dream' feelings of fear, sadness, loneliness and a lack of normality in everyday life, were prominent themes. Participating parents expressed anger, helplessness and guilt about being unable to help their children.

During the 'dream-come-true' experience, the predominant themes that emerged were excitement, amazement and gratitude. The theme of disbelief in the reality and experience of the 'dream' was also prominent. 'Post-dream', the participants reported a more positive, confident and hopeful outlook. This research appeared to yield some important information on the possible benefits of psychosocial intervention strategies, as they seemed helpful in addressing the challenges presented by LTIs in children/adolescents.

OPSOMMING

SLEUTELTERME: lewensbedreigende siekte; **hoop**; **positiewe denke; psigososiale intervensie programme;**; **ondervinding**; **'droom'-projekte**

Lewensbedreigende siektes (LBS) by kinders vertoon fisiese sowel as psigososiale newe-effekte, wat waarskynlik bydra tot wanhoop en vrees onder hierdie kinders en hul gesinne. Kinders met LBS'e ondergaan dikwels gereelde en pynlike behandeling dus raak 'n LBS nie net die kind nie, maar ook die gesin. LBS'e laat gesinne kwesbaar en in ongunstige omstandighede, wat verskeie emosies soos skok, ongeloof en vrees ontlok. Hoop en hanteringstrategieë blyk vir kinders, sowel as hul gesinne, noodsaaklik te wees wanneer hulle met die uitwerking van 'n LBS op 'n kind te kampe het. Mediese intervensiestrategieë word gebruik om die fisiese newe-effekte van LBS te verlig. Psigososiale intervensiestrategieë, soos daarna verwys word in hierdie navorsing, wat fokus daarop om die welstand van die kind en gesin te verbeter, , blyk egter beperk te wees. Psigososiale intervensies word gedefinieer as enige intervensie wat sielkundige of sosiale faktore, eerder as biologiese faktore, beklemtoon. Psigososiale intervensiestrategieë, soos 'droom-verwerkliking'-projekte, blyk stres te verminder, verligting te bied, isolasie te verminder, individue te bemagtig, selfvertroue te verhoog, en kinders die unieke geleentheid te bied om op 'n "normale" wyse met hul gesinne kontak te hê. In Suid-Afrika word sodanige psigososiale ingryping deur die Reik na 'n Droom-stigting (RNDS) gebied . Die fokus van hierdie studie was die ervarings van begunstigdes van RNDS 'droom-verwerkliking'-projekte. Die doel van die navorsing was om die psigososiale ervarings van 'droom-verwerkliking' van kinders/adolessente en hul gesinne te bestudeer, deur middel van 'n narratiewe ondersoek as ontwerp. Hierdie ontwerp het deelnemers toegelaat om hul verhale eerlik te vertel, wat aan die navorser die geleentheid gebied het om haarself in die persoonlike ondervinding van elke deelnemer te verdiep.

Deelnemers is deur middel van doelgerigte steekproefneming, en vervolgens met behulp van ewekansige seleksie, gekies vanuit 'n RNDS-kliëntelys. 'n Totaal van ses kinders/adolessente, tussen die ouderdomme van 8 en 18 jaar, is ewekansig gekies in Johannesburg en omliggende areas. Daar is onderhoude gevoer met die kinders/adolessente en die ouers van elkeen, afgesien van een pa wat nie teenwoordig was nie (17 deelnemers in totaal). Kinder/adolessente-onderhoude het prettige, taktiele kussinkies met uitbeeldings van gesigsuitdrukkings ingesluit om deelnemers te help om die emosies te herken wat hulle

ondervind het voor, tydens en ná hul 'droom-ervarings'. Semi-gestruktureerde, individuele in-diepte onderhoude waartydens hul narratief nie onderbreek is nie, is gebruik met die ouers, wat aan hulle die geleentheid gebied het om hul stories deurlopend te vertel. Na afloop van elke onderhoud het die navorser veldnotas gemaak omtrent die deelnemer se reaksies, lyftaal en emosies. Alle onderhoude is opgeneem en getranskribeer. Tesch (1990) se benadering is gebruik om patrone in die data te identifiseer, analiseer en rapporteer. Die bevindings van hierdie studie dui daarop dat intervensiestrategieë emosionele gesondheid en algemene welstand by deelnemers verbeter. Voor die droom-ervaring was die prominente temas dié van gevoelens van vrees, hartseer, eensaamheid en die afwesigheid van normaliteit. Deelnemende ouers het woede, hulpeloosheid en skuldgevoelens aangaande hul onvermoë om hul kinders te help, uitgespreek.

Tydens ondervinding van die droom-verwerkliking was die oorheersende temas dié van opwinding, verbasing en dankbaarheid. Verdere prominente temas was dié van ongeloof rakende die werklikheid van die droom-ervaring. Ná die droom-ervaring het die deelnemers 'n meer positiewe uitkyk en selfvertroue gerapporteer. Dit blyk dat hierdie studie belangrike inligting opgelewer het omtrent die moontlike voordele van psigososiale intervensiestrategieë in die hantering van die uitdagings rakende LBS by kinders/adolessente.

TABLE OF CONTENTS

**SECTION C: SUMMARY, EVALUATION, CONCLUSION AND
RECOMMENDATIONS**

SECTION D: APPENDICES

SECTION A: ORIENTATION

PART I: ORIENTATION TO THE RESEARCH

1.1   INTRODUCTION AND PROBLEM STATEMENT

Children in South Africa and throughout the world are diagnosed with many life-threatening illnesses (LTIs).   Potentially LTIs can cause the death of the child and, regardless of the outcome, LTIs represent severe trauma for the family (Cancer.org, 2012: online). LTIs include illnesses such as cancer, Hodgkin's lymphoma (cancer), asthma, the Human Immunodeficiency Virus (HIV), haemophilia and diabetes. According to the Childhood Cancer Foundation of South Africa (CHOC), one in 600 children develops cancer each year in South Africa (CHOC, 2011).   Asthma is increasing, especially in children. In 2011 the World Health Organization (WHO) "estimated that annually 15 million disability-adjusted life years are lost and 250,000 asthma-related deaths are reported worldwide". According to Statistics South Africa, in 2012 approximately 410 000 South African children aged 0 to 14 were living with HIV. According to the International Diabetes Federation (IDF), an estimated number of 6000 children under the age of 14 are diagnosed with diabetes each year in South Africa. In South Africa, one in 5000 males is born with haemophilia, but a vast number of patients who have haemophilia or other bleeding disorders remain undiagnosed or are diagnosed at a very late stage (Miller, 2012, personal interview). Children with other chronic conditions like cerebral palsy, developmental delays, epilepsy, Crohn's disease or Spina Bifida may also qualify as children living with LTIs (Sotrianakos, 2012, personal interview).

Medical interventions are almost entirely designed to treat the physical side effects of LTIs. However, LTIs simultaneously evoke psychosocial insecurities and fears because of the association with pain, uncertainty, powerlessness and premature death. The definition of 'psychosocial' in the Penguin Dictionary of Psychology is "a term covering any situation in which both psychological and social factors are assumed to play a role" (Reber, Allen & Reber, 2009:637). A child's premature death is devastating for the parents (McCubbin, Balling, Possin, Frierdich & Bryne, 2002:103). Families find difficulty functioning with constant pain, fear of death and the difficulty of hospital treatment (Clemency, 2009:7; Miller, 2011, personal interview; Serebro, 2012, personal interview).

LTIs appear to enervate children and the threat of premature death seems to rob them of the 'dreams' they hoped to fulfil one day. Children love to 'dream'; some 'dream' of a trip to the moon or a visit to the beach while others want to be a prince or princess (Miller, 2011, personal interview; Reach For A Dream Foundation, 2012). Realization of these 'dreams' or wishes could allow children with LTIs an opportunity to escape from the rigours of treatment if only for a short time. In the opinion of Sotrianakos (2011, personal interview), fulfilling the 'dreams' of children means that they appear to receive strength and joy, emotional support, inspiration, increased socialization and enhanced social health. The term 'dream' in the context of this study refers to the unfulfilled wishes and fantasies of a child, the hope children have that their 'dream' may one day come true.

In order to sustain a good quality of life (QOL) the concept of hope is important and appears to enable positive elements, and even to encourage possible recovery from severe illness in people with LTIs (Chartrand & Cheng, 2005:293; Itzhaky & Lipschitz-Elhawl, 2004:46; Mok, Ka-Po, Wai-Man, Lai-Ngor, Ng & Kin-Sang, 2010:877-883; Tusaie & Patterson, 2006:146). It is reported that intervention programmes deem hope to be important to patients suffering from LTIs (Eliott & Olver, 2002:609-638). Hope is a confident but uncertain expectation of a future good, a sense of having something to look forward to. As a result, the anticipation of a 'dream' experience among children with LTIs may provide them with an opportunity to engage in hopeful future-oriented planning (Clemency, 2009:15). 'Dream-come-true' intervention strategies for children suffering from LTIs are aimed at improving the QOL and provide enriching psychosocial experiences for both the children and their families. Psychosocial intervention strategies appear to give the children and their families the opportunity to focus on positive affective psychosocial experiences, better social interactions and improved family functioning rather than on the LTI itself.

There are a number of organizations that offer psychosocial intervention strategies. A few such organizations are: Children's Wish Foundation, Disneyland, The Dream Factory, Make-a-Wish Foundation; COPE (Creating Opportunities for Parent Empowerment); CCCP (The University of California – Los Angeles Children's Comfort Care Program) and, in South Africa, the Reach For A Dream Foundation (RFAD).

RFAD is a 'dream' realization organization that was established in July 1988. RFAD defines its core purpose as "fulfilling the 'dreams' of children of any race, colour and creed

between the ages of 3 and 18 faced with a LTI" (Miller, 2012, personal interview). According to Sotrianakos (2011, personal interview), RFAD has fulfilled the 'dreams' of over 9000 children and adolescents with LTIs since 2007. By engaging in 'dream-come-true' projects, it is argued that the children and their families were given the opportunity to focus on positive affective experiences in comparison to the fear, sadness and powerlessness experienced by children with LTIs and their parents prior to the 'dream-come-true' psychosocial experience.

Researching the psychosocial experiences of children and adolescents with LTIs and their families following 'dream-come-true' projects could be of value. With the connection between QOL, morbidity and mortality of children suffering from LTIs, the experiential link between promoting psychosocial well-being, resilience and coping abilities and the decrease of anxiety and depression associated with LTI needs to be studied. Through a narrative enquiry into 'dream-come-true' projects, some important knowledge about the psychosocial experiences of children and adolescents with LTIs and their parents could be gained.

From the problem statement presented above, the following research question was formulated: **What were the experiences of recipients of Reach For A Dream Foundation projects?**

1.2 RESEARCH AIM

The purpose of this study was to explore 'dream-come-true' psychosocial experiences of children and adolescents with LTIs and their families, to examine how these experiences relate to multiple dimensions of well-being and family functioning. Future-oriented intervention strategies such as 'dream-come-true' experiences appear to meet some of the challenges LTIs present for children: therefore achieving a deeper understanding of the recipients' psychosocial experiences could hopefully be utilized to further enhance such intervention strategies by making them more available, accessible and structured.

1.3   CENTRAL THEORETICAL STATEMENT

LTIs present with a wide range of physical and psychosocial side effects, distress, anxiety and fear in the child/adolescent and family, which contribute to the perpetuation of hopelessness. The 'dream-come-true' psychosocial experiences of children/adolescents suffering from LTIs could yield some important knowledge about future-oriented thinking, increased hope, positive attitude changes and improved physical and mental health. Research about therapeutic strategies and practices such as 'dream-come-true' projects could be crucial to the effective management of children/adolescents with LTIs and making these projects more available, accessible, and more structured could further enhance such intervention strategies.

1.4   CONCEPTUAL CLARIFICATION

The following concepts are clarified for the purpose of this research:

1.4.1 Life-threatening illnesses (LTIs)

A LTI is defined as an illness or state in which death is possible or imminent; an illness that could drastically affect or end a life (Clemency, 2009:3-9); an illness that potentially could cause life-threatening health problems (Sotrianakos, 2011, personal interview). LTIs present with not only a wide range of physical side effects but also a variety of emotional reactions (Bustamante, Mellman, David & Fins, 2001:49).

1.4.2 Impact of LTIs on the quality of life

A person's QOL is defined as the general well-being and overall quality of a person's daily life, physical, social and mental health (Gregory, Johnston, Pratt, Watts & Whatmore, 2009: 3287-9; Goldbeck & Melches, 2005:1915-1924). The physical dimension of a LTI on a person's QOL includes aggressive medical and treatment procedures and diagnostic examinations often resulting in pain and discomfort. (Sotrianakos, 2011, personal interview; Bustamante *et al.,* 2001:49; McCubbin *et al.*, 2002:103). LTIs can thus physically weaken the patient, it can affect their ability to walk or to feed themselves and can also interfere with the developmental stages of children (see Appendix 2) (Meijer, Sinnema, Bijstra, Mellenbergh & Wolters, 2002:1453). Owing to the continuous demands of caring for a sick child, families of the critically ill patient can also be affected physically. The social dimension presents with

obstacles such as isolation from friends, isolation from education, exclusion from peer groups and inability to plan for the future (Gum & Snyder, 2002:883; McCubbin *et al.*, 2002:103; Serebro, 2012, personal interview). The emotional well-being of a child suffering from a LTI encompasses the child and the family's coping ability, self-esteem and positive outlook and how to use these qualities to move in a positive direction (Snyder, 2002:249-275).

1.4.3   Hope

Improvement in a person's QOL is promoted by an emotional state which believes in a positive outcome (Chartrand & Cheng, 2005:293; Itzhaky & Lipschitz-Elhawl, 2004:46; Mok *et al.,* 2010:877; Tusaie & Patterson, 2006:146). An increase of psychological and physical well-being, adaptive coping and positive appraisal of stressful events is associated to hope (Roesch & Vaughn, 2006:62-64). To hope is to change a person's thought process from negative to positive: to choose positive emotions from stimuli in the environment and then to apply them to perceptions and beliefs (Isen, 2001:70-85).

Positive psychology is grounded in positive experience, focusing on people's strengths and how they can grow and thrive (Luthans, Avey & Patera, 2008:219-238). To encourage better outcomes in physical health and psychological adjustment hope is related to learned optimism, optimism, self-efficacy and self-esteem by Snyder's hope theory and other theories (Chan, 2009:14-31). Hope has been discussed in psychology and psychiatry for many years as having very little cross referencing, research on measurement or psychological intervention strategies (Gum & Snyder, 2002:884; Snyder, 2002:249-252).

1.4.4 Coping

To consciously try and solve personal and interpersonal problems and to control or minimise stress or conflict is defined as coping (Glanz, Rimer & Lewis, 2002:210-215; Snyder, 1994:3-21). Internal or external environmental demands cause stressors; these upset the balance in a person, thus affecting physical and psychological well-being (Glanz *et al.*, 2002:210-230). With the diagnosis of a LTI, the patient and family experience severe stress and seem to require unique coping mechanisms (Miller, 2011, personal interview). The framework used to support this study to evaluate the processes of coping and stressful events was the transactional model of stress and coping (Lazarus & Folkman, 1984; Lazarus, 1993:234-247). The basic assumption of Lazarus and Folkman's transactional theory of stress and coping is

that stressors are looked at in relation to one's perception, and are viewed as either threatening (stress) or challenging (Folkman *et al*., 1986: 992-1003).

In commenting on coping with stress, Glanz *et al.,* (2002:215) found that coping with stress is the way people look for medical care, social support and how much they accept advice from professionals. Research discusses various aspects of coping: more adaptive in the short run are the avoidant coping strategies, whereas in the long run there are the attentive-confrontative coping strategies (Glanz *et al.*, 2002:211-217). According to McGrath, Jordens, Montgomery & Kerridge (2006:665-668), coping can have a temporal aspect; it can occur before a stressful event takes place, while it is happening (for example, during the progress of a disease), or after the event (for example, in remission or cure). In studying adaptations to chronic diseases and relationships between high and low self-efficacy and specific health outcomes, patients with high self-efficacy appear to control pain better (Brister, Turner, Aaron & Mancl*,* 2006:116). Coping abilities and various health outcomes can benefit from social support (Krohne, Egloff, Varner, Burns, Weider & Ellis*,* 2000:297-311). Psychosocial intervention strategies are seen as one of these social support structures to assist with coping (Krohne *et al*., 2000:297-311).

1.4.5 Psychosocial interventions

Psychosocial intervention strategies are methods and activities used to motivate change in an individual or group's emotional state, or feelings (McCubbin *et al*., 2002:100-110). In order to alleviate existential suffering and effectively implement proactive psychosocial intervention strategies for LTI sufferers, an interdisciplinary team needs to identify those at psychosocial risk (Hirai, Arai, Tokoro & Naka, 2009:149-160; McCubbin *et al*., 2002:103). In research performed by Clemency (2009:15-17) and the Make-A-Wish Foundation (2011), it was reported that children suffering from LTIs benefited greatly from psychosocial intervention strategies. The children and their families reported a better QOL, and distraction and even respite from the illness. In order to assist in eliminating discomforts associated with LTIs, psychosocial intervention strategies can offer specialized and creative recommendations (Clemency, 2009:39-43). The influence of LTIs on children, the importance of a 'dream' and hope changes depending on a child's age (Meijer *et al.,* 2002:1453) (see Appendix 2). This research interviewed children in both the middle childhood and adolescent stages. RFAD and the medical profession need to be aware and sensitive to the fact that people react to and cope with a LTI diagnosis differently. In most

cases psychosocial interventions are found to be useful but on some occasions it might have stressful effects. It is found that some patients may prefer to be alone because they feel that other people feel pity for them. It is also found that continuous verbal communication about their problems often leads to depression in people suffering from LTIs (Sarah & Sostaric, 2004:39). In light of this research RFAD, the medical profession and family and friends need to monitor any potential negative impact of psychosocial interventions on the child/adolescent suffering from a LTI.

1.5   RESEARCH METHODOLOGY

1.5.1 Literature study

Literature was gathered from databases, various books and journal articles on a global scale owing to the lack of South African reports, studies, articles and statistics on this area. Subjects studied were **LTIs, fears, insecurities, hopelessness, hope** and **positive thought**, **QOL** and **psychosocial intervention strategies**. This research was framed by Lazarus and Folkman's transactional theory of stress and coping and Snyder's hope theory.

