

**An exploration of risk and protective variables in the
bio-psychosocial field of South African adolescents
with cystic fibrosis**

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DECLARATION

I declare that

**“An exploration of risk and protective variables in the bio-psychosocial field of
South African adolescents with cystic fibrosis”**

is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

SIGNATURE
(CJ Hugo)

DATE

This research study is dedicated to my sister who is living a life with CF and who was the inspiration and reason I chose this subject for the study.

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SUMMARY

The general aim for this research was to explore and describe the risk and protective variables in the bio-psychosocial field of adolescents with Cystic Fibrosis (CF) and to describe how these variables impact multi-dimensionally on such adolescents.

From the literature search it seemed as if interventions regarding CF focus mainly on the medical condition. No literature could be found on the experiences of adolescents with CF. It is clear that there is a dearth of research on adolescents with CF in general but also specifically on the bio-psychosocial impact of this illness on adolescents in this challenging time of maturing.

The research design was a case study and focused on exploration and description of risk and protective factors in the bio-psychosocial fields of adolescents with CF. Semi-structured interviews were used as a data collecting method. Questions were open-ended, but focused on the experience of adolescents having CF. Thematic analysis was used for data analysis based on the following steps, which entailed among others transcribing data, reading, re-reading, translation, coding, identifying and describing themes.

Facing a chronic illness and the intensive medical treatment required is a harsh reality that influences the entire field of adolescents with CF. This research results expanded knowledge of CF in adolescents within a Gestalt field perspective. Themes identified outline risk and protective factors related to faith, daily routines and especially the effect of medical procedures on time management, emotions, health and body-related aspects, frequent hospitalisation, social support and future concerns. If the risk and protective variables in the field of adolescents with CF is better understood from their own perspective, it is assumed that trans-disciplinary interventions with a multi-dimensional focus will be targeted more accurately in intervention strategies for this vulnerable group.

OPSOMMING

Die algemene doel van die studie was om die risiko en buffer faktore in die bio-psigososiale veld van adolessente met sistiese fibrose (SF) te eksploreer en te beskryf hoe hierdie veranderlikes die adolessente multidimensioneel beïnvloed. .

Uit die literatuurstudie wou dit voorkom asof intervensies rakende SF hoofsaaklik op die mediese toestand fokus. Geen literatuur kon gevind word oor die ervarings van adolessente met SF nie. Daar is duidelik 'n tekort aan navorsing rakende adolessente met SF in die algemeen, maar ook spesifiek gerig op die bio-psigososiale impak van die siekte op adolessente in hierdie moeilike tyd van ontwikkeling.

Die navorsingsontwerp was 'n gevallestudie wat gefokus het op die eksplorering en beskrywing van die risiko en buffer faktore in die bio-psigososiale veld van adolessente met SF. Semi-gestruktureerde onderhoude is as 'n data insamelingsmetode gebruik. Oop-einde vrae was gerig op die ervarings van adolessente met SF. Tematiese analise is vir data analise gebruik en het stappe ingesluit soos transkribering van data, lees daarvan, herlees, vertaling, kodering, identifisering en beskrywing van die temas.

Die hantering van 'n chroniese siekte en die intensiewe mediese behandeling wat dit vereis is die harde werklikheid wat die totale veld van adolessente met SF beïnvloed. Hierdie navorsingsresultate brei kennis uit oor adolessente met SF binne 'n Gestalt veldteoretiese perspektief. Temas wat geïdentifiseer is omskryf risiko en bufferfaktore ten opsigte van geloof, daaglikse roetine en veral die effek van mediese prosedures op die bestuur van tyd, gereelde hospitalisasie, sosiale ondersteuning en toekomsverwante aspekte. Indien die risiko en bufferfaktore in die veld van adolessente met SF beter verstaan word, vanuit hulle perspektief, word aanvaar dat trans-dissiplinêre intervensies met 'n multi-dimensionele fokus meer akkuraat gerig kan word in intervensie-strategieë vir hierdie kwesbare groep.

KEY TERMS

Adolescence

Awareness

Bio-psychosocial theory

Conservation of Resources theory (COR)

Creative adjustment

Cystic fibrosis

Gestalt Field theory

'Organismic' self-regulation

SLEUTEL BEGRIPPE

Adolesensie

Bewustheid

Bio-psigososiale teorie

Behoud van hulpbronne teorie (COR)

Kreatiewe aanpassing

Sistiese fibrose

Gestalt Veld teorie

Organismiese self-regulering

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Section A: Introduction and overview

1. Introduction

Cystic Fibrosis (CF) is a chronic, incurable illness which affects the entire body but with special impact on the lungs and digestive system (Cystic Fibrosis Foundation, 2011). CF is not confined to one population, but is affecting people across cultural borders worldwide (Cystic Fibrosis Worldwide, 2011). It is difficult to estimate an accurate figure of people with CF worldwide, but there are around 30 000 people with CF in the United States of America, over 7500 in the United Kingdom and approximately 30 000 in the European Union (Cystic Fibrosis Worldwide 2011; Ekvall & Ekvall, 2005:363). There is currently no conclusive database of CF patients in South Africa, although information from the three regional CF associations indicates that there are at present about 700 people with CF in SA. In the 1950s, few children with CF lived to attend elementary school, but today advances in research and medical care have further enhanced and extended the life expectation of people with CF who can now expect to live into their thirties, forties and beyond (Cystic Fibrosis Foundation, 2011). There are approximately 1000 new cases diagnosed worldwide each year; more than 70% of patients are diagnosed by the age of two years. More than 45% of the CF patient population is older than 18 years and the mid thirties is the predicted median age of survival for a person with CF (Cystic Fibrosis Foundation, 2011; US Department of Health and Human Services 2011).