1.5.2 Empirical investigation

1.5.2.1 Research approach and design

A qualitative approach was used in this study to give the participants the opportunity to describe complex experiences, and for considerable flexibility in scope and depth (Patton, 2002:200-244). Owing to the rich complexity of the stories, a qualitative approach was the most appropriate as it identified the 'human' side of the research: identifying behaviours, opinions, emotions and relationships effectively (Creswell, 2007:50-100; Denzin & Lincoln, 2000:1-28; Mack *et al.,* 2006:5265-5270).

The study used a narrative inquiry design. A narrative inquiry design was applicable for this research as the participants were allowed every opportunity to tell their stories as experts. The narrative of 'dream-come-true' experiences was an emotional journey and to employ a quantitative, statistical approach would not have provided such rich data. This design allowed the researcher the opportunity to immerse herself in the personal experiences of the children/adolescents and their families (Creswell, 2007:50-100; Dicicco-Bloom & Crabtree, 2006:314-321).

1.5.2.2 Participants

The participants were children/adolescents and their parents (or caregivers) who are or had been clients of RFAD and were living in Johannesburg and the surrounding areas. Participants were required to be English speaking and consisted of six children/adolescents, male and female, between the ages of 8 and 18 suffering from LTIs at various stages and 11 parent participants; one father was absent (17 participants in total). RFAD compiled a list according to the criteria above. The Foundation contacted all the families on the list, explained the purpose of the research and obtained each parent's permission to possibly be contacted by the researcher. The researcher was provided with the confidential client list from RFAD containing all clients who had agreed to be contacted. On receipt of the list, the researcher used a random numerical Excel program to select a group of six participants randomly (Yates, 2010:207-230). The researcher contacted these six participants by phone and followed up in writing explaining the purpose of the research and interview process. The researcher found that the initial six selected participants were not all available owing to illness or time constraints experienced by the participants. The Excel program selection process was repeated several times until six child/adolescent participants were selected.

1.5.2.3 Research procedure

- The researcher contacted RFAD, advised the details of the research, discussed the data collection procedure and research value and obtained their informed consent for the research.
- Ethical clearance was obtained from the North-West University (NWU-00060-12-A1).
- A literature study was conducted.
- The researcher informed the families and children/adolescents of the purpose of the research.
- As the research involved minors, informed consent was obtained from both parents. Assent was also obtained from all minors.
- Days and times for interviewing were arranged with each participant.
- Interviews were held in the comfort of the participant's own home.
- The data were collected, transcribed and analysed.

1.5.2.4 Data collection methods

Semi-structured individual in-depth interviews were used in this study. A semi-structured interview is open and allows new ideas to arise during the interview in comparison to a structured interview which has a rigorous set of questions which does not allow one to divert from the script. Semi-structured interviews do not limit participants to sets of pre-determined answers allowing flexibility in scope and depth and organized around areas of particular interest (Dicicco-Bloom & Crabtree, 2006:315). The interviewer in a semi-structured interview generally works from a framework of themes that are to be explored (DiCicco-Bloom & Crabtree, 2006:315). Semi-structured individual in-depth interviewing was the best suited data collection method for this research study as it allowed the participants' time to talk about their experiences. This method allowed for detailed and fluid accounting of the participants' experiences of 'dream-come-true' projects without continual interruption by additional questions.

The child/adolescent interviews differed from the interviews with parents in that the researcher used friendly, tangible items to facilitate the interview process (see Appendix 3). Recognising a child's need for development and to engage in play as prescribed by Section 2 of the Children's Act (38 of 2005), the researcher chose to use emotive cushions as children inherently find it difficult to verbalize their emotions (Getz, 2011:200). The cushions measured 20cm in diameter. They were pleasant to the touch and fun to play with. The cushions were shown to the children/adolescents at the start of the interview. They were not forced on them but they were available if needed. All four the children made extensive use of the cushions. The two adolescents (C3, 15 years and C6, 13 years) took note of them, but without handling them. The emotive cushions gave the child participants a fun way to help them recognize emotions, such as <u>happy</u>, <u>sad</u>, <u>peaceful</u>, <u>angry</u> and <u>frightened</u> to mention a few. The children were given the opportunity to create their own emotive cushions out of paper if a particular emotion was not found in the collection provided by the researcher. The researcher remained aware of the emotional reaction at different developmental stages in children suffering from LTIs, middle childhood children are more capable of understanding their illness and its treatment, and are able to begin to imagine different scenarios, or 'what if' something were to happen. Adolescents at the formal operational stage reason beyond a world of concrete reality to a world of possibilities problem solving begins with possibility and proceeds to reality.

The guiding questions posed to the children/adolescents required them to choose emotive cushions that identified their 'pre-dream' emotions, emotions during the 'dream', and finally the 'post-dream' emotions. The researcher used an interview schedule and the following questions were asked:

- 'Can you tell me how you felt when you found out you were sick? You can choose your feelings from these cushions or tell me about your own feelings';
- 'Can you tell me how you felt when your "dream" came true? You can choose your feelings from these cushions or tell me about your own feelings'; and
- 'Can you tell me how you feel now after your "dream"? You can choose your feelings from these cushions or tell me about your own feelings'.

The parent interviews consisted of semi-structured individual in-depth questions according to the interview schedule below, beginning with 'Can you share your story with me?' and followed by:

- When did you find out your son/daughter was ill?
- How did you feel when you were told about your daughter/son's illness?
- How did you feel when RFAD contacted you?
- Can you share your feelings with me about the "dream-come-true" experience?
- Now that the dream experience is over, how is the family?
- How are you feeling now, "post-dream?

Asking the parents to narrate their experiences in a fluid story allowed for rich emotional data to emerge. The researcher checked throughout the interviews that she understood the stories that evolved during the course of the interviews, as recommended by Leedy and Ormrod (2005:143). Field notes were made immediately after each interview detailing the researcher's observations and the participants' nonverbal reactions. The field notes were referred to by the researcher when analysing the data and searching for themes and sub-themes and this provided insights into interactions, helped capture context, helped the researcher understand the influence of the physical environment, culture and social situation (see Appendix 4). All participants gave permission for interviews to be audio-recorded.

1.5.2.5 Data analysis

Tesch's six step approach to data analysis was followed. In this study, ideas emerged, findings that were 'worth paying attention to' were plotted and themes were listed (Tesch, 1990:117). Thoughts were plotted in the margins and lists of topics were made. Similar topics were grouped together into columns, as themes and sub-themes. The lists of themes and sub-themes were reduced to categories by using a 'cut and paste' process. The process of data analysis was supported with field notes. A crystallization approach which entailed using different participant perspectives/methods to search for patterns and themes was followed (Borkan, 1999:179-194; Lincoln & Guba, 1985:290). After the interviews, feedback of all the participants about the findings was sought in order to further confirm and verify the accuracy of the transcribed data and themes. The participants are given the opportunity to confirm, verify, correct errors or challenge what could be perceived as wrong interpretations.

1.5.2.6 Trustworthiness

The purposive-cum-random sampling of this research assisted with the credibility of the results. When considering unknown influences in a sample, random sampling helps to ensure these influences are distributed evenly. According to Leedy and Ormrod (2005:146), in order to select a group that is a representative sample of a larger group, a random sampling procedure gives the greatest assurance for accuracy. Credibility was further ensured, in line with Lincoln and Guba's (1985:290) evaluative criteria, in that participants were not influenced or forced to share their experiences with the researcher. The researcher also checked throughout the interviews that she correctly understood the stories that evolved during the course of the interviews, as required by Leedy and Ormrod (2005:143), who state that data are valid and reliable if the researcher and participant have the same understanding of the information.

Transferability of this research could be confirmed as the researcher has provided dense description of the experiences of the recipients of RFAD projects to convey a baseline understanding and thereby allow subsequent readers to compare the findings of this research with those that may emerge in their own research. In addressing the issue of dependability, a varied and randomly chosen population was used. Dependability was further confirmed by the rich description of the planning and execution of this research. As to the confirmability of the results, the researcher took steps to ensure that the data and findings were shaped by the participants and not by the researcher. This was achieved by allowing participants to tell their

story voluntarily and without interference. The researcher's 'audit trail' consists of verbatim transcripts, data analysis documents, a field notes journal and the dissertation itself, and as these are available upon request, this confirms the dependability and confirmability of the research. The trustworthiness of the data was also enhanced by the collection methods through fluid narrative stories, the use of emotive cushions and field notes in which the research process and experiences were recorded.

1.5.2.7 Ethical considerations

Ethical approval for this research was obtained from the Ethics Committee of the North-West University (NWU-00060-12-A1), and guidelines as per the *Government Gazette* with specific reference to research and minors (*Government Gazett*e *of the Republic of South Africa*, 2013:575). Voluntary informed consent was obtained from all parents and adolescents and voluntary informed assent from the child participants. Parent and child/adolescent participants were informed verbally and in writing of the aim of the research and that the interviews would be audio-recorded. Parent participants were advised that the researcher followed the codes and practices of research ethics of social responsibility and respect for intellectual property; the same assurance was given to the children and adolescents in a manner appropriate to their age and level of understanding. The participant's right to privacy was considered by informing parents and children/adolescents that all identities would be kept confidential and that information from the list from RFAD would only be accessed by staff of RFAD and the researcher. The researcher would ensure that all participants' personal details including their names, would be protected by the use of pseudonyms. All records would be kept on a computer with password protection for the duration of the research (Resnik, 2010:3). Computer and printed records would be kept at the offices of CCYF in a locked cabinet for five years after the research was completed, thereafter all records would be destroyed after 5 years.

The dignity and rights of all child/adolescent and adult participants were respected by allowing them the right to tell their story as they wished; the right to stop at any time and the right to ask any questions. This ensured honesty and therefore credibility (Patton, 2002:200-244). The researcher showed moral responsibility, integrity and sensitivity throughout the process. The participant stories evoked deep emotions and the researcher ensured that regular emotional breaks were taken if it appeared emotionally necessary (Kvale & Brinkman, 2008:218). Questions, attitudes or comments that could be taken as judgmental or insensitive

to cultural values or that could reactivate a child/adolescent's or parent's pain and grief from traumatic events, were avoided. The participants were, at all times, made to feel comfortable and able to tell their stories without outside pressure by holding the interviews in the comfort and privacy of their own homes. The child/adolescent participants were allowed to choose where in their home to hold the interview. The researcher recognised the child's developmental needs and to engage in play as prescribed by the Children's Act 38 of 2005 by allowing the child/adolescent to tell his/her story through the use of emotive cushions. The researcher informed the parent participants beforehand that, owing to the intense emotions that might be experienced during the interviews, three counselling sessions with a registered psychologist would be made available for the parents and/or children/adolescents should this be required.

1.6 CHOICE AND STRUCTURE OF RESEARCH ARTICLE

This dissertation follows an article format and consists of the following sections:

Section A

Part I: Orientation of the research (Harvard referencing style)

Part II: Literature review (Harvard referencing style)

Section B

Article (Vancouver referencing style, in adherence to the instructions of the journal selected)

The *African Journal of Primary Health Care & Family Medicine* has been identified as a possible journal for submission.

Section C

Summary, evaluation, conclusion and recommendations (Harvard referencing style)

1.7 SUMMARY

LTIs in children represent both a life-threatening situation for the child and severe trauma for the family as a whole, evoking insecurity and fear in everybody involved because of the associated threat of premature death, pain, uncertainty and powerlessness. The purpose of this

study was to explore the experiences of children and adolescents suffering from LTIs pre-, during and post- RFAD 'dream-come-true' projects, and their effects on their families. It is hoped that this study may yield some important information on how 'dream-come-true' experiences could ameliorate distress and improve the mental and emotional health and overall wellness of the children/adolescents and their families.

REFERENCE LIST

African Journal of Primary Health Care & Family Medicine (PHCFM). 2013. Vancouver referencing style. Website: http://openjournals.net/files/Ref/VANCOUVER%20 Reference%20guide.pdf Date of access: 2 May 2013.

Borkan, J. 1999. Immersion/Crystallization. (*In* Crabtree, B.F. & Miller, W.L. eds. *Doing Qualitative Research* 2nd ed. Thousand Oaks, CA: Sage Publications:179-194).

Brister, H, Turner, J.A., Aaron, L.A., Mancl, L. 2006. Self-efficacy is associated with pain, functioning and coping in patients with chronic temporomandibular disorder pain. *Journal of Orofacial Pain,* 20(2):116.

Bustamante, V., Mellman, T., David, D. & Fins, A. 2001. Cognitive functioning and the early development of PTSD. *Journal of Traumatic Stress,* 14(4):791-797.

Cancer.org. 2012. Website: http://www.cancer.org/Treatment/ChildrenandCancer /WhenYourChildHasCancer/index Date of access: 10 Sept 2012.

Chan, Y.C. 2009. Hope, participation and subjective well-being of people with spinal cord injuries living in the community. Wisconsin-Madison: University of Wisconsin-Madison. (Dissertation – PhD). (Unpublished).

Chartrand, T.L. & Cheng, C.M. 2005. The role of non-conscious goal pursuit in hope. *Psychological Inquiry,* 13(4):276-32.

Childhood Cancer Foundation of South Africa (CHOC). 2011. Website: www.choc.co.za Date of access: 8 July 2011.

Children's Wish Foundation, 2012. Website: http://www.childrenswish.org/. Date of access: 1 August 2012.

Children's Act, Act No. 38 of 2005. Website: http://www.dsd.gov.za/index. php?option=com_docman &task=cat_view&gid=30&Itemid=39. Date of access: 13 July 2013.

Clemency, C.E. 2009. The impact of a wish experience on paediatric cancer patients and their families. Phoenix. Arizona State University. (Dissertation – PhD). (Un-published).

Creating Opportunities for Parent Empowerment (COPE). Website: 2013. http://www.copeforhope.com/cop_picuparentprogram.html Date of access: 12 April 2013.

Creswell, J.W. 2007. *Qualitative inquiry and research design: choosing among five approaches*. London: SAGE:50-110.

Denzin, N.K. & Lincoln, Y.S. 2000. Introduction: the discipline and practice of qualitative research. (*In* Denzin, N.K. & Lincoln, Y.S., eds. *Handbook of qualitative research*. 2nd ed. Thousand Oaks, CA: Sage:1-28).

Dicicco-Bloom, B. & Crabtree, B.F. 2006. The qualitative research interview. *Medical Education*, 40:314-321.

Disney 2012. Website: http://www.disney.co.za/index.jsp Date of Access: 15 June 2012.

Dream Factory 2012. Website: http://dreamfactoryinc.org/ Date of access: 3 April 2012.

Eliott, J.A. & Olver, I.N. 2009. Hope, life & death: a qualitative analysis of dying cancer patients' talk about hope. *Death Studies,* 33(7):609-638.

Folkman, S., Lazarus, R.S., Dunkel-Schetter, C., DeLongis, A. & Gruen, R.J. 1986. Dynamics of a stressful encounter: cognitive appraisal, coping and encounter outcomes. *Journal of Personality and Social Psychology,* 50(5):992-1003.

Getz, L. 2011. The power of play therapy. *Social Work Today*, 11(3):20.

Glanz, K., Rimer, B.K. & Lewis, F.M. 2002. *Health behavior and health education. Theory, research and practice.* San Francisco: Wiley & Sons: 210-230.

Goldbeck, L. & Melches, J. 2005. Quality of life in families of children with congenital heart disease. *Quality of Life Research,* 14:1915-1924.

Government Gazette see South Africa.

Gregory, D., Johnston, R., Pratt, G., Watts, M. & Whatmore, S. 2009. *Quality of Life. Dictionary of human geography.* 5th ed. Oxford: Wiley-Blackwell, 3287-9.

Gum, A. & Snyder, C.R. 2002. Coping with terminal illness: the role of hopeful thinking. *Jounal of Palliative Medicine,* 5(6):883-892.

Harvard referencing style. 2013. Website: http://www.nwu.ac.za/sites/default/files/ files/ library/ documents/ verwysings.pdf Date of access: 2 February 2013.

Hirai, K., Arai, H., Tokoro, A. & Naka, N. 2009. Self-efficacy, psychological adjustment and decisional-balance regarding decision making for outpatient chemotherapy in Japanese advanced lung cancer. *Psychology and Health,* 24:149-60.

International Diabetes Federation (IDF). 2013. Website: http://www.idf.org/ Date of access: 1 July 2013.

Isen, A.M. 2001. An influence of positive affect on decision making in complex situations: theoretical issues with practical implications. *Journal of Consumer Psychology*, 11:75-85.

Itzhaky, H. & Lipschitz-Elhawl, R. 2004. Hope as a strategy in supervising social workers of terminally ill patients. *Health and Social Work*, 29(1):46-54.

Krohne, H.W., Egloff, B., Varner, L.J., Burns, L.R., Weider, G. & Ellis, H.C. 2000. The assessment of dispositional vigilance and cognitive avoidance: factorial structure,

psychometric properties, and validity of the Mainz Coping Inventory. *Cognitive Therapy and Research,* 24:297-311.

Kvale, S. & Brinkmann, S. 2008. *InterViews*: *learning the craft of qualitative research interviewing.* 2nd ed. Thousand Oaks, CA: Sage: 210-220.

Lazarus, R.S. & Folkman, S. 1984. *Stress, appraisal and coping*. New York: Springer.

Lazarus, R.S. 1993. Coping theory and research: past, present and future. *Psychosomatik Medicine,* 55:234-247.

Leedy, P.D. & Ormrod, J.E. 2005. *Practical research: planning and design*. 8th ed. Upper Saddle River, NJ: Merrill Prentice Hall:143-203.

Lincoln, Y.S. & Guba, E.G. 1985. *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications, Inc:290.

Luthans, F., Avey, J.B. & Patera, J.L. 2008. Experimental analysis of a web-based training intervention to develop positive psychological capital. *Academy of Management Learning & Education*:7(2):219-238.

Mack, J.W., Wolfe, J., Grier, H.E., Clearly, P.D. & Weeks, J.C. 2006. Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. *Journal of Clinical Oncology,* 24:5265-5270.

Make a Wish Foundation 2011. Website: http://wish.org/ Date of access: 11 October 2011.

McCubbin, M., Balling, K., Possin, P., Frierdich, S. & Bryne, B. 2002. Family resiliency in childhood cancer. *Family Relations*, 50(2):100-110.

McGrath, C., Jordens, C.F., Montgomery, K. & Kerridge, I.H. 2006. 'Right' way to 'do' illness? Thinking critically about positive thinking. *Internal Medicine Journal,* 36(10):665-668.

Meijer S.A., Sinnema G., Bijstra J.O., Mellenbergh G.J. & Wolters W.H.G. 2002. Coping styles and locus of control as predictors for psychological adjustment of adolescents with chronic illness. *Social Science and Medicine Journal*, 54:1453-1461.

Mok, E., Ka-Po, L., Wai-Man, L., Lai-Ngor, C., Ng, J. & Kin-Sang, C. 2010. Health professional perspective on hope in the palliative care setting. *Journal of Palliative Medicine*. 1(7):877-883.

Patton, M.Q. 2002. *Qualitative research and evaluation methods*. 3rd ed. Thousand Oaks, CA: SAGE: 200-244.

Reber, A.S., Allen, R., Reber, E.S. 2009. *Penguin Dictionary of Psychology*. 4th ed. Penguin, London: 637.

Reach For A Dream Foundation, 2011. About us. Website: http://www.reachforadream.org.za Date of access: 5 July 2011.

Reach For A Dream Foundation, 2012. About us. Website: http://www.reachforadream.org.za Date of access: 1 June 2012.

Resnik, D.B. 2010. Genomic research data. *Ethics and Human Research Journal,* 32(1):1-6.

Roesch, S. & Vaughn, A. 2006. Attribution. (*In* Y. Jackson, ed. *Encyclopedia of multicultural psychology.* Thousand Oaks, CA. Sage Publications: 62-64).

Ruddy, R. & House, A. 2005. Metareview of high-quality systematic reviews of interventions in key areas of liaison psychiatry. *British Journal of Psychiatry*, 187:109-120.

South Africa. 2006. Children's Act 38 of 2005. *Government Gazette,* no 28944, 19 June, Notice No 610. Website: http://www.greengazette.co.za/publications/national-gazettes/20130510.575 Date of access 10 July 2012.

Snyder, C.R. 2002. Hope theory: rainbows in the mind. *Psychological Enquiry*, 13(4): 249-275.

Snyder, C.R. 1994. *The psychology of hope: you can get there from here*: New York, Free Press.,3-21.

Sarah, L. & Sostaric, M. 2004. Psychosocial coping strategies in cancer patients. *Radiation Journal,38*(1):39.

Tesch, R. 1990. *Qualitative research: analysis types and software tools*. Bristol: Falmer.

Tusaie, K.R. & Patterson, K. 2006. Relationships among trait, situational, and comparative optimism: clarifying concepts for a theoretically consistent and evidence-based intervention to maximize resilience. *Archive of Psychiatry Nursing*, 20(3):331-341.

UCLA Children's Comfort Care Program. (CCCP). 2013. Website: http://www. uclahealth.org/body_mattel.cfm?id=1179. Date of access 1 February 2013.

World Health Organization. (WHO). 2011. Website: http://www.who.int/en/ Date of access: 8 August 2011.

Yates, D.S., Starnes, S. & Moore, D. 2010. *The practice of statistics.* 3rd ed. New York: Freeman, 207-230.

Interviews

Miller, B. Reach For A Dream Foundation [personal interview]. 6 July 2012, Johannesburg.

Sotrianakos, J. Reach For A Dream Foundation [personal interview]. 6 July 2011 & 7 August 2012, Johannesburg.

Serebro, M. Reach For A Dream Foundation [personal interview]. 2 Feb 2012, Johannesburg.

PART 2: LITERATURE STUDY

2.1 INTRODUCTION

The literature study covered various subjects relating to LTIs and experiences of children suffering from LTIs and the impact on their families. The researcher hoped to gain some understanding of the challenges of LTIs and of intervention strategies intended to meet these challenges. Literature was gathered on a global scale owing to the lack of reports, papers and statistics in South Africa. Research shows that LTIs present with a wide range of physical and psychological side effects. These include fears, insecurities, hopelessness, hope and positive thought, QOL, and psychosocial intervention strategies and practices. Lazarus and Folkman's transactional theory of stress and coping (1984:226-258) and Snyder's hope theory (2002) support this study.

The literature shows intense emotions of fear and hopelessness when a child and family are faced with a LTI diagnosis (Sahler, Fairclough, Phipps, Mulhern, Dolgin & Noll, 2005:272-283; Sloper, 2000:79-91). Von Essen, Enskar, Kreuger, Larson & Sjoden (2000:229-236) considers the fears LTI sufferers face to include a fear of the treatment and its related side effects, in addition Von Essen *et al.*, reports on the way daily activities are controlled by an illness. LTI sufferers report changes in their physical appearance to be distressing and feel they are treated differently resulting often in depression, anxiety and low self-esteem (Von Essen *et al.,* 2000:229-236). When living with a LTI, patients are often faced with severe physical deterioration. Lazarus and Folkman's transactional theory of stress (1984) evaluates the process of coping with stressful events. Using Lazarus and Folkman's (1984) cognitive appraisal model, research shows when one is faced with a LTI it can be interpreted as threatening and harmful, and subsequently can be seen as intensely stressful. Snyder's hope theory considers hope as a therapeutic or healing factor (Snyder & McCullough, 2000:151-160). Hope with regard to dealing with LTIs can take on many forms: hope that pain will diminish or vanish; hope that an illness will disappear and hope of seeing friends and family again. Thinking positively, being hopeful and optimistic and not giving in to despair is both a cultural expectation and a moral norm for a LTI sufferer (McGrath *et al.*, 2006:665-668).

The importance of promoting hope in a patient, maintaining or even increasing it, is encouraged in Healthcare workers. After major traumatic events hope is restored; hope seems to flourish where it seems least warranted but is most important (Aspinwall & Leafe, 2002:285). Patients on the tortuous path of a LTI undergo a variety of emotional reactions prompting their doctors and families to request some type of intervention (Bustamante *et al.*, 2001:49). Psychosocial intervention strategies have been linked to promoting mental, emotional and social well-being, resilience, respite, hope and coping abilities. In the context of a LTI, hope appears to be crucial for both children and their families. Very little literature exists on the 'dream-come-true' experience and its relation to hope. In South Africa a 'dream-come-true' intervention strategy is offered by the Reach For A Dream Foundation (RFAD). This study aimed to explore the 'dream-come-true' experiences of recipients of RFAD projects with the hope that it may yield some important information about psychosocial intervention strategies and how these strategies appear crucial in ameliorating distress, offering respite, decreasing isolation, increasing a sense of empowerment and self-confidence, and decreasing anxiety and fear in children and their families.

While medical intervention strategies are used to alleviate physical side effects, psychosocial intervention strategies that focus on improving the well-being of the child and family appear to be limited. Psychosocial intervention strategies appear to increase a sense of empowerment and self-confidence in participants, giving them unique opportunities to connect with their family in a positive, normal way. Psychosocial intervention strategies such as 'dream-come-true' projects appear to ameliorate distress, offer respite, decrease isolation, and increase a sense of empowerment and self-confidence.

2.2   IMPACT OF LTIs ON FAMILY FUNCTIONING

Family functioning is defined in this study as the way a family copes, functions and continues with day to day activities when faced with a LTI diagnosis. McCubbin *et al.,* (2002:103-111) reports that the diagnosis of cancer or a LTI can severely impact the functioning of a family, putting the family into a immediate crisis with parents describing feelings of shock, disbelief, unreality and fear at hearing the diagnosis. Mild conditions demand less from the family, whereas severe conditions like cancer require extensive family involvement (Clemency, 2009:7-10). Due to the fact that one or both parents may need to stay at the hospital with their ill child, families may need to establish new patterns of functioning, the reallocating of roles, responsibilities, and living arrangements (McCubbin *et al.*, 2002:108-113). McCubbin *et al.*,

(2002:103-104) reports that families mobilise quickly at the time of a LTI diagnosis; they seem to adapt quickly to living as a split family during the periods a child is hospitalized. Despite research showing a positive reaction from families, other research reveals that siblings can react negatively to a brother or sister with a LTI, and often feel jealous and angry. This sibling rivalry has the potential to become a devastating vicious circle, as the child the who feels jealous or angry at the attention given to his or her sick sibling, then feels guilty for having felt angry towards them (Talbot, 2012:81).

Evaluating how individuals and families cope with stressful events with the onset of illness is in this study guided by The Transactional Model of Stress and Coping (Moskowitz, Hult, Bussilari & Acree, 2009:121-141). Families seek out aid, and have an enormous dependency on the health care team to 'save' their child and desperately need reassurance at this vulnerable time (Barrera, Wayland, D'Agostino, Gibson, Weksberg & Malkin, 2003:215-232). Boss's family stress theory (1987) predicts that a crisis in the family sphere is dependent not only on the hardships associated with this crisis but also on the family's pre-existing resources. Pre-existing resources may include social support, positive marital communication and/or financial resources. Despite the findings above, there are parents who do adjust relatively well following their child's diagnosis. Support from families and society, maintaining hope and seeing themselves as strong and adaptable may help buffer much of the impact (Barrera *et al.,* 2003:215-232).

2.3   IMPACT OF LTIs ON THE QUALITY OF LIFE

2.3.1   Quality of Life

The QOL of an individual refers not only to financial wellbeing of a person but also the physical, mental and social wellbeing (Gregory *et al.,* 2009:3287-3289). QOL has been increasingly used as an indicator of successful medical intervention strategies and encompasses three dimensions: physical, social, and emotional well-being (Goldbeck & Melches, 2005). Both physical and psychosocial symptoms appear to affect QOL, family functioning and expressions of hope among children with LTIs and their families by increasing physical pain, stress and isolation (Miller, 2011, personal interview). Serebro (2012, personal interview) observes that hope and looking forward to the future seem to decrease the sadness in terminally ill patients, increase happiness and are important in sustaining QOL. Hope appears to decrease anxiety and depression symptomology, and

promote mental, emotional and social well-being (Mok *et al.*, 2010:877-883; Serebro, 2012, personal interview; Snyder, 2002:250; Tusaie & Patterson, 2006:146).

2.3.2 Physical dimension

The physical dimension of the QOL in relation to this study is defined as the physical effect of LTIs on a critically ill person (McCubbin *et al.*, 2002:100-105). Physical weakening can dramatically affect the sick child's ability to walk, run or even feed themselves (McCubbin *et al.,* 2002:100-105). McCubbin *et al.*, (2002:103) and Bustamante *et al.,* (2001:49) report that children diagnosed with LTIs can be confronted with pain and discomfort and aggressive medical examinations and procedures. LTIs may also interfere with the developmental stages of children because of the extended hospital stays and exclusion from school (Meijer *et al.*, 2002:1453-1461) (see Appendix 2). Children may be rendered unable to participate in activities considered normal for their age. Research shows an increased prevalence of learning and speech difficulties, sensory dysfunctions and behavioural problems (Newachek *et al.*, 1991:41-46). The physical dimension also covers the physical toll on the family; the constant, unrelenting nature of the 24-hour-a-day, 7-day-a-week nature of care. Sleep deprivation and the physical demands of lifting children in and out of beds, baths and wheelchairs can be physically taxing.

2.3.3 Social dimension

The social dimension of a person's QOL when affected by a LTI may present many obstacles. According to Gum & Snyder (2002:883), the LTI can contribute substantially to the isolation of the child and family owing to the extended stays in hospital and the physical restrictions placed on the child (too ill to play, too ill to do school work). The effects of chemotherapy treatment can cause changes in functional status and can alter relationships: the child is no longer part of his or her peer group, cannot take part in normal childhood activities and often loses established friendships (Gum & Snyder, 2002:882-885). McCubbin *et al.* (2002:453-455) comment that in the social context, the effects of LTIs on the appearance of the children (hair and extreme weight loss, or weight increase, pale skin) mean that they often feel rejected by their peers because of their 'look' of ill health. Planning for the future and maintaining normal social contact can prove difficult for a family when a child is diagnosed with a LTI (McCubbin *et al.*, 2002:103; Serebro, 2012, personal interview). In the opinion of Sotrianakos (2011, personal interview), social well-being increases with the fulfilling of the children's 'dreams'. The results of the 2011 Make-a-Wish Foundation impact study reveal

that the fulfilled wish experience contributes substantially to 'dream' children's social well-being by increasing socialisation, reducing isolation and increasing feelings of being accepted by others.

2.3.3 Emotional well-being dimension

The emotional well-being of an individual in the context of this study is related to the coping ability, self-esteem and positive outlook of a child with a LTI. A person's ability to move forward in their life in a positive way is known as their emotional strength (Maxfield, 2010:106-108). A useful definition of emotional well-being is offered by the USA Mental Health Foundation: "A positive sense of well-being which enables an individual to be able to function in society and meet the demands of everyday life; people in good mental health have the ability to recover effectively from illness, change or misfortune" (USA Mental Health Foundation. Online. 2013). Research shows that LTIs present not only with physical pain but also affect the emotional well-being of children with LTIs and their families (Aspinwall & Leafe, 2002:280-283; Maxfield, 2010:105-108; Miller, 2011, personal interview). The psychosocial effects on children depend on the developmental stage of the child (see Appendix 2). This research interviewed middle school and adolescent participants. Maxfield's qualitative results (2010:105) reveal that participants attempt to maintain a positive attitude in the face of many obstacles presented by LTIs.

Health consequences of emotional problems include poor self-esteem, morbidity, stress, and psychiatric disorders (Collins, Devine, Johnson, Pinkerton & Thaler, 2002:10-16). Addressing emotional problems is seen as a key health care intervention (Rubin & Peyrot, 2001:457-478). Positive psychology recognizes that people have the capacity to thrive even in the face of adversity. This ability sets the stage for a feeling of emotional well-being, and looks to the future in the expectation of a better tomorrow (Aspinwall & Leafe, 2002:281; Saleh & Brockopp, 2001:308-314; Seligman, Steen, Park & Peterson, 2005:410-415). LTIs in a child appear to affect not only their QOL but also many aspects of the functioning of their family (Seligman & Csikszentmihalyi, 2000: 5-14; Seligman et al., 2005:410-415; Snyder, 2000:25-30).

2.4   IMPACT OF LTIs ON HOPE

Snyder defines hope as a motivational, open to change positive goal-directed state (2002:249-251). Hope is defined by Hall and Herth as both a coping strategy, and an important factor in enhancing QOL for patients with LTIs (Hall, 1990:178; Herth, 1989:67). If children who suffer from LTIs are encouraged early on in their lives to explore goals and achieve, they become increasingly hopeful. Many researchers agree that hope is characterized by an expectation that a desired goal will be attained (Bruininks & Malle, 2005:327-355; McGeer, 2004:100-127). LTI suffers may be helped to have more positive emotions and be less hopeless or apathetic when they are encouraged to pursue and attain goals (Snyder, 1994:3-21). Eliott and Olver (2002:609-638) in an exploration of the difference between hope as a noun or verb, arrive at the conclusion that hope as a noun presents as an existing entity, hope for a cure and a future beyond the patient's control. When used as a verb, it is seen as determined by the patient, personally meaningful, depicting a positive future.

Hope is essential to patient well-being (Herth, 1995:67-72). In order to improve QOL and encourage the patient's compliance with treatment programmes, hope is essential (Good, Good, Schaffer & Lind, 1990:59-79; Gordon, 1990:273-295). Healthcare workers are encouraged to consider, instil, encourage, and foster hope in their patients (healthcare workers can include physicians, oncologists, palliative care physicians, nurses, and psychologists) (Begley & Blackwood, 2000:26-31). Research has found that higher optimism and hope appear to be mechanisms of coping with pain and appear to reduce LTI antigens (DeMoor, DeMoor, Basen-Engquist, Kudelka, Bevers, & Cohen, 2006:555-558). Cognitive, behavioural and affective components are provided by the hope theory (Snyder, 1994:3-21), hope measurements (Sympson, 1999:57-85) and guidelines for psychosocial intervention strategies (Klausner, Clarkin, Spielman, Pupo, Abrams & Alexopoulas, 2000:707-716). Most research has shown hope as a prominent emotion in patients with LTIs. However research by Rosenfeld, Pessin, Lewis, Abbey, Olden, Sachs, Amakawa, Kolva, Brescia & Breitbart, on hope and hopelessness in terminally ill patients showed that in a number of responses, patients conveyed a sense of futility, giving up on trying to live, feeling they had no hope and being pitied by others. This may be why some patients with LTIs may not want help and could feel depressed. (Rosenfeld *et al.,* 2001:325-336; Sarah & Sostaric, 2004:39).

Studies report that a LTI patient values hope and deems it something that should be considered through psychosocial intervention strategies by the healthcare professional (Eliott & Olver, 2002:609-638). Data show that optimism is a modifiable variable and can increase through certain psychosocial intervention strategies (Gillham & Reivich, 2004:146-148; Tusaie & Patterson, 2006:144-148). Gum & Snyder (2002:885) discuss research on psychotherapeutic interventions which have been encouraged by the association of the hope theory and positive outcomes in different life arenas.

2.5   IMPACT OF LTIs ON COPING

Coping strategies and skills are psychological coping mechanisms. Adaptive or constructive coping strategies to reduce stress levels can be seen as 'coping' (Glanz *et al.*, 2002:215). The nature of a stressful environment, personal traits and the social context influences a person's coping response (Carver, 2010:679-704). LTIs in children evoke feelings of uncertainty, powerlessness and stress in both the child and their family (Miller, 2011, personal interview). Coping strategies of dealing with stressors brought on by various health conditions have been researched extensively. Lazarus and Folkman's transactional theory of stress and coping guides this study although other theories have also been noted in the literature study. These are Freud's theory of coping and repression or intellectualization (Krohne *et al.*, 2002:5); Erikson's theory of coping and denying or minimizing the stressor (Krohne *et al.*, 2002:6) and the theory of coping and averting attention from the stressor (Krohne *et al*., 2000). The basic assumption of Lazarus and Folkman's transactional theory of stress and coping is that stressors are looked at in relation to one's perception, viewed as either threatening (stress) or challenging (Moskowitz *et al*., 2009:121-141) and self-efficacy is seen as an important factor with regard to coping (McGrath *et al*., 2006:665-668). McGrath (2006:665-668) further discusses the temporal aspect of coping. Coping can be demonstrated before, during (during a disease) or post stressful events.