2. Orientation and problem statement

From the literature search it seems that interventions regarding CF often focus mainly on the medical condition (Cystic Fibrosis Foundation, 2011; Ekvall & Ekvall, 2005:363-368; Harris & Super, 1991:1-32), including aspects such as patient care (Quittner, Barker, Marciel & Grimley, 2009:271-286) and medical assessment/screening (Powers, 2008:1-4). A search on EBSCOhost on the psycINFO database yielded 742 articles on various aspects regarding CF. These articles focus mainly on the medical condition with only 18 articles directly related to adolescence. No literature could be found on the experience of adolescents with CF (Dumont & Provost, 1999:344). One article focuses on the importance of mental health in the context of CF (Quittner, 2010:1-2) with emphasis on how depression and anxiety affect overall health in the

context of CF. It is clear that there is a dearth of research on adolescents with CF in general, but specifically on the bio-psychosocial impact of this illness on adolescents.

Through the researcher's personal experience of having a sister with CF it was observed that there is enough medically related therapy for CF patients, but that there seems to be a lack of knowledge of what an adolescent is experiencing having a chronic illness at this challenging stage of maturing. This research focus is therefore relevant as the current main emphasis on the medical side in scientific literature can lead to neglecting the other affected areas such as socialization, adolescent development, emotional experience, impact on the self, repetitive trauma and cognitive functioning. When taking into account the symptoms of CF such as persistent coughing, frequent lung infections, wheezing or shortness of breath, and digestive complications with frequent bulky and greasy stools, it is clear that the impact of CF on adolescents is multi-dimensional. If these areas are not addressed appropriately adolescents with CF may become a neglected population with long-term negative consequences related to their overall functioning. Understanding the risk and protective factors in the fields of adolescents with CF is a first step in the appropriate management of this chronic health issue from a bio-psychosocial perspective. If adolescents with CF are not adequately supported, and if the support is not based on a solid understanding of the risk and protective variables in their field, they can fall into negative resource loss cycles (Van der Merwe & Kassan-Newton, 2007:350-361; Hobfoll, Dunahoo & Monnier, 1995) with non-adaptive or non-constructive coping efforts. An exploration as intended in this study may form a basis for future intervention research to plan strategies to assist adolescents with CF and thereby enhance multidisciplinary intervention for this target group.

An adolescent living with CF is confronted by specific challenges in a phase of life where a number of developmental tasks must be completed in preparation for adulthood. The adolescent years were specifically selected as target age for this research as it is possible that the challenges of managing CF take so much energy and internal resources that ordinary adolescent development may be adversely impacted. Both middle and late adolescent stages were chosen because of the small number of participants available in one stage group only.

In this research study the following two questions will be investigated:

- What are the risks and protective variables in the bio-psychosocial field of adolescents with cystic fibrosis?

- How do the risk and protective variables impact multi-dimensionally on adolescents with cystic fibrosis?

As suggested by Fouché and Delport (2011:108) the research problem and research question guide the formulation of research aims and objectives:

3. Aims and Objectives

3.1 General aim

The general aim of this research is to explore and describe the risk and protective variables in the bio-psychosocial field of adolescents with CF and to describe the multi-dimensional impact of these variables on such adolescents.

3.2 Objectives

In order for the researcher to achieve the goal of this research, objectives were put into place to serve as a roadmap to guide the researcher. The objectives should be specific, clear and achievable (Fouché & De Vos, 2011:90).

- To conduct an in depth literature study as background to the study, focusing on the aspects mentioned in 6.1
- To conduct semi-structured interviews with adolescents with CF in order to explore the risk and protective variables in their field and to describe the bio-psychosocial impact of this illness. It is planned to include a sufficient number of participants to achieve data saturation
- To use thematic analysis (Whittaker, 2009:91-97) to identify themes and report patterns in the data
- To reflect the obtained data in a research article.

4. Central Theoretical Argument

The interplay of risk and protective variables in the field of adolescents with CF has not been adequately researched. It is hoped that research results will expand knowledge of CF in

adolescents within a *gestalt* field perspective. If the risk and protective variables in the field of adolescents with CF is better understood from their own perspective, it is assumed that multidisciplinary interventions with a multi-dimensional focus will be targeted more accurately in intervention strategies for this vulnerable group.