Further research appears to show that high self-efficacy appears more important when controlling pain and adapting to the stressors presented by a LTI (Brister *et al.,* 2006:116; Stoeber & Janssen, 2011:477-97). Social support, whether tangible (gift), information (advice), or emotional (reassurance) can assist with coping and exerting beneficial effects on various health outcomes (Carver & Connor-Smith, 2010:679-700). Research suggests that when LTI sufferers are provided with social support, slowing of the illness's progression or

an influence on the recovery process is evident (Cohen & Williamson, 1991:5-24). In order to increase a person's QOL, coping strategies and interventions can help people to deal more effectively with stress in their lives (Folkman & Moskowitz, 2004:745-774). Findings suggest that psychological intervention strategies should be focused on enhancing coping mechanisms and creating a therapeutic window to help LTI patients to achieve a better QOL (Keller, Weis, Schumacher & Griessmeier, 2003:109-117). Psychosocial intervention strategies including cognitive behavioural techniques, humour or social support resources are seen as vital in assisting with coping (Krohne *et al*., 2000:297-311).

2.6 PSYCHOSOCIAL INTERVENTIONS

Psychosocial intervention strategies offered by the medical profession and other organizations are aimed at improving the QOL of children suffering from LTIs and their families. Hirai (2009) argues that little is known by professionals on the concepts and efficacy of integrated care for existential suffering in palliative care, to effectively alleviate existential suffering in LTI suffering patients, integrated care by an interdisciplinary team is necessary.

By identifying the families' psychosocial risk, the medical professional can identify and implement sound proactive psychosocial intervention strategies (McCubbin, 2002:103). Clemency's study in 2009 of one particular psychosocial intervention strategy (Make-A-Wish Foundation - MAWF) appears to show that children with LTIs benefit greatly from MAWF's psychosocial intervention strategies, the fulfilment of a child's 'dream'. The child and family reported better QOL post the 'dream-come-true' experience. The child was given the opportunity to be treated like a 'normal' child, provided a unique opportunity to connect with family and offered respite and distraction from the illness (Clemency, 2009:39-43). MAWF led an independent study in 2010 which confirmed Clemency's findings. The psychosocial intervention strategies offered by MAWF were designed to identify and measure how their psychosocial intervention strategies could enrich the human experience with hope, strength and joy. The research found a number of other psychosocial intervention strategies designed to help the terminally ill and their families. Two such intervention strategies are COPE (Creating Opportunities for Parent Empowerment), which offers workbooks and audiotapes to help parents and children though the life of a LTI (COPE for hope − online, 2012.); and CCCP (The UCLA Children's Comfort Care Program), which "provides specialized and

creative recommendations to help eliminate pediatric pain, nausea, anxiety, and other discomforts associated with serious illnesses" (UCLA Health online, 2013). The programmes mentioned offer psychosocial interventions both in hospital and in the home environment.

Fantasies and 'dreams', aspirations and, most of all, fun, are part of childhood. Children love to 'dream' of something special; something they may think will never come true (Clemency, 2009:16; Make-a-wish Foundation, 2011:D3; Sotrianakos, 2012, personal interview). Realization of this 'dream' could allow a child facing a LTI an opportunity to escape from the rigours of LTI treatment. In South Africa, the Reach For A Dream Foundation (RFAD) offers psychosocial intervention strategies ('dream-come-true' experiences) for children and adolescents suffering from LTIs (Miller, 2011, personal interview). On 7 July 1988, RFAD made the very first child's 'dream' come true, when the first dreamer, little J.C. Steinman, was treated to a wonderful birthday celebration with rides on a pony and a motorcycle (Miller, 2012, personal interview). Although the importance of psychosocial interventions is shown in the above research, due to insufficient data regarding the clinical relevance of psychosocial interventions, Carrico and Antoni (2009:574-584) in their study on the effects of psychological interventions, questioned whether psychological interventions should be tailored to meet the needs of individuals with different LTIs to provide more definitive information.

Contact between RFAD and the 'dream' child generally begins with a referral by a medical professional who determines eligibility of the child for a 'dream' experience. Eligibility is dependent on the criteria determined by RFAD: children between 5 and 18 years; suffering from a life threatening illness; the illness must be on the approved illness list of RFAD (see Appendix 8); the child's mental and physical strength and ability to partake in a dream must be determined by the child's physician and parents.

The 'dream' can be realised at any stage of a LTI depending on the severity of the illness and physical strength of the 'dream' child. RFAD will only initiate contact with the 'dream' child on approval by the 'dream' child's medical team and parents. The 'dream' child is interviewed and provides RFAD with three 'dreams'. The child is encouraged to 'dream' without restrictions. RFAD attempts to make the first 'dream' a reality; however, if this is not possible the second or third 'dream' becomes a priority. No 'dream' child is left without a 'dream-come-true' experience, and additional 'dreams' are obtained from the family if

necessary. The 'dream' is embellished, the family is included and the 'dream' is presented in a magical way to the child. The families enjoy ongoing support throughout the 'dream' experience and invitations to regular group outings with RFAD 'post-dream' until the 'dream' child reaches the age of 18. RFAD currently fulfils approximately 1000 'dreams' per year (Sotrianakos, 2013, personal interview).

2.7 CONCLUSION

The literature study has shown that LTIs in children and their families present with a wide range of physical and psychological side effects including intense emotions of fear and hopelessness. Children and families experience high levels of stress when presented with a LTI and research has shown that various coping mechanisms are used to deal with a LTI. Although the literature covers information on LTIs, aspects of hope, family functioning and QOL, there is very little research on psychosocial intervention strategies that could help to alleviate the impact of LTIs on children and their families. With the information gathered from the literature study, the researcher has become convinced that there is a need to understand how psychosocial intervention strategies and practices for children with LTIs can improve the QOL of critically ill children and their families.

REFERENCES

Aspinwall, L.G. & Leafe, S.L. 2002. In search of the unique aspects of hope: pinning our hopes on positive emotions, future-oriented thinking, hard times, and other people. *Psychological Inquiry*, 13(4):276-321.

Barrera, M., Wayland, L.A., D'Agostino, N.M., Gibson, J., Weksberg, R. & Malkin, D. 2003. Developmental differences in psychological adjustment and health-related quality of life in pediatric cancer patients. *Children's Health Care,* 32:215-232.

Begley, A. & Blackwood, B. 2000. Truth-telling versus hope: a dilemma in practice. *International Journal of Nursing Practice,* 6:26-31.

Boss, P. 1987. Family stress. (*In* Sussman, M.B. & Steinmetz, S.K., eds. *Handbook of marriage and the family*. New York: Plenum Press: 695-723).

Brister, H, Turner, J.A., Aaron, L.A., & Mancl, L.2006. Self-efficacy is associated with pain, functioning and coping in patients with chronic temporomandibular disorder pain. *Journal of Orofacial Pain,* 20(2):116.

Bruininks, P. & Malle, B.F. 2005. Distinguishing hope from optimism and related affective states. *Motivation and Emotion,* 29(4):327-355.

Bustamante, V., Mellman, T., David, D. & Fins, A. 2001. Cognitive functioning and the early development of PTSD. *Journal of Traumatic Stress,* 14(4):791-797.

Carrico, A.W. & Antoni, M.H. 2009. The effects of psychological interventions on neuroendocrine hormone regulation and immune status in HIV-positive persons. *Psychosomatic Medicine, 70(5):*575-584.

Carver, C.S. & Connor-Smith, J. 2010. Personality and Coping. *Annual Review of Psychology,* 61:679-704.

Clemency, C.E. 2009. The impact of a wish experience on paediatric cancer patients and their families. Phoenix: Arizona State University. (Dissertation – PhD). (Unpublished).

Cohen, S. & Williamson, G.M. 1991. Stress and infectious disease in humans. *Pshychological Bulletin*, 109(1):5-24.

Collins, J. J., Devine, T. D., Johnson, E. A., Pinkerton, C. R., & Thaler, H. T. 2002. The measurement of symptoms in young children with cancer: the validation of the Memorial Symptom Assessment Scale in Children Aged 7-12. *Journal of Pain and Symptom Management,* 23:10-16.

COPE (Creating Opportunities for Parent Empowerment). 2013. Website: http://copeforhope.com Date of access: 10 October 2013.

DeMoor, J.S., DeMoor, C.A., Basen-Engquist, K., Kudelka, A., Bevers, M.W. & Cohen, L. 2006. Optimism, distress, health related quality of life, and change in cancer antigen 125 among patients with ovarian cancer undergoing chemotherapy. *Psychosomatic Medicine,* 68:555-562.

Eliott, J.A. & Olver, I.N. 2009. Hope, life & death: a qualitative analysis of dying cancer patients' talk about hope. *Death Studies,* 33(7):609-638.

Folkman, S. & Moskowitz, J.T. 2004. Coping: pitfalls and promise. *Annual Review of Psychology,* 55:745-774.

Gillham, J. & Reivich, K. 2004. Cultivating optimism in childhood and adolescence. *Annals of the American Academy of Political and Social Science,* 591:146-163.

Glanz, K., Rimer, B.K. & Lewis, F.M. 2002. *Health behavior and health education. Theory, research and practice*. San Francisco: Wiley & Sons: 210-230.

Goldbeck, L. & Melches, J. 2005. Quality of life in families of children with congenital heart disease. *Quality of Life Research,* 14:1915-1924.

Good, M.J., Good, B., Schaffer, C. & Lind, S. 1990. American oncology and the discourse on hope. *Culture, Medicine and Psychiatry*, 14(1): 59-79.

Gordon, D. 1990. Embodying illness, embodying cancer. *Culture, Medicine and Psychiatry*, 14(2): 273-295.

Gregory, D., Johnston, R., Pratt, G., Watts, M. & Whatmore, S. 2009. Quality of life. *Dictionary of Human Geography.* 5th ed. Oxford: 3287-3289.

Gum, A. & Snyder, CR. 2002. Coping with terminal illness: the role of hopeful thinking. *Jounal of Palliative Medicine,* 5(6):883-892.

Hall, B.A. 1990. The struggle of the diagnosed terminally ill person to maintain hope. *Nursing Science Quarterly,* 8:177-184.

Hirai, K., Arai, H., Tokoro, A. & Naka, N. 2009. Self-efficacy, psychological adjustment and decisional-balance regarding decision making for outpatient chemotherapy in Japanese advanced lung cancer. *Psychology and Health,* 24:149-60.

Herth, K. 1989. The relationship between level of hope and level of coping response and other variables in patients with cancer. *Oncology Nursing Forum,* 16:67-72.

Keller, M., Weis, J., Schumacher, A. & Griessmeier, B. 2003. Psycho-oncology in a united Europe - changes and challenges. *Critical Reviews in Oncology/Hematology,* 45:109-17.

Klausner, E.J., Clarkin, J.F., Spielman, L., Pupo, D., Abrams, R. & Alexopoulas, G.S. 2000. Late-life depression and functional disability: the role of goal-focused group psychotherapy. *International Journal for Geriatric Psychiatry,* 13:707-716.

Krohne, H.W. 2002. Stress and coping theories. Available: Science Direct. Date of access: 1 February 2014

Krohne, H.W., Egloff, B., Varner, L.J., Burns, L.R., Weider, G. & Ellis, H.C. 2000. The assessment of dispositional vigilance and cognitive avoidance: factorial structure,

psychometric properties, and validity of the Mainz Coping Inventory. *Cognitive Therapy and Research,* 24:29-311.

Lazarus, R.S. & Folkman, S. 1984. *Stress, appraisal and coping*. New York: Springer: 226-258.

Make-A-Wish Foundation. 2011. Impact Study. MAWF Intelligence Team. Phoenix, Arizona, USA.

Maxfield, J.M. 2010. Conceptualising hope in the presence of terminal illness. Minneapolis: Capella University. *The Sciences and Engineering*, 71:3-B. (Dissertation – MBA).

McCubbin, M., Balling, K., Possin, P., Frierdrich, S. & Byrne, B. 2002. Family resiliency in childhood cancer. *Family Relations*, 50(2):103-111.

McGeer, V. 2004. The art of good hope. *Annals of the American Academy of Political and Social Science*, 592(3):100-127.

McGrath, C., Jordens, C.F.C., Montgomery, K. & Kerridge, I.H. 2006. 'Right' way to 'do' illness? Thinking critically about positive thinking. *Internal Medicine Journal,* 36(10):665-668.

Meijer, S.A., Sinnema, G., Bijstra, J.O., Mellenbergh, G.J. & Wolters, H.G. 2002. Coping styles and locus of control as predictors for psychological adjustment of adolescents with a chronic illness. *Social Science and Medicine,* 54:1453-1461.

Mok, E., Ka-Po, L., Wai-Man, L., Lai-Ngor, C., NG, J. & Kin-Sang, C. 2010. Health professional perspective on hope in the palliative care setting. *Journal of Palliative Medicine,* 1(7):877-883.

Moskowitz, J.T., Hult, J.R., Bussilari, C. & Acree, M. 2009. What works in coping with HIV: a meta-analysis with implications for coping with serious illness. *Psychological Bulletin,*135(1):121-141.

Newachek, M., McManus M. & Fox H. 1991. Prevalence and impact of chronic illness among adolescents. *Archives of Paediatrics and Adolescent Medicine*, 145(12):41-46.

Rosenfeld, B., Pessin, H., Lewis, C., Abbey, J., Olden, M., Sachs, E., Amakawa, L., Kolva, E., Brescia R., & Breitbart, W. 2011. Assessing hopelessness in terminall ill cancer patients: development of the hopelessness assessment in illness. *Psychological Assessment*: 23(2):325-336.

Rubin, R.R. & Peyrot, M. 2001. Psychological issues and treatments for people with diabetes. *Journal of Clinical Psychology, 57(4):457-478.*

Sahler, O.J.Z., Fairclough, D.L., Phipps. S., Mulhern, R.K., Dolgin, M.J. & Noll, R.B. 2005. Using problem-solving skills training to reduce negative affectivity in mothers of children with newly diagnosed cancer: report of a multisite randomized trial. *Journal of Counseling and Clinical Psychology,* 73:272-283.

Saleh, U.A. & Brockopp, D.Y. 2001. Hope amongst patients with cancer hospitalized for bone marrow transplantation: a phenomenological study. *Cancer Nursing*, 24(4):308-314.

Seligman, M. & Csikszentmihalyi, M. 2000. Positive psychology: an introduction. *American Psychologist*, 55:5-14.

Seligman, M.E.P., Steen, T., Park, N. & Peterson, C. 2005. Positive psychology progress: empirical validation of interventions. *American Psychologist*, 60(5): 410-421.

Sloper, P. 2000. Predictors of distress in parents of children with cancer: a prospective study. *Journal of Pediatric Psychology*, 25(2):79-91.

Snyder, C.R. 1994. *The psychology of hope: you can get there from here*: New York, Free Press.,3-21.

Snyder, C.R. & McCullough, M. 2000. A positive psychology field of dreams: if you build it, they will come. *Journal of Social and Clinical Psychology*, 19(1):151-160.

Snyder, C.R. 2002. Hope theory: rainbows in the mind. *Psychological Enquiry*, 13(4): 249-275.

Stoeber, J. & Janssen, D.P. 2011. Perfectionism and coping with daily failures: positive reframing helps achieve satisfaction at the end of the day. *Anxiety, Stress & Coping,* 24(5):477-97.

Sympson, S. 1999. Validation of the domain specific hope scale: exploring hope in life domains*. (In* C.R. Snyder (Eds.), *Handbook of Hope Theory, Measures and Applications*. San Diego: Academic Press.3-21).

Talbot, B.D. 2012. The prediction of psychological well-being in children and adolescents with chronic, life threatening illnesses. Bloemfontein: University of Free State. (Thesis – PhD). (Unpublished).

Tusaie, K.R. & Patterson, K. 2006. Relationships among trait, situational, and comparative optimism: clarifying concepts for a theoretically consistent and evidence-based intervention to maximize resilience. *Archive of Psychiatry Nursing*, 20(3):331-341.

UCLA Children's Comfort Care Program (CCCP). 2013. Website: http://www.uclahealth.org Date of access: 15 July 2013.

USA Mental Health Foundation. Website: http://americanmentalhealthfoundation.org/ Date of access: 1st Augut 2013.

Von Essen. L., Enskar, K., Kreuger, A., Larsson, B. & Sjoden, P.O. 2000. Self-esteem, depression and anxiety among Swedish children and adolescents on and off cancer treatment. *Acta Paediatrica*, 89:229-236.

Interviews

Miller, B. 2011, 2012. Reach For A Dream Foundation [personal interview]. 6 July, Johannesburg.

Sotrianakos, J. 2011, 2012. Reach For A Dream Foundation [personal interview]. 6 July, Johannesburg.

Serebro, M. 2011, 2012. Reach For A Dream Foundation [personal interview]. 2 Feb., Johannesburg.

SECTION B: ARTICLE

EXPERIENCES OF THE RECIPIENTS OF REACH FOR A DREAM FOUNDATION PROJECTS

Cover page

Experiences of the recipients of Reach For A Dream Foundation projects

Author: Debra A. Myburgh

Affiliations: Psychology Department, North-West University, Potchefstroom Campus

Correspondence to: Debra Myburgh

Email: debram@jankelow.co.za

Postal address: PO Box 1807, Magaliesview, 2067, South Africa

Possible reviewers: Dr Jonathan Victor Larsen, 181 Amberfield, Private Bag X010, Howick 3290; jon.larsen@iuncapped.co.za

Professor Haya Itzhaky, Bar Ilan University, Ramat Gan, Israel; Tel (972) 3 5318616; Haya.Itzhaky@biu.ac.il

Jennifer M Maxfield, 5407 N Charles St Baltimore, MD 21210; Tel (410) 433 8861

Summary: Number of words: 7283

Number of pages: 23

Supplementary material: Table 1; Figure 1; Figure 2

Experiences of the recipients of Reach For A Dream Foundation projects

Abstract

Background: Life threatening illnesses (LTIs) cause not only physical pain but also deep emotional side effects. The relationship between quality of life, morbidity and mortality when children have a LTI has been brought into question. Psychosocial intervention strategies are aimed at decreasing anxiety and depression symptomology and have been linked to promoting mental, emotional and social well-being, resilience, respite and coping abilities. One such psychosocial intervention strategy is provided by the Reach For A Dream (RFAD) Foundation.

Objective: This study aimed to explore the psychosocial experiences of the recipients of RFAD 'dream-come-true' projects.

Methods and setting: In 2012 a narrative inquiry design was used to explore the psychosocial experiences of recipients of RFAD projects with children/adolescents and their parents from Gauteng, South Africa. Semi-structured individual in-depth interviews were conducted with randomly selected participants who are or have been clients of RFAD.

Results: The pre-dream contextual narrative constructed by children/adolescents and parents covered fear, anger, sadness, loneliness, helplessness, and lack of normality and family support. Eexperiences during the 'dream' projects indicated happiness, excitement, magical feelings, family inclusion, relaxation, feelings of normality and connection with other sick children. Post-dream findings suggested various forms of improved mental and emotional states in participants, and unique opportunities to connect with their family in a positive, normal way.

Conclusion: As a psychosocial intervention strategy to meet some challenges of LTIs in children, a 'dream-come-true' experience appears to ameliorate distress, offer respite, decrease isolation, increase a sense of empowerment and self-confidence, and decrease anxiety and fear in children and their families.

Introduction

Life-threatening illness (LTI) in children represents both a life-threatening situation for the child and severe trauma for the family.[1] The likelihood of death is high when a person suffers from a LTI unless the course of the disease is interrupted with treatment to prevent possible death.[2] According to the Childhood Cancer Foundation of South Africa (CHOC), one in 600 South African children develops cancer each year.[3] The prevalence of asthma is increasing and is seen as the most common chronic disease among children.[4] Other LTIs in children include Human Immunodeficiency Virus (HIV), haemophilia, Hodgkin's lymphoma (cancer), heart disease, cystic fibrosis, Duchenne's muscular dystrophy, the need for organ transplants and diabetes.

A LTI in children evokes insecurity and fear in everybody involved because of its association with premature death, pain, uncertainty and powerlessness.[5] Children diagnosed with LTIs are confronted with almost daily routines of hospital visits and painful treatments. The realization that a child can predecease an adult is devastating for a parent.[6] A family's ability to function normally or plan for the future is dramatically affected when they have to witness a child's pain, fear and are constantly facing the fear of death. [7] Emotional side effects are often considered more highly distressing than the physical side effects.[8]

A magical time in a person's life can be their childhood, filled with fantasies and 'dreams' such as simply owning a bicycle, visiting the beach, or meeting a celebrity.[9] The fulfilment of such 'dreams' for children suffering from LTIs appears to offer hope and an escape from the rigours of treatment and pain, if only for a short time.[10] The anticipation of 'dream' fulfilment increases positive thought, hope and resilience and may improve the quality of life by tapping into social or emotional well-being.[11,12] Hope enables a search for positive elements at times of severe distress, and engages in hopeful future-oriented planning.[13] Hopelessness creates a future that seems intolerable and futile while hope can encourage a feeling of well-being. Hope seems to be an inherently future-orientated concept,[14,15] an optimistic belief that one can expect a better tomorrow;[16] it is about imaginatively exploring what a person can and cannot do in the world.[17] Patients work harder to live if they are encouraged and given hope, and hope increases the likelihood of a good outcome.[18] Serebro argues that hope and looking forward to the future seem to decrease the sadness in patients with LTIs and to increase

happiness, thus even enhancing the quality of life and leading in many cases to extended remission.[19] This claim, however, needs to be confirmed by research.

Organizations around the world, such as the Children's Wish Foundation, Disneyland, The Dream Factory, the Make-a-wish Foundation, the Sunshine Foundation and the Wishing Star Foundation, make the 'dreams' of children with LTIs a reality, enriching the experience of the children with hope, strength and joy. Having a 'dream' come true is an uplifting experience which, it is argued, could dramatically affect the lives of children with LTIs.[20] In South Africa, the Reach For A Dream Foundation (RFAD) believes that no child should live without hope and have fulfilled over 9000 dreams since 2007.[21,22]

As yet, referral processes and ease of access to appropriate organizations that engage in psychosocial intervention strategies and practices for children with LTIs are limited and appear in-accessible to many, and very little research on the experiences of such psychosocial intervention strategies and practices could be found. The purpose of this study was to explore the experiences of the recipients of RFAD 'dream-come-true' projects. The results of the research could hopefully yield some important information about psychosocial intervention strategies that could be used to improve the mental and emotional health and overall wellness of critically ill children/adolescents and their families. The research question that guided the study was: *What were the experiences of the recipients of a RFAD 'dream' project?* This question was unpacked to address the psychosocial experiences of both children/adolescents and their parents.

Research design and method

This was a qualitative study that used a narrative inquiry design, in the form of semi-structured individual in-depth interviews with children/adolescents and their parents. Semi-structured interviews is a technique that allows the participants time, scope and flexibility to talk about their areas of particular interest. A narrative inquiry allows the participants an opportunity to be the experts in telling their life experience stories in relevant and meaningful ways, giving this researcher the opportunity to be absorbed in the personal experiences of the children/adolescents and their families.[23,24]

RFAD provided the researcher with their confidential list of all the families that had participated in a 'dream' experience. The list was sorted according to the following selection criteria: male and female participants aged 8 to 18, with LTIs at various stages, who were or had been beneficiaries of RFAD projects, and their parents. Participants were based in Johannesburg and surrounding areas and the research was done within one year after the children/adolescents had experienced their 'dreams'. Six child/adolescent participants were randomly selected with a numerical Excel program. A representative sample of the larger group has greater assurance of been selected by using this random process. Characteristics of the participants are shown in Table 1.

Insert Table 1 approximately here.

Participants' ages ranged from 9 to 15 years which could expectedly, from a developmental perspective, enable them to verbalize their thoughts and feelings sufficiently to ensure the trustworthiness of the data. The age range could further influence the data in that older child participants, C6 and C3, might show greater interest in their future and the setting of goals. Younger children, C1, C2 and C4, could be expected to focus more on the 'dream' experience itself and less on their future. The 'dreams' were all about experiences of an active nature, suggesting a reaction against the participants' experience of the LTI as a disabling force in their lives. Three (C1, C4 and C5) expressed a desire to experience free physical movement, and three (C2, C3 and C6) to experience a real, interactive occasion. The tendency towards experiences lends confirmation to a survey by the Make-a-Wish Foundation in which experience-based 'dreams' represented more than 80% of all 'dreams' requested.[25] All the child/adolescent participants belonged to intact families and all the parents were interviewed, except for F4, who was on contract away from home at the time of the interview.

Interviews took place in English in the safety of the participants' own homes. The child/adolescent interviews took place prior to the parent interviews so that these data could not be influenced by the parent. During the child/adolescent interviews emotive cushions were used. The cushions measured 20cm in diameter. They were pleasant to the touch, fun to play with and covered a variety of easily recognizable emotions ranging from <u>happy</u> and <u>peaceful</u> to <u>angry</u> and <u>frightened</u> (see Figure 1). The emotive cushions were used

predominantly for middle childhood participants. The adolescent participants were allowed to express feelings verbally, although the emotive cushions were available if needed.

Insert Figure 1 approximately here.

The child/adolescent was guided conversationally (that is, step-wise by means of appropriate questions) to choose emotive cushions for identifying and relating his/her 'pre-dream' emotions, then the emotions experienced during the 'dream', and finally the present or 'post-dream' feelings. All child/adolescent/ participants were shown the same emotive cushions. However a few chose to create their own emotive cushions from paper additionally as no available cushion represented their experience. The researcher re-created these paper cushions after the interview (see Figure 2). The researcher remained aware of the emotional reaction at different stages in children suffering from LTI's, adolescents start to develop their own identity, self-image becomes important and physical changes due to illness have a greater impact on them than middle childhood children. Middle childhood child however do become more capable of understanding their illness and its treatments and are able to imagine different scenarios, or 'what if' something were to happen.

Insert Figure 2 approximately here.

The parent interviews consisted of semi-structured individual in-depth questions, but without emotive cushions: 'Can you share your story with me: When did you find out your son/daughter was ill? How did you feel when you were told about your daughter/son's illness? How did you feel when RFAD contacted you? Can you share your feelings with me about the "dream-come-true" experience? Now that the dream is over, how is the family? How are you feeling now, that is, post-dream?

Field notes were made after each interview, detailing the participants' reactions, body language and emotions and were referred to by the researcher when analysing data to provide insights into interactions, helping to capture context and understand the influence of the physical environment, culture and social situation. Field notes can assist with the credibility of the research being an alternative method contribution to the triangulation of the

research. The contents of and reason for the notes were explained to the participants beforehand.

Data analysis

In the qualitative data analysis, the researcher not only noted the unique experiences of each child/adolescent and the parents but also scrutinized the data for findings that were 'worth paying attention to'. Following Tesch's approach[26], the researcher formed an overall picture by carefully reading all the transcripts and noting ideas that emerged; then plotting thoughts in a margin and listing all the topics indicated in the margin. Similar topics were grouped together into columns, as main themes and sub-themes. A 'cut and paste' method was used to create categories from the list of themes and sub-themes, this thematic analysis was further supported with field notes. Data analysis followed a **crystallization** approach. This entailed using different methods and/or participant perspectives to gather and analyse data, searching for patterns or themes in an infinite spectrum of possiblities.[27,28] Further checks included feeding back the findings to the participants for verification of the transcribed data and identified themes.

To ensure the trustworthiness of this data, Lincoln and Guba's evaluative criteria were followed.[29] Confidence in the 'truth' of the findings was grounded in the voluntary nature of the narratives and interviews. The findings showed much potential for transferability and may not only encourage further therapeutic practices for children but could also be used for psychosocial intervention strategies with families of children with LTIs. The findings could further be used by the medical profession to explore the effects of instilling hope and offering respite to a child with a LTI. The findings were dependable due to the consistency of the results throughout all the interviews and the findings were shaped by the participants and not the researcher.

Ethical considerations

Ethical approval for this research was obtained from the Ethics Committee of North-West University. Participants' right to privacy and confidentiality was continually considered and voluntary informed consent was obtained from parents and adolescents and assent from child

participants. All records were kept on a computer with password protection. Participants' names were replaced by pseudonyms on all documentation. Participants were informed of the aim of the research and that interviews would be audio-recorded. The dignity and rights of all child/adolescent participants were respected, their right to tell their story at their own pace, the right to stop at any time and the right to be heard. Participants were given the opportunity to refuse to participate or to withdraw at any time.

The best interests of each child/adolescent were protected over any consideration, story or image which might put the child, adolescent or family at emotional risk. The researcher ensured that all participants were comfortable that their stories would be printed in the dissertation and possibly in a journal, but using pseudonyms and not divulging their true identities. The participants were informed beforehand that three counselling sessions would be made available for any who required it with a registered Psychologist and paid for by the researcher. Questions, attitudes or comments that could be taken as judgmental or insensitive to cultural values or that could reactivate a participant's pain and grief from traumatic events were avoided. The participants were at all times made to feel comfortable and able to tell their story without outside pressure, and regular breaks were taken if deemed emotionally necessary.

Results

The main findings of the study were clustered into two formats: pre-dream and post-dream contextual narratives, and a thematic analysis of the participants' experiences of RFAD projects. All experiences and themes are presented in an order of frequency and findings are substantiated by quotes from participants' statements. Coding indicates 'child/adolescent' (C), 'mother' (M) and 'father' (F). The first number refers to the participants (M2) and the second number refers to the line in the data transcript on which the quote appears (M2.4). All names appearing in quotes are pseudonyms.

A pre-dream contextual narrative

All parents described the **fear and panic** they experienced when finding out their children were suffering from a LTI. Child/adolescent participants were fearful of the physical aspects of the illness and hospital procedures:

> 'Utter fear Debra, fear, fear, fear and panic, you know I could hardly breathe that day'. (M2.4)
>
> 'I was so scared, you just don't know what is happening'. (C6.5)

Sadness and **loneliness** featured prominently in nearly all the families. Parent participants experienced a dichotomy: their feelings of sadness and loneliness were strong but they felt they had to hide them in order to support their ill child. Child/adolescent participants expressed sadness about being left out of social events by friends, excluded because of ill health or feeling 'different' as a result of the physical side effects of treatment for their LTI, and lack of peer contact because of extended absence from school:

> 'quite alone...we had friends and family around but you're really still on your own, you know'. (F5.3)
>
> 'sad, that is the one (a cushion) I can use for when Susan and Johan run off without me'. (C1.8)

The children's LTIs had resulted in many months of hospitalization and regular treatments. The intensive treatment often resulted in disturbance of the family sphere as families attempted to incorporate the child's illness into their daily routines in an attempt to cope and maintain balance. **Lack of normality** in everyday life coupled with **anger** was experienced more strongly by child/adolescent participants than their parents. The anger of child/adolescent participants was aimed predominantly at the medical procedures they had to endure:

> 'I was very cross, very, very cross, Dad even had to hold me down'. (C5.6)

Parent participants experienced anger at feeling helpless against the enormity of LTIs and the distress medical procedures were causing their child:

> 'I get very angry when Annabel has to go through this and I can do nothing about it'. (F1.8)
>
> 'I could do absolutely nothing to help her, you feel so useless, like you're not a good mom, you know'. (M5.2)

With the diagnosis of a LTI, the impact was felt not only by the child/adolescent and parents, but by the **family** in its entirety. Family support and the ability to withstand months of invasive treatments were crucial to the survival of the family unit:

'The impact on the whole family is just unbelievable; our life came to an absolute standstill'. (M1.4)

'I had to come back to the hospital really often... poor mom and dad were back and forward, back and forward'. (C6.5)

Four parent participants had **preconceived**, **negative ideas** about why RFAD contacted children with LTIs, thinking RFAD contacted only poor families or families whose children were dying, with no chance of recovery:

'I thought they only did dreams for kids from really poor families'. (F3.9)

'I was angry as my perception of Reach For A Dream is that they contact families only if the children are dying'. (M1.11)

Feeling sick was, surprisingly, mentioned by only one child and his parent.

The 'pre-dream' contextual narratives gave little evidence of recognising and implementing coping resources. The theories which support the interpretation of findings in this study are Lazarus and Folkman's transactional theory of stress and coping and Snyder's hope theory.[30,31] Stressors, such as a LTI diagnosis, affect physical and psychological well-being.[32] To cope with these stressors, a conscious effort to solve the problems, seek to master them, and minimise or tolerate stress or conflict is important.[33] Lazarus and Folkman's cognitive appraisal model shows that being faced with a LTI is interpreted as threatening and harmful, and consequently, as stressful.[34] Appraisal of the significance of the stressor is important, as this will indicate what the person can do about the situation.[35] In contrast, Snyder's hope theory is associated with many positive outcomes. A person suffering from LTI may benefit from the pursuit and attainment of goals, as this may lead to experiencing more positive emotions, and less negative emotions, such as hopelessness. Psychotherapeutic interventions, such as the pursuit and attainment of goals, have led to more positive emotions in people suffering from a LTI.[36]

Thematic analysis of participants' experiences of RFAD projects

Themes identified from the participants' experiences of the RFAD projects differ in terms of prevalence from those occurring in the pre-dream contextual narrative, in that these were expressed uniformly, and suggest a strikingly cohesive pattern between happy feelings and family-social well-being. The themes cover happiness, disbelief, guilt feelings, the family, and the child with LTI *versus* the 'normal' child. These themes reflect a stronger sense of hope, a more positive outlook, decreased fear, a sense of respite and increased social well-being. Snyder, whose hope theory is seen as one of the most comprehensive theories of hope,[37] proposes that in hopeful thinking we have a goal that we imagine or desire, and our willpower drives the force to achieve this[38]. Goals chosen by critically ill individuals are positively associated with well-being. Positive outcomes in different areas of an individual's life are associated with the hope theory and have resulted in research on related Psychotherapeutic interventions.[39,40] This study aimed to gain some understanding of the 'dream-come-true' experiences of the children/adolescents with LTIs and examine how these experiences relate to the wellbeing and functioning of the children and their families.

Happiness

Most prominent and pervasive were feelings of happiness. All child/adolescent and parent participants expressed one or more of the sub-themes, ranging from *general/magical/ overjoyed happiness,* through *happy amazement/fun/excitement/gratefulness,* to *happiness about their luck* and *feeling happily relaxed*:

'I was so spoilt...it felt like someone has just used a magic wand'. (C5.15)

'…overjoyed looking at Annabel having such a wonderful time'. (M1.16)

'I felt like jumping around, I was so happy'. (C2.14)

'It was amazing…all my dreams came true'. (C6.10)

'…take my family on holiday, I really wanted them to have fun'. (C6.9)

'I was so excited...it was so nice to be with other kids having fun'. (C4.8)

'Happy is too simple...I would say thankful'. (F2.16)

'I couldn't believe it...I was so happy...I was the luckiest person in the world'. (C2.14)

'…so grateful and at ease, we could just relax and enjoy the day'. (M4.9)

Disbelief

Children/adolescents and parents expressed at least one of the sub-themes of disbelief: *disbelief in the experience of the dream* and *disbelief in the reality of the dream*:

'a real Ferrari...so fast...I just couldn't believe it'. (C1.15)

'I never thought I could ever have something like that'. (C3.10)

Guilt feelings

Children/adolescents and parents all expressed *feeling guilty about accepting the dream*:

'I could ask for anything...I felt bad...I was being selfish asking for so much'. (C3.7)

'Ours must have cost so much money...I really feel bad'. (M4.10)

The family

All child/adolescent and parent participants expressed one or both of the sub-themes referring to the family: *family inclusion* and *importance of the family feeling normal again*:

'The best was that mom, dad and my sister and brother were there'. (C6.10)

'We could…just be normal and happy...the pressure an illness puts on a family is enormous'. (F1.17)

Child with LTI vs. **'normal' child**

Children/adolescents and parents all expressed one or more of the sub-themes : *being treated like other children* and *'dream' child spending time with other 'dream' children*:

'I felt just like the other kids, like I wasn't sick any more'. (C4.11)

'She could then do things with other kids which is great, they're all sick in some way'. (F1.21).