5. Scientific paradigm

5.1 Gestalt field theory

The researcher's theoretical paradigm relevant to this study is predominantly *gestalt* field theory (Kirchner, 2000) with the assumption that everything is of a field (Woldt & Toman, 2005:41-63; Yontef, 1993:323; Perls, Hefferline & Goodman, 1951) and that human beings constantly configure their experiences within their environment. In *gestalt* field theory human behaviour is the function of the person and the environment. A person's performance, action and deeds are related to all the characteristics and the social context of the person (Yontef, 1993). It entails everything the person comes in contact with, a whole in which the parts are in relationship and responsive to each other—all influenced by what else is going on in the field (Yontef, 1993). Joyce and Sills (2010) describe the process of continuous contact between organisms and their field where there should be ongoing mutual regulation because the conditions in the field are constantly altered. Within this process people should ideally adjust in a creative manner to the challenges in the internal and external field. In contact with the field there is a constant configuration of experience and needs are met and managed in many different ways. Contact is defined by Yontef (1993) as a meeting between the person and his environment. The relationship of the person with the environment is termed the 'organismic environment' or 'the field'. Support from the external field is probably an essential protective variable and one of the factors the researcher will be interested in. Kirchner (2000) said: 'There is no self independent of field or contact; it is rather something given in contact that comes to life in the encounter with the world'. The interest of this study is the interplay of risk and protective variables in the internal and external fields of adolescents with CF. No literature was found linking CF with *gestalt* field theory. The research will expand knowledge on this link and the researcher intends that this research will add to and build into Gestalt related theory pertaining to a special area, namely CF.

5.2 Conservation of resources theory

The Conservation of Resources (COR) theory will also be incorporated because it offers a psychosocial approach to people exposed to continuous, repetitive stress (Van der Merwe & Kassan-Newton, 2007:353). According to the COR theory, psychological stress occurs when there is the threat of significant resource loss. If the movement of the downward loss spiral is more rapid than that of the gain spiral, it is suggested that immediate efforts be made to slow down the downward spiral (Van der Merwe & Kassan-Newton, 2007:361). Hobfoll et al. (1995) describe four categories of resources, namely object resources such as a car and a house, condition resources such as networks and relationships, personal resources such as optimism, a sense of hope and resilience and energy resources such as money and time. This offers a framework for risk and protective variables in the field of participants.

6. Method of investigation

6.1 Review of the literature

The literature review focused on relevant books, articles, research reports and journals. The literature was obtained from the North-West University library and by making use of internet searches on databases such as EPSCOhost.

A further in depth literature study focused on the following:

- *Gestalt*, Phenomenology and Field theory (Joyce & Sills, 2010; Mackewn, 2007; Woldt & Toman, 2005:41-78; Blom, 2004; Reber & Reber, 2001; Kirchner, 2000; Van Aalderen, Mannes, Bosma, Roorda & Heymans,1995; Yontef, 1993:323; Clarkson, 1989; Spiegelberg, 1975; Frankl, 1963; Perls et al., 1951)
- Conservation of Resources theory (Van der Merwe & Kassan-Newton, 2007:350-361; Hobfoll et al. 1995)
- The multi-dimensional impact of CF (Quittner, Barker, Marciel & Grimley, 2009:271-286; Bilton, 2008; Ekvall & Ekvall, 2005:363; Monroe 2001; www.sacfa.org; http://www.nhlbi.nih.gov/health/dci/Diseases/cf/cf_risk.html; <http://www.aboutcysticfibrosis.com/port-a-cath.htm> ; <http://kidshealth.org>)

- The adolescent life cycle (Woldt & Toman, 2005:191; Park, 2004:50; Mwamwenda, 2004:60; Louw et al., 2002; Dumont & Provost, 1999:344)

6.2 Empirical Investigation

6.2.1 The design

This qualitative study will reflect applied research mainly, since it focuses on producing recommendations that apply to a specific group in a particular situation; in this study, adolescents with CF. Because it is envisaged that a link will be made between *gestalt* field theory and adolescents with CF, it is expected that there will be some contribution to theory-building, which adds an element of basic research as described by Fouché and De Vos (2011:94).

The search design is that of a case study (Fouché & Schurink, 2011:320-323; Nieuwenhuis, 2010b:75-76) and will focus on exploration and description of risk and protective factors in the bio-psychosocial fields of adolescents with CF. This research will be exploratory in nature in order to gain insight into an individual's views on his/her illness. It will also be descriptive, since themes will be described as they emerge from collected data.

6.2.2 Participants

Sampling will be used to select a sample of the population for the study. Purposive sampling will be employed, meaning that participants will be selected because of a defining characteristic that makes them the holders of the data needed for the study (Maree & Van der Westhuizen, 2009:79). The researcher will interview adolescents in the middle and late adolescent years between the age groups 15 and 22 years (Dumont & Provost, 1999:344) with the defining characteristic, i.e. CF. The participants will be given the opportunity to relate the stories of their experiences and the meanings they attach to living with a chronic illness. Exploring a chronic illness from this perspective may therefore provide a better understanding of what the participants view as risk and protective factors in their field, thereby giving them a voice.

The broad age group cited above was selected because of the small numbers of people with CF. The South African Cystic Fibrosis Association (S.A.C.F.A.) is the national governing body of the three regional based bodies situated in Western Cape Province, Gauteng and Kwa-Zulu Natal respectively (Cystic Fibrosis Foundation, 2011). This study will focus on adolescents with CF living in Gauteng as face to face interviews will be done and it will not be feasible to travel to

other provinces. The CF foundation will be contacted to assist in contacting potential participants to ask if they will be prepared to take part in the research group. The Facebook CF group will be used and the researcher's sister with CF will also assist in identifying participants in this specific age group, therefore incorporating snowball sampling (Maree & Pietersen, 2010:177-178).

Criteria for selection of participants:

- Adolescents in their middle and late adolescent years (15-22yrs) with CF, living predominantly in Gauteng Province.
- The medical condition of potential participants needs to be sufficiently controlled for a participant to be able to participate.

6.2.3 Method of data collection

Specific methods for collecting data were selected (Eve, 2008:25). Semi-structured interviews of about 90 minutes were used as a data collecting method. Questions asked were open-ended, but focused on the experience of adolescents with CF. The researcher needed to bracket her own personal experience and interest to prevent preconceived ideas and assumptions from influencing the process of data collection and analysis. Field notes were written after interviews to capture additional aspects such as non-verbal conduct of participants.

Procedures

- Identify all the participants as mentioned in 6.2.2
- Obtain written consent from parents of participants under the age of eighteen years and consent from participants eighteen years and older. They are also required consent to tape recording of interviews.
- Compile questions for the semi-structured interviews
- Make appointments with participants
- Conduct individual semi-structured interviews with each participant until the research meets the criteria for data saturation (Nieuwenhuis, 2010:79).

6.2.4 Data analysis

Qualitative data analysis tends to be an on-going and non-linear process, implying that data collection, processing, analysis and reporting are intertwined. Nieuwenhuis (2010b:99-100) refers to the work of Seidel who mentioned three essential elements of data analysis namely noticing, collecting and reflecting. Thematic analysis as described by Whittaker (2009:91-97)

was used in this research, based on the following steps which entailed, among others, transcribing data, reading, re-reading, coding, identifying and describing themes.

6.2.5 Ethical matters

The ethical aspects as described by Strydom (2000:17-32; 2011) and Mouton (2005:238-245) were taken into account throughout this research. The researcher was mindful of aspects such as informed consent, avoidance of any physical or emotional harm to the participants, confidentiality and the participants' right to privacy. For this study it was especially important to ensure that participants were not physically or emotionally harmed, especially in the light of their frail physical condition. As it were, four participants were interviewed while they were hospitalized. The researcher was aware that participants might experience physical discomfort due to the illness and monitored this during interviews. Strydom (2011:115) mentions that researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the proposed investigation. In this regard the researcher employed her knowledge and skills in dialogue to engage participants and to facilitate discussions. An essential ethical aspect that was respected in this study is the issue of the confidentiality of the results and findings of the study and the protection of the participants' identities (Maree & Van der Westhuizen, 2009:37-42). While the researcher interviewed some participants in hospital, she adhered to the rules and regulations of the institution. When participants were questioned some coughed but the researcher had compassion because she was familiar with their condition, having a sister with CF. The researcher acted professionally at all times and dealt with each participant's individual experiences in a respectful way. Past experience and exposure qualified the researcher to conduct the interviews with the necessary wisdom and insight.

7. Definition of main concepts

7.1 *Adolescence*

Adolescence stands out as a fascinating, interesting and challenging period of human growth and development. It is a period of considerable social, physical, psychological, emotional and psychosocial change (Mmamwenda, 2004:60). For the purposes of this study the adolescent will be defined as a person in the developmental stage that occurs between childhood and adulthood (Park, 2004:50). According to Louw, Van Ede and Louw (2002:388) the adolescent developmental stage start from 11 to 13 years and ends at roughly 17 to 21 years. The

adolescent phase of development can be divided into three stages: early adolescent years which include children between 10 and 14 years, middle adolescence (15-17 years) and late adolescence (18-22 years). The researcher will interview adolescents in the middle and late adolescent years in the age group 15-22 years (Dumont & Provost, 1999:344).

7.2 Bio-psychosocial approach

As far back as 1977, Engel introduced the bio-psychosocial approach in the medical professions. He postulated that patients need to feel others' understanding on the three dimensions of illness, namely biological, psychological, and social (Borrell-Carrió, Suchman & Epstein, 2004). The term 'bio-psychosocial' is relevant because in this study the researcher worked with CF patients in which biological factors played a role due to their chronic illness. This illness influences their psychological dimension like thoughts, behaviors and feelings, but also their social life (when the illness evolved and their social functioning was impaired). It is therefore important to view patients holistically: incorporating biological, psychological and social dimensions. Lakhan (2006) refers to Engle's opinion that medical models should incorporate the patient and his/her social context.

7.3 Chronic illness

Chronic illness can be defined as follows: '...an illness that is permanent or lasts a long time; it may get slowly worse over time; it may lead to death, or it may finally go away; it may cause permanent changes to the body; it will certainly affect the persons' quality of life'(www.chronicillness.org.au/). Some examples of chronic illnesses are asthma, diabetes, cerebral palsy, sickle cell anemia, cystic fibrosis, cancer, AIDS, epilepsy, spina bifida and congenital heart failure (University of Michigan Health System, 2008:1).

7.4 Cystic fibrosis

Cystic fibrosis or CF is an inherited disease which affects the entire body, but with specific impact on the lungs and digestive system (Cystic Fibrosis Foundation, 2011). The term 'Inherited' means that the disease is passed through the genes from parents to children. People who have CF have two faulty CF genes—one from each parent, but the parents do not have the disease themselves. CF mostly affects the lungs, pancreas, liver, intestines, sinuses and sex organs. The symptoms and severity vary from person to person. Some people with CF have serious lung and digestive problems; others have a milder form of the disease that does not show up until adolescence or adulthood. The symptoms and severity of CF also vary over time.