A 'post-dream' contextual narrative

The effects of the 'dream-come-true' experience were not limited to the immediate emotional effects on the children/adolescents and their families described above. The **positive effects** were elaborated on in stories of emotional and social benefit, life enrichment, social awareness, inspiration, respite, and seemingly even an improved physical strength and desire in the child/adolescent participants to overcome their illnesses. The children/adolescents' and parent's mental and emotional health seemed to improve after their "dream-come-true" experiences and allowed them to connect with their family in a positive 'normal' way. The child/adolescent participants showed enthusiasm and a positive attitude to life. The

attainment and pursuing of a goal may help an individual suffering with a LTI to be more positive and less hopeless and apathetic.[41,42] This **influence on the child's positive outlook** was the most prominent outcome.

'I now feel like I can do anything, you know'. (C3.14)

'She is definitely more positive and willing to try lots of things'. (M1.21)

The effect of experiencing how the 'dream' had become real **influenced and encouraged** the children/adolescents to try things which perhaps they would not have done 'pre-dream' owing to the physical and emotional pressures of a LTI:

'It seems to have encouraged her to try things that before she would not have thought of'. (F1.17)

'I want to do it...I am going to save all my money and go back to the snow'. (C5.20)

Whereas LTIs had restricted the 'dream' child/adolescent's contact with peers because of prolonged hospital stays and medical treatment, the 'dream-come-true' experience had now increased peer contact for them. **Contact with other children** with LTIs had decreased their isolation and increased their sense of being accepted by others:

'It's nice to be just like them...I still go on other dreams with them'. (C1.25)

'She made good friends in hospital...it is nice, they keep in contact'. (M6.20)

'Post-dream', child/adolescent and parent participants' level of **general happiness** remained positively affected. The 'dream-come-true' experience had improved the quality of their lives by temporarily breaking the illness cycle and had increased their awareness of the positive happy aspects of their lives. The illness cycle describes the phases of a patient's and their family's experience of a LTI, the regular and painful treatments, distress, anxiety, and perpetuation of hopelessness, recovery and relapse. Parents were happy about seeing their child's happiness and the child/adolescent participants expressed an increase in general happiness:

'The one I feel the most is happy'. (C2.27)

'very happy to see him passionate about something'. (F3.24)

Although 'post-dream' effects were generally positive, **fear** was expressed by some children/adolescents, particularly the fear of getting sick again:

'I am frightened of getting sick again, I just don't want to get sick again'. (C2.24)

The effects of the 'dream-come-true' experience were not limited to just the child/adolescent but also touched their family as a whole. The comments on **positive effects** on the family were unique to the parent interviews:

'All of us...we were all encouraged to have an even more positive outlook'. (M1.19)

Health and physical conditions of an individual are often difficult to determine however choices and behavioural changes are easier to observe. Parents affirmed behavioural changes in their child as a result of experiencing his/her 'dream' in that the child/adolescent demonstrated increased **courage**, a sense of **hope**, **confidence**, an **improved outlook** and **positive forward thinking**:

'It seems to have given her so much courage'. (M1.18)

'The dream really helped me see a lot of hope in Annabel'. (M1.21)

'The dream made some amazing changes in him...he has become so much more sure of himself'. (M3.1)

'Now he thinks he is going to take over the world....it seemed like he felt invincible'. (F3.15-17)

The parents were, however, still **worried** about their child:

'still worried about him...but definitely less than before...encouraged by his attitude'. (M3.23)

Cognitive and behavioural components are recognized within the hope theory.[43] The results of this study suggest that the achievement of a goal by means of a 'dream-come-true' psychosocial intervention strategy may help children with a LTI and their family to experience more positive emotions and avoid becoming hopeless or apathetic.[44]

Discussion

Despite improvements in medical interventions, LTIs in children remain a grim reality which necessitates psychosocial intervention strategies for the child as well as the family. The experiences of children who have LTIs give rise to various emotions and evoke insecurity and fear in everybody involved because of the association of a LTI with the idea of death, pain, uncertainty and powerlessness.[45] This was confirmed by Serebro[46] and by similar findings that emerged from this study. Collins and colleagues report symptoms of sadness and worry in children with LTIs[47], symptoms that endorse the 'pre-dream' feelings of **fear, sadness and loneliness** that were prominent in all the participants in this research, as was a

lack of normality in everyday life. Social isolation, changes to physical appearance and social rejection are only a few of the treatment side effects experienced by the child with a LTI, others include fear, sadness, loneliness, depression, anxiety and low self-esteem.

Intense feelings of **anger**, **helplessness** and **guilt** about being unable to help their children were prominent among the parent participants in this research, but have not, however, been encountered in the research literature. The findings suggest that **family support** contributed to reduced levels of fear and anxiety, parent and child/adolescent participants stressed the importance of family support. A Make-A-Wish Foundation impact study of 2011 reported an increased sense of **empowerment** after experiencing the 'dream-come-true' experience in 93% of parent participants.[48] The parent participants in this study confirmed that the 'dream-come-true' experience seemed crucial to the survival of the family unit by not only empowering the family unit but also contributing to a sense of stability during difficult times. The value of respite from medical procedures even if only for a short period of time, as indicated by research [49,50], was confirmed by the participants in this study, who related that by temporarily breaking the illness cycle their quality of life was enriched. The researcher however observed a lack of interest in the psychological care of patients by the medical profession that may cause many children to miss out on the opportunity of a 'dream-come-true' experience.

The **inclusion of the family** and importance of **feeling normal**, being treated like other children and given hope for even a short period of time, were identified as prominent themes in experiencing a 'dream-come-true' project. Child/adolescent and parent participants alike expressed **excitement, amazement** and **gratitude** that they could just relax and enjoy the project. Inclusion of the family in the dream-come-true model must be recognized as a notable strength of the work undertaken by RFAD. Herth's report that hope within the close family circle has a reciprocal role in maintaining hope among patients [51], lends explanatory support to continue the practice.

The sense of **guilt** at accepting the 'dream' project expressed by child/adolescent and parent participants alike in this study, has not been noted in the literature. A contributing factor to this expression of guilt could emanate from empathy-based guilt. Participants, when seeing other children suffering from LTIs, experience empathy, leading to their thinking that something should also be done to relieve the other person's pain, thus resulting in feelings of

guilt while they experience their own dream coming true.[52] A second contributing factor to the sense of guilt could be that due to their suffering they felt undeserving, or unworthy of anything so positive.

A further seemingly unique response from participants was the expression of **disbelief** in the reality and experience of their dream coming true. They could not believe their dream would happen or was actually happening. This suggests that participants, in this time of having little or no control over their illness or their lives, seemed to lose hope that anything outside their painful frame of reality could actually happen.

The Make-A-Wish Foundation impact study of 2011[53] showed that 95% of their participants valued the **connection with other 'dream' children** and being treated like '**normal'** children during a 'dream-come-true' experience. This was confirmed by a number of child/adolescent participants in this study. The value of this experience is highlighted by the pre-dream contextual narrative which showed up the sadness and loneliness of most of the child/adolescent participants resulting from their social isolation. Research on the feasibility and effects of including a close friend from their circle prior to their illness in the 'dream' experience thus seems strongly indicated.

'Post-dream', all participants highlighted that having a wish come true had influenced the 'dream' child/adolescent's **outlook in a positive way**, encouraging them to be more positive, confident and hopeful. This endorses Clemency's findings that children whose 'dreams' had been granted reported better quality of life 'post-dream' than children whose 'dreams' had not been granted.[54] Similar findings of psychosocial intervention strategies improving depressive and anxiety symptoms were reported by Claar and Blumenthal in 2003.[55] Even though some participants expressed fear and worry about becoming ill again, hope and thankfulness played a prominent role in 'post-dream' emotions. The study can be aligned with existing theories on **hope** inspiring and providing coping strategies in children with LTIs, theories that explore the connection between hope and psychological adjustment, and hope as a positive element at times of severe distress that assists possible recovery from a serious physical condition and gives the patient a reason for living.[56,57,58,59,60] Although the importance of hope is confirmed in the scholarly literature and by this research, Snyder questions whether hope is always a good thing, and contends that it might sometimes be "pie in the sky" thinking that could give children and their families unrealistically high

expectations and unachievable goals, leading to the possibility that the 'dream' might not produce the desired results and could actually be counter-productive.[61] While the research focused the 'dream-come-true' experiences of children with LTIs, 'pre-dream' and 'post-dream' questions were asked for further clarity. While medical intervention strategies can ameliorate some insecurity and uncertainty caused by LTIs in children, there is a paucity of literature on empirically evaluated **psychosocial intervention strategies** focused on enhancing child and family well-being.[62] Psychosocial intervention strategies in South Africa that meet the wellness challenges of children with LTIs are limited. The 'dream-come-true' experience is just one way to promote future-oriented thinking. It is therefore important for paediatric health professionals to continue to promote positive coping skills and improvements in the psychological and social dimensions of QOL even in the face of physical deterioration.[63]

Strengths and limitations

The strengths of this research were that rigorous application of the principles of research interviewing, especially with children who are at risk, successfully helped in obtaining rich and trustworthy descriptions of the participants' experiences. The transcribed interviews showed similar findings and common themes were evident throughout. The honesty of the participants was revealed in the positive and negative comments and emotional openness during the interviews. The use of emotive cushions provided a fun way for the children/adolescents to express their feelings. Neither lack of interest nor feeling obliged to participate in the interview process posed a problem; the participants were willing and even eager to share their experiences.

The limitations of the study included the availability of only a small number of participants, which proved challenging. Many of the 'dream' children and their families did not meet the selection criteria because they were visiting from other African countries, were non-English speaking, or the children were under the age of eight. Planned interviews were often cancelled or repeatedly moved because of the precarious health status of the 'dream' child. Intense emotions from the participants made interviews stressful for interviewer and participants alike. Participants were limited to Gauteng and surrounding areas which impacted on social and geographical diversity. As parents had prior notice of

the interviews and the reason for the study, they had the opportunity to 'script' stories of the 'dream-come-true' experience with their children before the interviews.

Recommendations

The findings of this study represent a significant step forward in understanding the experiences of a 'dream-come-true' project by children/adolescents and their parents and how this may possibly ameliorate distress, offer respite, decrease isolation, and increase a sense of empowerment and self-confidence. While the findings concerning the 'dream' and 'post-dream' experiences are encouraging, the researcher found that psychosocial intervention strategies available in South Africa are limited, appear in-accessible to many and the establishment of similar practices appear crucial to ensure that all children with LTIs in South Africa are reached. The referral of children with LTIs in South Africa to RFAD is initiated by their doctors. It is recommended that increased involvement and support from medical professionals be encouraged to ensure that all possible 'dream' children are reached. This research was done within one year after the children/adolescents had experienced their 'dreams'. Future research may be needed not only to confirm the findings, but also to examine if the effect of the 'dream-come-true' experience changes if the time lapse between diagnosis, treatment and referral to RFAD varies.

Conclusion

Children and adolescents suffering from LTIs present with a wide range of physical and psychosocial side effects which contribute to the perpetuation of hopelessness and fear among the children, adolescents and their families. This study yielded some important information about future-oriented thinking using a 'dream-come-true' experience and the implementation of psychosocial intervention strategies and practices which appear crucial in order to address the challenges presented by LTIs in children and adolescents.

References

1. Cancer.org.[cited 10 September 2012]. Available from: http://www.cancer.org/treatment/childrenandcancer/whenyourchild has cancer/index.

2. Reach For A Dream Foundation. [About Us page on the Internet]. [cited 5 July 2011]. Available from: http://www.reachforadream.org.za.

3. Childhood Cancer Foundation of South Africa (CHOC). [home page on the Internet]. [cited 8 July 2011]. Available from: www.choc.co.za.

4. World Health Organization (WHO). [fact sheet page on the Internet]. [cited 8 August 2011]. Available from: http://www.who.int/mediacentre/factsheets/fs307/en/.

5. Bustamante, V., Mellman, T., David, D. & Fins, A. 2001. Cognitive functioning and the early development of PTSD. *Journal of Traumatic Stress,* 14(4):791-797.

6. McCubbin M., Balling K., Possin P., Frierdich S., Bryne B. Family resiliency in childhood cancer. Family Relations. 2002; 50(2):103.

7. Serebro M. Reach For A Dream Foundation. [Personal interview, 2 February] Johannesburg; 2012 (Unpublished).

8. Clemency CE. The impact of a wish experience on paediatric cancer patients and their families. (Unpublished dissertation). Phoenix. Arizona State University; 2009.

9. Reach For A Dream Foundation. [About Us page on the Internet]. [cited 5 July 2011]. Available from: http://www.reachforadream.org.za.

10. Miller B. Reach For A Dream Foundation. [Personal interview, 6 July] Johannesburg; 2012 (Unpublished).

11. Barrera M., Wayland LA., D'Agostino NM., Gibson J., Weksberg R., Malkin D. Developmental differences in psychological adjustment and health-related quality of life in paediatric cancer patients. Children's Health Care. 2003;32:215-232.

12. Goldbeck L., Melches J. Quality of life in families of children with congenital heart disease. Quality of Life Research. 2005*;*14:1915-1924.

13. Tusaie KR., Patterson K. Relationships among trait, situational, and comparative optimism: clarifying concepts for a theoretically consistent and evidence-based intervention to maximize resilience. Archive of Psychiatry Nursing. 2006;20(3):331-341.

14. Aspinwall LG., Leafe SL. In search of the unique aspects of hope: pinning our hopes on positive emotions, future-oriented thinking, hard times, and other people. Psychological Inquiry. 2002;13(4):276-321.

15. Saleh UA., Brockopp DY. Hope amongst patients with cancer hospitalized for bone marrow transplantation: a phenomenological study. Cancer Nursing. 2001;24(4):308-314.

16. Rackner V. Hopes & dreams: a critical ingredient in the lives of caregivers and their loved ones. Ezine articles [online] 2006. [cited 11 July 2011]. Available from: http://ezinearticles.com/?Hopes-and-Dreams:-A-Critical-Ingredient-In-The-Lives-Of-Caregivers-And-Their-Loved-Ones&id=294895.

17. McGeer V. The art of good hope. Annals of the American Academy of Political and Social Science. 2004; 592(3):100-127.

18. Snyder CR. Hope theory: rainbows in the mind. Psychological Enquiry. 2002;13(4): 249-275.

19. Serebro M. Reach For A Dream Foundation. [Personal interview, 2 February] Johannesburg; 2012 (Unpublished).

20. Miller B. Reach For A Dream Foundation. [Personal interview, 6 July] Johannesburg; 2012 (Unpublished).

21. Reach For A Dream Foundation. [About Us page on the Internet]. [cited 5 July 2011]. Available from: http://www.reachforadream.org.za.

22. Sotrianakos J. Reach For A Dream Foundation. [Personal interview, 6 July] Johannesburg; 2011 (Unpublished).

23. Smith PC., Harre R., Van Langehoven L. Rethinking methods in psychology. London: Sage. 1995:9-26.

24. Borkan J. Immersion/Crystallization. In: BF Crabtree and WL Miller (Eds.) Doing Qualitative Research (2nd edition). Thousand Oaks, CA: Sage Publications. 1999;179-194.

25. Make-A-Wish Foundation (MAWF). Impact Study. MAWF Intelligence Team; 2011;3 (Unpublished).

26. Tesch R. Qualitative research: Analysis types and software tools. New York: Falmer Press. 1990;117.

27. Lincoln YS., Guba EG. Naturalistic inquiry. Beverly Hills, CA: Sage Publications, Inc. 1985;290.

28. Borkan J. Immersion/Crystallization. In: BF Crabtree and WL Miller (Eds.) Doing Qualitative Research (2nd edition). Thousand Oaks, CA: Sage Publications. 1999;179-194.

29. Lincoln YS. Emerging criteria for quality in qualitative and interpretive research, Qualitative Inquiry 1.1995;275-289.

30. Folkman S., Moskowitz JT. Coping: pitfalls and promise. Annual Review of Psychology. 2004; 55:745-774.

31. Snyder CR. Hope theory: rainbows in the mind. Psychological Enquiry. 2002; 3(4): 249-275.

32. Glanz K., Rimer BK., Lewis, FM. Health behavior and health education. Theory, research and practice. San Francisco: Wiley & Sons. 2002; 210-230.

33. Snyder CR. The psychology of hope: you can get there from here: New York, Free Press. In: Snyder, C.R., ed. Handbook of hope theory, measures and applications. San Diego: Academic Press, 1994; 3-21).

34. Folkman S., Moskowitz JT. Coping: pitfalls and promise. Annual Review of Psychology. 2004; 55:745-774.

35. Krohne HW., Egloff B., Varner LJ., Burns LR., Weider G. & Ellis HC. The assessment of dispositional vigilance and cognitive avoidance: factorial structure, psychometric properties, and validity of the Mainz Coping Inventory. Cognitive Therapy and Research. 2000; 24:29-311.

36. Snyder CR. Hope theory: rainbows in the mind. Psychological Enquiry. 2002; 3(4): 249-275.

37. Gum A., Snyder CR. Coping with terminal illness: the role of hopeful thinking. Journal of Palliative Medicine. 2002; 5(6):883-892.

38. Snyder CR. The psychology of hope: you can get there from here: New York, Free Press. In: Snyder, C.R., ed. Handbook of hope theory, measures and applications. San Diego: Academic Press, 1994; 3-21).

39. Gum A., Snyder CR. Coping with terminal illness: the role of hopeful thinking. Journal of Palliative Medicine. 2002; 5(6):883-892.

40. Bustamante V., Mellman T., David D., Fins A. Cognitive functioning and the early development of PTSD. Journal of Traumatic Stress. 2001; 14(4):791-797.

41. Snyder CR., McCullough M. A positive psychology field of dreams: if you build it, they will come. Journal of Social and Clinical Psychology. 2000; 19(1):151-160.

42. McGeer V. The art of good hope. Annals of the American Academy of Political and Social Science. 2004; 592(3):100-127.