Medical intervention for CF constantly progresses and the life expectation of patients has increased to the point where people with CF now live into their forties, fifties, or older (National Heart Lung and Blood Institute. Disease and Conditions Index: 4 July 2011).

7.5 Conservation of Resources (COR)

The Conservation of Resources (COR) theory was conceptualized by Hobfoll (Hobfoll & Lilly, 1993) as a general stress theory within the broad context of community psychology. COR theory provides a broad framework for understanding intricate dynamics of resource loss and gain. Hobfoll et al. (1995) outline general principles of COR such as that loss of resources cascades into further loss of even more resources; that it is important to assess loss and gain spirals and to halt resource loss cycles as soon as possible. They also state that resource loss is a rapid process, whereas resource gain can be tedious and slow. Resource loss in one domain can reflect in other domains, i.e. physical impact of illness on appearance can impact negatively on self-image which is a personal resource. Resources are defined as those objects (e.g. home and car), personal characteristics (e.g. sense of hope, resilience), conditions (e.g. networks and relationships) or energies (e.g. money, credit, time) that are valued by the individual or that serve as a means for attainment of objectives (Van der Merwe & Kassan-Newton, 2007:352; Hobfoll et al.,1995:516).

7.6 Field theory

Field Theory is based on the work of Kurt Lewin (1951) and offers a primary way of looking at the world (The Gestalt Counselling and Training Institute - Ann Arbor). Field theory is a method of exploring that views the currently occurring event as part of the whole field. The parts are in immediate relationship and responsive to each other and all parts are influenced by what is happening elsewhere in the field. The emphasis is on observing, describing, understanding and explaining the exact structure of whatever is being studied (Yontef, 1993). In this study the field dynamics of participants were observed according to the risk factors and protective variables in their field.

7.7 Responsibility

According to Clarkson (1999:27) the essence of *gestalt* therapy is that people should take responsibility for their own lives and as such should be the primary agents in determining their own behaviour. Perls (1969:65) described responsibility as response– ability, in other words the ability to respond. If people choose their thoughts, reactions, emotions and responses, they are

taking responsibility for who they are and what they do (Yontef, 1993:56). The basic assumption of this approach is that people can deal adequately with their own life problems if they know what they are and that they can bring all their abilities into action to solve them. In the context of adolescents with CF 'responsibility' is a relevant concept since they have to take responsibility for their physical condition from early on. They are confronted with a serious, chronic, life threatening illness. More should be known about how they make meaning of this fact and how they cope and take responsibility.

7.8 Gestalt perspectives

Clarkson (1999:1) describes *gestalt* as '...the shape, pattern, the configuration'. The well-known concept of the whole being much more than the sum of its parts forms one of the pillars of *gestalt*, namely holism. In this regard Parlett and Lee (2005:44) refer to the unitary perspective which implies taking into account: '... whole configurations and complex interactions, rather than chopping up nature and experience ...'. The aim of the *gestalt* approach is for a person to discover, explore and experience his or her own shape, pattern and wholeness. *Gestalt* therapy is a holistic process-oriented and existential-phenomenological approach to human change; (Yontef, 1993). The approach is existential because it is grounded in the notion that people are always in the process of becoming and re-discovering themselves. It is also phenomenological because it focuses on the individual's perception of reality (Corey, 2005). Important for this study, is the notion that a person's behaviour can only be fully understood if all dimensions of the person, including his/her thoughts, feelings, behaviour, body, dreams and environment, as well as sensory and spiritual aspects are taken into account. All these aspects fit together into an integrated whole (Perls et al., 1951). *Gestalt* therapy's view of human nature is grounded in four major concepts: field theory, the organism, the need for contact and relationship. The basic goal of *gestalt* therapy is to create awareness and self-support which implies contact with other people. Awareness includes knowing the environment, knowing and accepting oneself, and being able to make contact with others. Through awareness change will automatically occur (Yontef, 1993). Although this study did not focus on therapeutic intervention, the researcher's skill and knowledge of *gestalt* dialogue and processes served her well during the research interviews.

7.9 Phenomenology

Phenomenology is grounded in the work of Husserl, Dilthey, Heidegger, Schleiermacher amongst others (Heppner & Heppner, 2004:168) and the emphasis in phenomenology is on the

subjective experience of events; happenings, occurrences, and so forth (Reber & Reber, 2001). It reflects the various levels of awareness and the degree of focus that people attend to as they give significance to their lives. The uniqueness of each individual is accepted and noted (Arbor, 2010).

8. Report layout

In Section A, the planning for this research study is explained. Attention is given to various aspects regarding the research, for instance the research methodology, defining the concepts and the ethical aspects. Section B will be written in article format, where the main focus will be on themes extracted from the narratives of participants. In Section C the findings, conclusions and recommendations of the research study will be summarized, followed by a consolidated reference list.