43. Snyder CR. The psychology of hope: you can get there from here: New York, Free Press. In: Snyder, C.R., ed. Handbook of hope theory, measures and applications. San Diego: Academic Press, 1994; 3-21).

44. Snyder CR. The psychology of hope: you can get there from here: New York, Free Press. In: Snyder, C.R., ed. Handbook of hope theory, measures and applications. San Diego: Academic Press, 1994; 3-21).

45. Bustamante, V., Mellman, T., David, D. & Fins, A. 2001. Cognitive functioning and the early development of PTSD. *Journal of Traumatic Stress,* 14(4):791-797.

46. Serebro M. Reach For A Dream Foundation. [Personal interview, 2 February] Johannesburg; 2012 (Unpublished).

47. Collins JJ., Devine TD., Johnson ED., Pinkerton CR., Thaler HT. The measurement of symptoms in young children with cancer: The validation of the Memorial Symptom Assessment Scale in Children Aged 7-12. Journal of Pain and Symptom Management. 2002; (23):10-16.

48. Make-A-Wish Foundation (MAWF). Impact Study. MAWF Intelligence Team; 2011;3 (Unpublished).

49. Clemency CE. The impact of a wish experience on paediatric cancer patients and their families. (Unpublished dissertation). Phoenix. Arizona State University; 2009; 40.

50. Make-A-Wish Foundation (MAWF). Impact Study. MAWF Intelligence Team; 2011; 4 (Unpublished).

51. Herth K. Hope in the family caregiver of terminally ill people. Journal of Advanced Nursing, 1993; (18):538-548.

52. Bybee J. Guilt and children. California, Academic Press.1998:91-108.

53. Make-A-Wish Foundation (MAWF). Impact Study. MAWF Intelligence Team; 2011 (Unpublished).

54. Clemency CE. The impact of a wish experience on paediatric cancer patients and their families. (Unpublished dissertation). Phoenix. Arizona State University; 2009:40.

55. Claar RL., Blumenthal JA. The value of stress-management interventions in life-threatening conditions. Current Directions in Psychological Science, 2003; (12):133-137.

56. Kwon P. Hope, defence mechanisms, and adjustment: implications for false hope and defensive hopelessness. Journal of Personality, 2002; 70(2):207-231.

57. Meegan SP., Berg CA. Whose life is it anyway? Social appraisal and life task pursuit. Journal of Personality. 2001; 69:363-389.

58. Tusaie KR., Patterson K. Relationships among trait, situational, and comparative optimism: clarifying concepts for a theoretically consistent and evidence-based intervention to maximize resilience. Archive of Psychiatry Nursing. 2006; 20(3):331-341.

59. Snyder CR. Hope theory: rainbows in the mind. Psychological Enquiry. 2002; 3(4): 249-275.

60. Saleh UA., Brockopp DY. Hope amongst patients with cancer hospitalized for bone marrow transplantation: a phenomenological study. Cancer Nursing. 2001; 24(4):308-314.

61. Snyder CR. Hope theory: rainbows in the mind. Psychological Enquiry. 2002; 3(4): 249-275.

62. Clemency CE. The impact of a wish experience on paediatric cancer patients and their families. (Unpublished dissertation). Phoenix. Arizona State University; 2009:11.

63. Clemency CE. The impact of a wish experience on paediatric cancer patients and their families. (Unpublished dissertation). Phoenix. Arizona State University; 2009:11.

Table 1 Characteristics of child/adolescent participants

Child/ adolescent participant*	Age	Sex	Dream	Illness	Parent participant
C1	12	F	Drive, fly and ride on fast bikes, cars and planes	Congenital Myopathy – muscle disorder present at birth	M1; F1
C2	11	M	Shopping experience	Neurofibrosarcoma – malignant tumour	M2; F2
C3	15	M	Being a DJ	Cardiomyopathy – heart muscle disease	M3; F3
C4	11	F	Swim with dolphins	Hodgkins Lymphoma – cancer of white blood cells	M4
C5	9	F	Ski in the snow	Brain Tumour	M5; F5
C6	13	F	Family holiday	Leukaemia – blood or bone marrow cancer	M6; F6

* C: child; M: mother; F: father

Figure 1 Emotive cushions presented to child/ adolescent participants

Figure 2 Additional emotive cushions created by researcher. Based on paper versions drawn by child/adolescent participants

| *Happy with balloons* | *Sick - bandage on Head* | *Tired* | *Feeling bilious* | *Friends* |

SECTION C

SUMMARY, EVALUATION, CONCLUSION AND RECOMMENDATIONS

3.1 INTRODUCTION

Section A of this dissertation described the reason for the research and the research background, and the article in Section B presented the findings and discussion. This Section contains an overview and evaluation of the research and recommendations are made to paediatric health professionals to improve therapeutic psychosocial intervention strategies and practices for children with LTIs that focus on enhancing child and family well-being even in the face of physical trauma. This section outlines the research, considers how the findings met the aims and objectives of the study and finally provides the researcher's recommendations.

3.2 OVERVIEW OF THE RESEARCH

3.2.1   Research Problem and aim.

LTIs in children represent both a life-threatening situation for the child and severe trauma for the family. Research shows that the emotional side effects are often considered more distressing than the physical effects of the illness. While medical interventions try to ameliorate the physical side effects, psychosocial intervention strategies focussed on generally enhancing the child and family's well-being generally, seem limited. 'Dream-come-true' realization projects are just one way to improve the child's quality of life (QOL) even in the face of physical deterioration.

The goal of this research was to explore the 'dream-come-true' psychosocial experiences of the child/adolescent with LTIs and their family through semi-structured individual in-depth interviews, allowing considerable flexibility in scope and depth to ensure detailed and fluid accounting by the participants. The research meets a need to understand how intervention strategies and practices for children and adolescents with LTIs can improve the mental and emotional health and overall wellness of critically ill children and their families.

3.2.2 Research Question

LTIs present with a wide range of physical and psychosocial side effects which appear to contribute to hopelessness and fear among the children and their families. Psychosocial intervention strategies such as future-oriented 'dream-come-true' experiences appear to hold some promise in addressing the challenges of LTIs in children. From the above research problem the researcher formulated the research question: *What were the experiences of recipients of RFAD 'dream' projects*? This question was answered by examining those experiences of both children and adolescents with LTIs and their parents using a narrative enquiry design that covered the 'pre-dream', 'dream' and post-'dream experiential phases with a view to understanding what changes, if any, were apparent in the participants' overall wellness. The aim of this study was to explore the 'dream-come-true' experience of the child/adolescent and the parents and to examine how these experiences relate to family functioning and the multiple dimensions of well-being.

3.2.3 Research Procedures

Parent interviews were semi-structured individual in-depth interviews. Interviews were conducted with 'dream' children, adolescents and their parents (17 participants in total). A confidential client list was supplied by RFAD which consisted of all families that had participated in a 'dream-come-true' experience. RFAD had obtained permission from all families to allow the researcher to contact them. The list was sorted according to the selection criteria and six child/adolescent participants and their parents were randomly selected by the researcher with a numerical Excel program. The chosen participants were contacted telephonically by the researcher explaining the purpose of the research and interview process. The initial group of six selected were not all available because of illness or time restraints. The process of random selection was repeated three times until six participants were available. All interviews were taped and later transcribed verbatim. Participants were not interrupted and were given the opportunity to tell their stories in detail. Field notes detailed the participants' reactions and were recorded immediately after each interview.

The child/adolescent interviews took place prior to the parent interviews. In the child/adolescent interviews emotive cushions were used to facilitate the interview process. These cushions were presented to elicit the various emotions possibly felt 'pre-dream', during the 'dream' and 'post-dream'. The adolescents were asked the same questions as the other child participants, the emotive cushions were shown to them and were accessible if they felt

that they could not verbalise their feelings. Due to the difficulty many children have in expressing emotions, the use of emotive cushions gave each child/adolescent participant the opportunity to easily recognize emotions ranging from <u>happy</u> and <u>peaceful</u> to <u>angry</u> and <u>frightened</u>. During the child/adolescent interviews, each child/adolescent's choice of, and comments on, the emotive cushions were recorded.

Transcripts were studied intensively; similar ideas and themes were noted. Emerging themes and sub-themes of the experiences of participants were collated using a 'cut and paste' process, using the field notes to support the process. The methodology used was effective and the researcher is of the opinion that no other research methodology could have yielded more meaningful and trustworthy outcomes.

3.3 REFLECTIONS ON THE RESEARCH
3.3.1 Research methodology
This research was done within one year after the children/adolescents had experienced their 'dreams'. Participants were from a cross section of socio-economic standing and various ethnic groups. The researcher was not connected to, nor had met, any of, the 'dream' children or their families prior to the research and had no preconceived thoughts or ideas as to which direction the research would follow.

A literature study showed that despite improvements in medical interventions in children with LTIs, the need for emotional and social support necessitates psychosocial intervention strategies for the child as well as the family (Clemency, 2009; Make-A-Wish Foundation, 2011; Miller, 2011, personal interview). The researcher found psychosocial intervention strategies in South Africa other than RFAD to be limited (Charity SA, 2013; CHOC, 2012; Rainbow Nation, 2012). The researcher visited the RFAD offices and various oncology units at paediatric hospitals in order to gain insight into the process of the 'dream-come-true' projects.

During the interactions with all the participants, the researcher experienced intense emotions. Yet it was rewarding being able to experience the participants' narratives with them. The researcher strove to understand the participants' experiences by putting herself in the interviewees' shoes, while bracketing her own assumptions and understanding of any intervention strategies intended to meet the challenges of LTIs in children. At times the

researcher had to re-focus the narrative when it came to a standstill at an intensely emotional point by breaking for coffee or a cool drink or taking the focus off the issue for a short period of time. The researcher had been encouraging, but remained impartial when working with the child/adolescent participants. The use of emotive cushions assisted greatly in getting the child/adolescent to relax. It was important that the child/adolescent felt comfortable but not too familiar; encouraged but not influenced; understood and willing to answer the questions richly and authentically without the researcher leading them.

3.3.1 Findings

LTIs in a child appear to affect not only the child's QOL but also many aspects of family functioning (Snyder, 2000:25-30). The inclusion of the entire family unit in the 'dream-come-true' experience was an important factor. This correlated with 'pre-dream' data showing distress at the exclusion of the family unit from 'normal' life experiences because of the demands of caring for a child with a LTI. The 'dream-come-true' experience evoked positive responses and expressions of happiness at being treated like 'normal' children; this linked inversely to 'pre-dream' experiences which mentioned the lack of normality.

The researcher was aware of the emotional reaction at different developmental stages in children suffering from LTIs, middle childhood children are more capable of understanding their illness and its treatment, accepting body image and changes in their body due to illness easier. Middle childhood childre are able to begin to imagine different scenarios, or 'what if' something were to happen. Adolescents at the formal operational stage reason beyond a world of concrete reality to a world of possibilities problem solving begins with possibility and proceeds to reality. Adolesncets start to develop their own identity, self-image becomes extremely important and appearance change as a result of illness can impact the adoloscents self-image. Manhy adolescnets will also go through stages of denial which can effect their compliance in taking medication and following medical procedures.

Children/adolescents and their parents all expressed 'pre-dream' feelings of fear, sadness, a lack of every day normality and feelings of uncertainty and powerlessness. Research confirms that LTIs in children evoke insecurity, fear and stress. The process of coping with stressful events is evaluated by Lazarus and Folkman's transactional theory of stress and coping (Lazarus & Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986:

992-1003). The parents' feelings of helplessness appeared to be among the strongest emotive 'pre-dream' experiences that emerged – the inability to cope with the situation, help their child or 'fix' what was wrong with him/her. According to Lazarus and Folkman's transactional theory of stress, coping with stress is looking for medical care, social support and acknowledging the advice of professionals (Glanz, Rimer, & Lewis, 2002:210-230). Treatment options need to contain primary, secondary and specific coping strategies. Coping strategies which are emotion-focused, problem-focused and meaning-based can be used (Glanz *et al.,* 2002).

'Pre-dream', the child/adolescent participants presented strong feelings of sadness about not being treated like 'normal' children and being unable to do what other 'normal' children do. Snyder's hope theory is based on goal directed energy (agency) and plans to meet goals (pathways). Therefore after the development of a LTI, hope could help the patient find ways to cope better with pains, disabilities and adjustment (Crapanzano, 2003:3-32). Snyder's hope theory proposes that patients who have LTIs learn new ways to cope; negative life experiences may enhance agency and pathway thinking instead of compromising them (Aspinwall & Leaf, 2002:283). Snyder studied many effects of LTIs such as pain and medical regimen tolerance and found that high-hope persons produced more psychosocial intervention strategies to deal with the stressors of LTIs. These findings could correlate with the data found in this study during the 'dream' and 'post-dream' experiences, suggesting of the value of presenting hope and forward thinking strategies to LTI suffers.

'Post-dream' data showed the influence that the experience of a 'dream' coming true had on the child/adolescent's outlook, seeming to encourage them to be more positive, confident and hopeful in comparison with the despair and hopelessness felt 'pre-dream'. Snyder observes that people who have sustained a serious illness report that they can withstand more severe adversity than they thought possible and learn new ways of coping (Aspinwall & Leaf, 2002:283-284; Crapanzano, 2003:3-32; Eliott & Olver, 2009:609-638). 'Post-dream', the child/adolescent was experiencing frequent contact with other 'dream' children in comparison with their 'pre-dream' feelings of loneliness and sadness and lack of peer contact due to ill health. 'Post-dream', parent participants expressed happiness that the experience of the 'dream' coming true had mitigated their child's isolation, had improved the family's life by temporarily breaking the illness cycle and had increased their awareness of the positive and happy aspects of their lives.

Parents also affirmed behavioural changes in their children such as increased courage, hope and confidence. The achievement of a goal, in this study, by means of a 'dream-come-true' experience, appears to have helped the child/adolescent with a LTI as well as his/her family to be more positive and less hopeless or apathetic (Snyder, 1994:3-21; Aspinwall & Leaf, 2002:283). Snyder's hope theory considers hope as a therapeutic healing factor (Snyder & McCullough, 2000:151-160). Coping psychosocial intervention strategies are considered by Lazarus and Folkman as important in helping people deal more effectively with stress and can eventually increase the quality of their lives (Folkman & Moskowitz, 2004:745-74; Krohne, Egloff, Varner, Burns, Weidner & Ellis, 2000:297-311).

The child/adolescent participants appeared relaxed and encouraged to participate when presented with the emotive cushions since they were pleasant to the touch, fun to play with and covered a variety of emotions. Some responses from the children/adolescents were:

'Ahaa, they are so soft and bouncy...that one...it has to be happy' (C1.7)

'The sad one hey...I really feel sad when I get left out'. (C1.14)

'...this one with the tears...it is really not nice when you have chemo'. (C2.6)

'...I like them all... this one, he's a happy one'. (C4.5)

Parent participants were all asked the same questions during the interviews. Parent participants appeared to converse openly, in great detail, and expressed intense emotions during the interviews. It appeared that the opportunity to share the story of their child's LTI validated the experience for them.

3.3.3   Strengths and Limitations of the study

The research did succeed in exploring the experiences of children and adolescents with LTIs and their families. The strengths of this research include the strict application of research methodology principles. The use of emotive cushions created a relaxed and fun atmosphere for the child/adolescent participants, not only assisting them with emotional descriptions but also encouraging them to become more deeply involved in the interview process. The child/adolescent as well as parent interviews produced rich and authentic descriptions of the 'dream-come-true' experiences yielding common themes throughout. Due to the flexibility of the semi-structured in-depth interviews, each interview evolved without restrictions. The parents appeared eager to tell their stories resulting in fluid, detailed narratives.

Limitations of this study included the failure to involve a geographically diverse group of participants as the study was limited to a small population in Gauteng and surrounding areas. The medical profession appears to customarily refer potential 'dream' children when they have almost completed their initial treatment or when the child is in remission. Although the child/adolescent participants in this study were therefore mostly in remission at the time of interviewing, a small number of the potential participants fell ill just prior to interviews and had to be excluded from the study. This exclusion may have introduced the risk of bias into the data. If interviews had been conducted with children and adolescents who were more severely ill and perhaps even with parents of children and adolescents who had passed away, this could have allowed a more comprehensive look at the 'dream-come-true' experiences across a more representative population.

A number of potential participants were also foreign (and did not remain in the country long enough to be interviewed), non-English speaking or under the selection age criterion. The small sample size of this study (six children/adolescents and their parents), less than .006% of the estimated South African 'dream' population (an average of 1000 'dreams' per year) is sure to have limited the range of experiences related (Sotrianakos, 2011, personal interview). However the continuity of findings appears consistently to show 'dream-come-true' experiences improve family functioning and multiple dimensions of well-being.

3.4 RECOMMENDATIONS

Prior to the establishment of RFAD in 1998, no organizations existed in South Africa that aimed to alleviate the emotional and social strain that a LTI places on children and their families. This research showed the importance of such organizations. While the findings are limited, they appear to highlight a need for understanding how psychosocial intervention strategies and practices for children with LTIs can improve the QOL of critically ill children, adolescents and their families. Building on this understanding, psychosocial intervention strategies could contribute to more children, adolescents and their families experiencing improved mental and emotional health and overall wellness when challenged by LTIs.

The purpose of this study was to explore the experiences of children/adolescents with LTIs and their families prior to, during and after the 'dream-come-true' project. 'Post-dream' experiences suggest some improvement in the participants' psychosocial well-being even

when their physical condition had not improved. By engaging children/adolescents in 'dream-come-true' projects, the children/adolescents and their families were given the opportunity to focus on positive affective experiences, better social interactions and improved family functioning rather than on the illness itself. Themes that emerged from the research show that the 'dream-come-true' experience increased hope, and helped participants maintain a positive outlook and improvements in their QOL by tapping into the social and emotional well-being of the child/adolescent and family.

In spite of the limitations, the study did yield some important indications for future research in psychosocial intervention strategies for children with LTIs and their families. This study was limited in the sample size chosen. The researcher recommends that future research use a larger sample in order to gain more comprehensive understanding across age and diagnostic category. This research suggests that making 'dreams' that are more family inclusive come true, such as travel wishes, may then have a greater influence on family functioning than wishes that are more child-centred (for example, a shopping spree or being a DJ for a day). This study only interviewed the 'dream' child/adolescent and parents. Future research may also examine the influence of the 'dream-come-true' experience on siblings. Given the notion from research that psychosocial intervention strategies may be most effective during the period when the child is ill, it may be valuable for future research to examine whether early referral results in better outcomes for 'dream' children, adolescents and their families.