9. Conclusion

The purpose of this section was to outline the direction this research study took to partly answer the existing need for understanding the experience of adolescents having the chronic illness cystic fibrosis. Most of the literature available to the public focus almost exclusively on the medical and treatment side of the illness. Very little is written about the bio-psychosocial aspects of the illness and how it influences the adolescent on a multi-dimensional level. Furthermore, no literature could be found that linked CF with the scientific paradigms of *gestalt* field theory and Conservation of Resources theory.

There seems to be a lack of knowledge of what an adolescent with a chronic illness is experiencing at this challenging phase of maturing. The current main emphasis on the medical side can lead to the neglect of the other affected areas such as socialization, adolescent development, affect, impact on the self, repetitive trauma and cognitive functioning.

10. References

About Cystic Fibrosis, 2011, what is a Port-a-cath? <http://www.aboutcysticfibrosis.com/port-a-cath.htm>

Arbor, A. 2010. 'The *Gestalt* Counseling and Training Institute of Ann Arbor 2010 – Holistic Therapy for mind, body and soul 2010'- *Gestalt Counseling & Training*. <http://www.gestalt-annarbor.org>. Date of access: October 2011.

Bilton, D. 2008. *Cystic fibrosis*. *Medicine* 36, p. 273 – 278.

Blom, R. 2004. *Handbook of Gestalt Play Therapy: Practical guidelines for child therapists*. Bloemfontein: Drufooma.

Borrell-Carrió, F., Suchman, A.L & Epstein, R.M. 2004. *The Bio-psychosocial Model 25 Years Later: Principles, Practice and Scientific*, *Inquiry Annals of Family Medicine*, Inc.

Clarkson, P. 1989. *Gestalt counselling in action*. Dryden ed. London: Sage publishers.

Corey, G. 2005. *Theory and practice of counseling and psychotherapy*, United States of America: Brooks/Cole.

Crocker, S.F. 1999. *A well-lived life*. Essays in *Gestalt* therapy. Cleveland: *Gestalt* Institute of Cleveland Press.

Cystic Fibrosis Foundation. 2011. *About Cystic fibrosis*. www.cff.org/AboutCF/index.cfm&www.cff.org. Date of access: September 2011.

Cystic Fibrosis Worldwide. 2011. www.cfww.org /http://en.wikipedia.org/wiki/Cystic_fibrosis. Date of access: October 2011.

De Vos, A.S., Strydom, H., Fouché, C.B. & Delpont, C.S.L. 2011. *Research at Grass roots: For the Social Science and Human Services Professions*. 4th Ed. Pretoria: Van Schaik Publishers, p. 89-99.

Dumont, M. & Provost, M.A. 1999. '*Resilience in adolescents: protective role of social support, coping strategies, self esteem, and social activities on experience of stress and depression*', Journal of Youth and Adolescence, June 28 no.3.

<http://psycnet.apa.org/index.cfm?fa=search.searchResults>.

Ekvall, S.W. & Ekvall, V.K. 2005. *Pediatric nutrition in chronic diseases and developmental disorders. Prevention, assessment and treatment*. United States of America: Oxford University Press, p. 363-368.

Eve, J. 2008. *Writing a research proposal: planning and communicating your research ideas effectively*. *Library and information research*, 32(102):18-28.

Fouché, C.B. & De Vos, A.S. 2011. Formal formulations. (In De Vos, A. S., Strydom, H., Fouché, C. B. & Delport, C. S. L. (Eds.) 2011. *Research at grass roots: For the social sciences and human service professions* (4th Ed.). Pretoria: Van Schaik, p. 89-100.)

Fouché, C. B. & Schurink, W. 2011. Qualitative research designs. (In De Vos, A.S., Strydom, H., Fouché, C. B. & Delport, C. S. L. (Eds.) 2011. *Research at grass roots: For the social sciences and human service professions* (4th Ed.) Pretoria: Van Schaik, p. 307-327.)

Frankl, V.E. 1963. *Man's Search for Meaning: An Introduction to Logotherapy*. New York: Washington Square Press.

Harris, A. & Super, M. 1991. *Cystic Fibrosis: The Facts*. Oxford university press: Great Britain, p. 1-116.

Heppner, P.P. & Heppner, M.J. 2004. *Writing and publishing your thesis, dissertation & research*. Belmont: Brooks Cole.

Hobfoll, S.E. & Lilly, R.S. 1993. *Resource Conservation as strategy for community psychology*, Journal of Community Psychology 21: 128-148.

Hobfoll, S.E., Dunahoo, C.A. & Monnier, J. 1995. *Conservation of resources and traumatic stress*. (In Freedy, J.R. & Hobfoll, S.E. (Eds.) *Traumatic stress. From theory to practice*. New York: Plenum Press, p. 29-47.)

Joyce, P. & Sills, C. 2010. *Skills in Gestalt Counseling and Psychotherapy*. Londen: Sage Publishers Ltd. p. 107

Kirchner, M. 2000. Gestalt therapy: An overview. www.g.gej.org. Date of access: October 2011.

Lakhan, S.E. 2006. *The Bio-psychosocial Model of Health and Illness*.
<http://cnx.org/content/m13589/latest/>. Date of access: September 2011.

Lewin, K. 1951. *Field theory in social science; selected theoretical papers*. D. Cartwright (ed.). New York: Harper & Row.

Louw, D.A., Van Ede, D.M. & Louw, A.E. 2002. *Menslike ontwikkeling. 4de uitgawe*. Kaapstad: Kagiso Tersiër.