In order to meet the wellness challenges of children and adolescents with LTIs as well as those of their families, it is recommended that the use of therapeutic practices and psychosocial intervention strategies be increased, thereby enhancing the QOL of the child/adolescent and their family. The 'dream-come-true' experience is just one psychosocial intervention strategy that could be implemented. The researcher recommends that organizations continue offering and developing other such psychosocial intervention strategies by making them more accessible, available and structured.

Reference List

Aspinwall, L.G. & Leafe, S.L. 2002. In search of the unique aspects of hope: pinning our hopes on positive emotions, future-oriented thinking, hard times, and other people. *Psychological Inquiry*, 13(4):276-321.

Charity, S.A. 2012. Website: www.charitysa.co.za/database-of-organisations. Date of access: 1 August 2012.

CHOC, 2011. Website: www.choc.co.za. Date of access: 8 July 2011.

Clemency, C.E. 2009. The impact of a wish experience on paediatric cancer patients and their families. Phoenix: Arizona State University. (un-published dissertation – PhD).

Crapanzano, V. 2003. Reflections on hope as a category of social and psychological analysis. *Cultural Anthropology,* 18(1):3-32.

Eliott, J.A. & Olver, I.N. 2009. Hope, life & death: a qualitative analysis of dying cancer patients' talk about hope. *Death Studies,* 33(7):609-638.

Folkman, S., Lazarus, R.S., Dunkel-Schetter, C., DeLongis, A. & Gruen, R.J. 1986. Dynamics of a stressful encounter: cognitive appraisal, coping and encounter outcomes. *Journal of Personality and Social Psychology,* 50(5):992-1003.

Folkman, S. & Moskowitz, J.T. 2004. Coping: pitfalls and promise. *Annual Review of Psychology,* 55:745-774.

Glanz, K., Rimer, B.K. & Lewis, F.M. 2002. *Health behavior and health education. Theory, research and practice.* San Francisco: Wiley & Sons: 210-230.

Krohne, H.W., Egloff, B., Varner, L.J., Burns, L.R., Weider, G. & Ellis, H.C. 2000. The assessment of dispositional vigilance and cognitive avoidance: factorial structure, psychometric properties, and validity of the Mainz Coping Inventory. *Cognitive Therapy and Research,* 24:29-311.

Make-A-Wish Foundation. 2011. Impact Study. MAWF Intelligence Team. Phoenix, Arizona.

Rainbow Nation, 2012. Website: http://www.rainbownation.com/search/index.asp?cx=partner-pub-5736355482830404%3Aurvxov-62t2&cof=FORID%3A10&ie=ISO-8859-1&q=charities&z=web&sa=Search Date of access: 1 August 2012.

Snyder, C.R. 1994. *The psychology of hope: you can get there from here*: New York, Free Press.,3-21.

Snyder, C.R. & McCullough, M. 2000. A positive psychology field of dreams: if you build it, they will come. *Journal of Social and Clinical Psychology*, 19(1):151-160.

Interviews

Miller, B. 2012. Reach For A Dream Foundation [personal interview]. 6 July 2012, Johannesburg.

Serebro, M. 2012. Reach For A Dream Foundation [personal interview]. 2 Feb 2012, Johannesburg.

Sotrianakos, J. 2011. Reach For A Dream Foundation [personal interview]. 6July 2011, Johannesburg.

SECTION D

APPENDICES

Appendix 1:   Technical guidelines for journal

Journal submission guidelines
African Journal of Primary Health Care & Family Medicine

Articles to the African Journal of Primary Health Care & Family Medicine (PHCFM) should provide an overview of innovative research in a particular field within or related to the focus and scope of the journal, presented according to a clear and well-structured format (between 3500 and 7000 words with a maximum of 60 references).

Manuscript Style

Manuscipts can be written in English or French. When presenting article in English, British English is to be used. Addtional general style information regarding submission is as follows:

- Line numbers: Insert continuous line numbers.
- PHCFM recommend UNIcode fonts such as Palatino, Times New Roman, Helvetica and Symbol.
- PHCFM supports a limited range of formats for text and graphics. Text files can be submitted in Microsoft Word (.doc) and Rich Text Format (RTF) documents.
- Symbols font type: Times New Roman.
- General font size: 12pt.
- Line spacing: 1.5.
- Vancouver Style Referencing will be the only referencing style accepted.
- Headings: Ensure that formatting for headings is consistent in the manuscript.
    - First headings: normal case, bold and 14pt
    - Second headings: normal case, underlined and 14pt
    - Third headings: normal case, bold and 12pt
    - Fourth headings: normal case, bold, running-in text and separated by a colon.

Further style information can be obtained at http://www.phcfm.org/index.php/phcfm/ pages/view/format

Types of Articles

Original articles: Original articles inform readers of innovative research in a particular field within or related to the focus and scope of the journal presented according to a clear and well-structured format. Research published in this section should add to the existing body of knowledge published in this field (between 3500–6000 words with a maximum of 60 references).

Review articles: Review articles inform a broad readership about fields in which there have been recent, important advances of immense, fundamental importance and highlight unresolved questions and future directions. Standard headings are not always appropriate, but the review should have clear subheadings to provide order to the manuscript (between 2500–4000 words with a maximum of 40 references; abstract required).

Opinion papers: Short opinion pieces or personal perspectives (not research papers) on any primary health care and family medicine topic. These essays are meant to express a personal viewpoint, with rare exception and should have no more than two authors (between 1000–2000 words).

Scientific letters: These are discussions on material, whereby the authors raise their opinion on a particular aspect of primary health care and family medicine studies or their reaction to a previously published paper in the *African Journal of Primary Health Care & Family Medicine*. This section encourages debate amongst authors and readers on topical issues of national and global importance to the field of primary health care and family medicine. Letters will be published at the editors' discretion. In the case of critical letters, the original author will be given an opportunity to provide a short rebuttal which will be published along with the critical letter (up to 800 words).

Case studies: documented test, diagnosis and treatment of a patient/animal or group (between 500 and 1500 words).

Conference reports, proceedings and abstracts: Such manuscripts may be published by the journal. Should you wish that the journal publish proceedings from a conference you are organising, please contact the Editor. Conference reports should be no longer than 1500 words.

Educational material: Such material includes education module or course content, or any material used in the education and training of students. Submissions must be less than 3500 words and free from copyright.

Book reviews: The book reviews are normally requested by the editor or book review editor on any books relevant to aspects of primary health care and family medicine. Please contact the Editor if you would like to suggest a review or book for consideration.

Publication policies

AOSIS Open Journals endorses and applies the standards of the Committee on Publication Ethics (COPE), which promotes integrity in peer-reviewed research publications.

Experimental research on animals and/or humans must follow internationally recognised guidelines. A statement to this effect must appear in the Ethical Considerations Section of the manuscript, including the name of the body that gave approval, with a reference number where appropriate. Informed consent must also be documented. Manuscripts will be rejected if the editorial office considers that the research has not been carried out within an ethical framework (e.g. if the severity of the experimental procedure is not justified by the value of the knowledge gained.)

Plagiarism: It should be noted that salami publishing and parallel publishing detract from the innovative nature of research findings. The journal publisher, AOSIS Open Journals, is a member of the CrossCheck plagiarism detection initiative. In the event of suspected plagiarism in submitted works CrossCheck, is available to the Editors of the *African Journal of Primary Health Care & Family Medicine* to detect instances of overlapping and similar text.

Appendix 2: The effect of LTIs on children in different developmental stages (9 – 15 years) and on their concept of something being possible (Meijer *et al.*, 2002:1453).

Emotional Reaction at different developmental stages in children suffering from LTIs	
Middle childhood 9 – 11 years	**Adolescence 13 – 15 years**
Reaction to LTIs	**Reaction to LTIs**
Middle childhood children are more capable of understanding their illness and its treatment, but they should not be expected to react as adults do. They may feel left out when they miss school or activities with their peers. Parents may feel the need to protect their children by restricting them from activities with other children. This is a natural reaction, but it can interfere with the child's independence and sense of mastery. To the extent allowed by the child's doctors, parents should help the child to participate in school or other activities. Younger children also accept body image change easier with certain illnesses as they have not as yet have come to recognise and appreciate their body image.	Adolescents begin to develop their own identity separate from their family. Self-image becomes extremely important during the teenage years. That can be a problem when the teen's appearance is altered by illness or medication. Teens are also beginning to develop a real independence from their families. Parents who have been very involved in their teen's care for many years may find it difficult to let go of their role as primary caregiver. Many teens will go through times of denial of their illness when they may neglect to take medications, follow special diets, or check blood sugars. In addition, the adolescent's body is rapidly changing, which may change the symptoms of the illness or the doses of medications needed. It is important to help the teen to gain control of their disease management. Teens will however also need to be involved in normal teenager issues: independence, college planning, sexuality, substance abuse and normal teenage expectations.
Reaction to dreams, belief that something could happen	**Reaction to dreams, belief that something could happen**
During the Concrete Operational Stage, children are able to begin to imagine different scenarios, or 'what if' something were to happen. This is because they now have more 'operational' thought.	The formal operational stage begins around age 11 and is fully achieved by age 15, bringing with it the capacity for abstraction. This permits adolescents to reason beyond a world of concrete reality to a world of possibilities problem solving begins with possibility and proceeds to reality.

Appendix 3:   EMOTIVE CUSHIONS

Emotive cushions presented to child participants

Additional emotive cushions created by researcher. Based on paper versions drawn by child participants

Happy with balloons   *Sick - bandage on*   *Tired*   *Feeling bilious*   *Friends*
                          Head

Appendix 4:   Sample of field notes

7/1/2013 (Child 01 Annabel (12))   NA x -

Congenital myopathy

Large house - warm - friendly - lots of children. Lots of stuff for her, rails on the walls - stuff to help her.

Frail girth, limps, sure of herself - led to lounge - speaks easily - looks lot younger than 12 due to hunched over and bones brittle

Mum)   Brother 17
)   Sister 14
Dad   }   Annabel 12
            Sister 8

Lots of pets
likes to sit close - if you move away she moves closer. Connects with people well - speaks easily. likes the cushions with hands - keep on her lap
Dresses in pink
Touches pillows often, rubs them also against face - likes feeling of pillow (needement)

Seems to get uncomfortable - moves around a lot, shuffles seat - keeps good eye contact.

Touching all pillows again - likes to put them in order? What order - seems to have happy together + unhappy together.

* At end also chose angry one.   * Friend of Key Family
* Came in sparkly dress

Appendix 5:   Participant Information

Child participant	Age	Sex	Dream	Illness	Parent participant
C1	12	F	Drive, fly and ride on fast bikes, cars and planes	Congenital Myopathy – muscle disorder present at birth	M1; F1
C2	11	M	Shopping experience	Neurofibrosarcoma – malignant tumour	M2; F2
C3	15	M	Experience being a DJ	Cardiomyopathy – heart muscle disease	M3; F3
C4	11	F	Swim with dolphins	Hodgkins Lymphoma – cancer of white blood cells	M4
C5	9	F	Experience snow skiing	Brain Tumour	M5; F5
C6	13	F	Experience family holiday	Leukaemia – blood or bone marrow cancer	M6; F6

Appendix 6:   Sample of consent form for participants

CONSENT FORM

INVITATION TO PARTICIPATE

You are asked to participate in this research study because you were identified as the parent of a child with a life-threatening illness by the doctor or the teacher of your child.

THE PURPOSE

The researcher intends to explore the experience(s) that the Reach for a Dream Foundation has brought to critically ill children in South Africa and what attitude changes having a dream might elicit in critically ill children which could lead potentially to better health outcomes. As indicated by Sotirianakos (2011), the Foundation has fulfilled over 9000 dreams since 2007. However, the Foundation faces the same question year after year: 'How does Reach for a Dream measure the benefit the dream experience has on the children and their families?'

RISKS

Some of the questions may touch on sensitive areas. However, every effort will be made by the researcher to minimise your discomfort. If at any time you feel you would like to withdraw from the research study, you will be free to do so.

INTERVIEWS

All interviews will be taped. The recordings will be kept in a locked cabinet on the property of the researcher and will only be used by the interviewer for transcribing and extracting themes for qualitative results.

COSTS AND FINANCIAL RISKS

There are no financial costs directly associated with participation in this project.

BENEFITS AND COMPENSATION

There is no guarantee that you will benefit directly from the study. You will not receive any compensation for participating in this study. There will be no financial gain for participating in this study.

PARTICIPATION

Participation in this research project is entirely voluntary and you may choose not to participate.

CONFIDENTIALITY

Every attempt will be made by the researcher to keep all information collected in this study strictly confidential, except as may be required by court order or by law. If any publication results from this research, you will not be identified by name. Information will only be accessed by the researcher, the transcriber and the personnel of North-West University.

ADDITIONAL INFORMATION

Your participation in this study is entirely voluntary, and you are free to refuse participation. You may discontinue your participation at any time without prejudice. If you discontinue participation in this project, you may request the researcher not to use the information already given to her. You are encouraged to ask questions concerning the study at any time. Any significant new findings developed during the course of the study that may relate to your willingness to continue participation will be provided to you.

FEEDBACK

You hereby give consent that the feedback after the research will be available to all participants if requested.

DISCLAIMER / WITHDRAWAL

You agree that your participation in this study is completely voluntary and that you may withdraw at any time.

SUBJECT RIGHTS

If you have any questions pertaining to your participation in this research study, you may contact the researcher at any time (Debra Anne Myburgh 082 897 0775).

CONCLUSION

By signing below, you are indicating that you have read and understood the consent form and that you agree to participate in this research study.

_____   _____

Participant's signature   Date

_____   _____

Researcher's signature   Date

Appendix 7:   Consent from RFAD to proceed with research

reach for a dream
inspiring hope

10th December 2010

TO WHOM IT MAY CONCERN

Re: Debra Myburgh research proposal

The Reach For A Dream Foundation would like to confirm that we are aware of the proposal that Debra Myburgh is submitting for her Masters Degree and we fully support the concept.
We are willing to give Debra access to our volunteers, children, families and any resources that she may need to complete her research.
We undertake to provide Debra with the resources and access to ensure the best possible results.

Warm Regards

Julia Sotirianakos

Appendix 8: RFAD approved illnesses

Reach For A Dream Foundation: List of illnesses November 2013

A

1. Acute Lymphoblastic Leukaemia
2. Acute Myeloid Leukaemia
3. Adrenocortical Carcinoma
4. Adrenoleukodystrophy (ALD)
5. Alexandra disease
6. Alpha -1-Antitrypsin
7. Anaplastic Dysgerminoma
8. Aplastic Anaemia
9. Astrocyptic tumours
10. Astrocytoma
11. Ataxias SpinoCerebella
12. Autoimmune hepatitis

B

13. B Cell Lymphoma
14. Bernard-Soulier Syndrome
15. Biliary Atresia
16. Bone marrow transplant
17. Bowel cancer
18. Brain tumour
19. Bronchiectasis
20. Bruton's Agammaglobulinemia
21. Burkett Lymphoma

C

22. Cancer of the bladder
23. Cancer of the kidney
24. Cancer of the rectum
25. Carcinoma nasopharynx
26. Cardiomyopathy
27. Central nervous system tumour
28. Chondrosarcoma
29. Choriocarcinoma
30. Choroid Plexius Carcinoma
31. Chronic liver disease
32. Chronic lung disease

33. Chronic myeloid leukaemia
34. Chronic renal failure
35. Clear cell sarcoma
36. Colon Cancer
37. Composite Ggandlioneuroblastoma
38. Cor Pulmonale
39. Craniopharyngioma
40. Cystic Fibroses

D

41. Dandy-Walker Syndrome
42. Diffuse pontine glioma

E

43. Ectomesenchymoma
44. Ependymomas
45. Ewing Sarcoma

F

46. Fanconi's Anaemia
47. Fibrosarcoma

G

48. Germ Cell tumours
49. Germinoma
50. Giant Cell Atrocytoma
51. Glanzmann thrombasthenia
52. Glioblastoma
53. Gliomas

H

54. Haemangioblastoma
55. Heart transplant

56. Hepatoblastoma
57. HIV (CD4 count below 200)
58. Hodgkin's Lymphoma
59. Hutchinson-Gilford-Progery Syndrome

I

60. Inoperable congenital heart defect

K

61. Kaposi's Sarcoma

L

62. LeioMyoSarcoma
63. Leukaemia
64. Leukodystrophy
65. Liver cancer
66. Liver transplant
67. Lymphoma

M

68. Malignant Rhabdoid Tumour of kidney
69. MDR & XDR TB
70. Medullablastoma
71. Melanoma
72. Metachromatic leukodystrophy
73. Multiple Organ Dysfunction Syndrome
74. Muscular Dystrophy
75. Myelodysplastic Syndrome

N

76. Nasopharyngeal Carcinoma
77. Nephroblastoma
78. Nephrotic Syndrome
79. Neuroblastoma
80. Non Hodgkin's Lymphoma

O

81. Osteogenic Sarcoma
82. Osteopetrosis
83. Ovarian Cancer

P

84. Parotid tumours
85. Peripheral T-Cell lymphoma
86. Pineoblastoma
87. Post Fossa Tumour
88. Primitive Neoro Ectodermal Tumours
89. Pulmonary Blastoma

R

90. Rectal tumours
91. Red Cell Aplasia
92. Renal transplant
93. Retinoblastoma
94. Rhabdomyosarcoma

S

95. Sarcoma
96. Sickle Cell Anaemia
97. Spina Bifida – only severest form – should be motivated by doctor
98. Spinal Muscular Atrophy
99. Spinal Tumour
100. Systemic Lupus Erythematosus (SLE)

T

101. T Cell Lymphoma
102. Testicular Cancer
103. Tetralogy of Fallot
104. Thalamic & basal ganglia tumours
105. Thymoma
106. Thyroid Cancer
107. Truncus Arteriosus

U

108.   Univentricular heart
109.   Uterine Cancer

W

110.   Wilms Tumour