Mackewn, J. 2007. *Developing Gestalt counseling- a field theoretical and relational model of contemporary Gestaltcounseling and psychotherapy*. Londen: Sage publications Ltd.

Maree, K. & Van der Westhuizen, C. 2009. *Head start in Designing research proposals in the social science*. South-Africa: Juta& company Ltd.

Maree, K. & Pietersen, J. 2010. Sampling. (In Maree, K. (Ed.) 2010. *First steps in Research* (5th Ed.). Pretoria: Van Schaik, p. 172-180.)

Monroe, J. 2001. Cystic Fibrosis: Perspective on disease and illness. Capstone Press, p.1-64

Mouton, J. 2005. *How to succeed in your master's & doctoral studies*. Pretoria: Van Schaik.

Mwamwenda, T.S. 2004. *Educational Psychology: An African perspective*. Heinemann Higher and Further Education Ltd.

National Heart lung and blood institute. Disease and conditions index.

http://www.nhlbi.nih.gov/health/dci/Diseases/cf/cf_what.html. Date of access: 4 July 2011.

Nieuwenhuis, J. 2010a. *Introducing qualitative research*. (In Maree, K. (Ed.). 2010. *First steps in Research* (5th Ed.). Pretoria: Van Schaik, p. 47-66.)

Nieuwenhuis, J. 2010b. Qualitative research designs and data gathering techniques. (In Maree, K. (Ed.) 2010. *First steps in Research* (5th Ed.). Pretoria: Van Schaik, p. 70-92.)

Park, A. 2004. 'What makes teens tick?'. Time Magazine, 7 June, p. 50-60.

Parlett, M. & Lee, R.G. 2005. *Contemporary Gestalt therapy: Field theory*. (In Woldt, AL & Toman, SM. 2005. *Gestalt therapy History, theory and Practice*. Sage publications.)

Perls, F., Hefferline, R.F. & Goodman, P. 1951. *Gestalt Therapy: Excitement and Growth in the Human Personality*,. London: Souvenir Press.

Perls, F. 1969. *Gestalt Therapy Verbatim*. Real people press.

Powers, S.W. 2008. *Introduction to the special series on cystic fibrosis: Viewpoints on clinical trials, genetic screening, and behavioural medicine*, Children's Health Care 37: 1-4.

Quittner, A., Barker, D.H., Kristen, K. & Grimley, M.E. 2009. *Cysticfibrosis: A model for drug discovery and patient care*. (In Roberts, M.C. & Steele, R.G. (Eds.) 2009. *Handbook of pediatric psychology* (4th Ed). New York: Guilford Press, p. 271-286.)

Quittner, A. 2010. *CF Research Shows Importance of Mental Health*, September 2010, p. 1-2.

Reber, A.S & Reber, E.S. 2001. *The penguin dictionary of psychology*, (3rd Ed), wik.ed.uiuc.edu/index.php/schemas. England: Penguin.

Roberts, M.C. & Steele, R.G. (Eds.) 2009. *Handbook of pediatric psychology* (4th Ed). New York: Guilford Press.

Strydom, H. 2000. *Maatskaplike navorsing diktaat vir MWKG 321-411*. Potchefstroom: Universiteit vir Christelik Hoërondewys.

Strydom, H. 2011. *Ethical aspects of research in the social sciences and human services professions*. (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delpont, C.S.L. 2011. *Research at grass roots: For the social sciences and human service professions* (4th Ed.). Pretoria: Van Schaik, p. 113-129.)

The South African Cystic Fibrosis Association. www.sacfa.org

University of Michigan Health System. 2008. *Children with Chronic Conditions*. <http://www.med.umich.edu/yourchild/topics/chronic.htm>.

US Department of Health and Human Services. 2011, *National heart, lung and blood institute*. www.nhlbi.nih.gov/.

Van Aalderen, W.M., Mannes, G.P., Bosma, E.S., Roorda, R.J. & Heymans, H.S. 1995. Home care in cystic fibrosis patients. PubMed PMID: 8526136. 20 p. 378 & 535-537. <http://www.ersj.org.uk/content/8/1/172.full.pdf>

Van der Merwe, M., & Kassan-Newton, K. 2007. *Conservation of Resources: A Primary intervention for continuous traumatic stress in South Africa*. *Social Work*, 43(4): 350-365.

Whittaker, A. 2009. *Research skills in social work*, Glasgow: Learning Matters.

Wikipedia. 2011. Spiegelberg, H. 1975. *Doing Phenomenology: Essays on and in Phenomenology*. en.wikipedia.org/wiki/Herbert_Spiegelberg. The Hague: Nijhoff, p. 1-290.

Woldt, A.L. & Toman, S.M. 2005. *Gestalt therapy: History, theory and practice*. USA: SAGE, p. 41-78.

Yontef, G. 1993. *Awareness Dialogue and process: Essays on Gestalt Therapy*. www.gestalt.org/yontef.htm. Highland New York: The Gestalt journal press.

Section B: Article

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Reference list: Full references should be given at the end of the article in alphabetical order, using double spacing. References to journals should include the authors' surnames and initials, the full title of the paper, the full name of the journal, the year of publication, the volume number, and inclusive page numbers. Titles of journals must not be abbreviated. References to books should include the authors' surnames and initials, the year of publication, the full title of the book, the place of publication, the publisher's name. References should be cited as per the examples below (please note the absence of punctuation):
Haynie DL (2000) *The Peer Group Revisited: A Network Approach for Understanding Adolescent Delinquency*. PhD Thesis, Pennsylvania State University, Pennsylvania, USA
Louw J (1990a) Comorbidity of conduct and anxiety disorders. *Southern African Journal of Child and Adolescent Psychiatry* 5: 43–51
Louw J, Mkize AC and Naidoo DH (1990) Cultural disorders. In: Isaacs S (ed.), *Psychiatric Disorders in South African Children*. Cape Town: Juta & Co. pp 84–96
McRoy RG, Grotevant HD and White KL (1988) *Openness in Adoption: New Practices, New Issues*. New York: Praeger Publishers
PRB (Population Reference Bureau) (2002) Untitled fact sheet. Available at: http://www.prb.org/content/navigation-Menu/Other_reports/2000–2002/sheet1.html. [Accessed 22 February 2002]
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style.

Manuscript format: All pages must be numbered consecutively, including those containing the references, tables and figures. The

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important keywords (preferably <10 words).

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author must be indicated. The authors' respective addresses where the work was done must be indicated.

An

e-mail address, telephone number and fax number for the corresponding

author must be provided.

Abstract: For data-based contributions, the abstract should be structured as follows: *Objective* — the primary purpose of the paper, *Method* — data source, subjects, design, measurements, data analysis, *Results* — key

findings, and *Conclusions* — implications, future directions.

For all other contributions (except editorials, letters and book

reviews) the abstract must be a concise statement of the content of the paper. Abstracts must not exceed 200 words. It

should summarise the information presented in the paper but

should not include references.

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in the manuscript. Format headings as follows: **First Level**

heading. Second level heading. Third level heading. Fourth

level heading: Followed by the text in the same line.

Referencing:

References in text: References in running text should be quoted as follows: Louw and Mkize (1990), or (Louw 1990),

or Louw (1990, 1991a, 1991b) or (Louw and Mkize 1992),

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subsequent citations. Note, however, that all authors are

in which they are to appear, must be on a separate sheet of paper with the table number and an appropriate stand-alone caption.

Tables may include up to five horizontal lines but no vertical lines.

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chronologically as referred to in the text using Arabic numerals. Figures must not repeat data presented in the text or tables. They must be executed in black on a clean white background. Figures can be submitted in the following

electronic formats: TIFF, PDF, EPS or JPEG. Particular attention should be paid to the proportions of illustrations so that they can be accommodated in the 140 mm column width. Graphs and histograms should preferably be twodimensional

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Research paper

The experience of South African adolescents with cystic fibrosis: An exploration of their bio-psychosocial field

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Objective: The study was conducted to explore the risk factors and protective variables in the bio-psychosocial fields of adolescents living with CF.

Method: Participants included adolescents in the middle and late adolescent years in the age group 15-22 years who had the defining characteristic of CF and were living in Gauteng Province. It was deemed that data saturation has been achieved after inclusion of six participants when themes repeated consistently.

Results: Through the researcher's lens themes were identified that emerged from each individual interview. An integration of the themes of all participants was discussed. The fundamental human need to be understood and to understand was negatively affected as the illness impacted socialization and learning. They experienced an array of emotions including loss and bereavement when friends with CF died. Constructive internal dialogue and positive thinking emerged as protective variables. Participants generally showed awareness of how they regulated their contact with the illness and how they self-regulate. Despite the severity of their symptoms and the taxing demands of managing CF, participants still expressed hope for their futures and could find some meaning in the illness.

Conclusion: Adolescents with CF who participated in this study indicated that they felt different from their peers. Apart from the general developmental tasks typical to adolescence they faced the challenge of managing a severe chronic and potentially terminal illness. Themes were identified regarding the impact of CF on their faith, and also regarding resources such as time and finances.

Keywords

Cystic fibrosis; Gestalt Field theory; Conservation of Resources theory (COR); Bio-psychosocial theory; organismic self-regulation and awareness

1. Introduction

Cystic fibrosis (CF) is a chronic, incurable illness which affects the entire body, but with special impact on the lungs and digestive system (Cystic Fibrosis Foundation 2011). A review of relevant literature revealed that interventions regarding CF often focus mainly on the medical condition (Cystic Fibrosis Foundation 2011, Ekvall and Ekvall 2005, Harris and Super (1991), including aspects such as patient care (Quittner, Barker, Marciel and Grimley 2009) and medical assessment/screening (Powers 2008). This tendency has been confirmed by the researcher's own experience with her sister (now 22 years old) who has CF and where medical care was the main intervention. No literature could be found on the experience of adolescents with CF (Dumont and Provost 1999). Research is needed on the risk and protective variables in the field of adolescents with CF from their own perspectives, because it seems essential to hear the voices of this vulnerable group.

It is difficult to estimate an accurate figure of people having CF worldwide, but there are around 30 000 people with CF in the United States of America, over 7 500 in the United Kingdom and approximately 30 000 in European Union (Cystic Fibrosis Worldwide 2011; Ekvall and Ekvall 2005). There is currently no conclusive database of CF patients in South Africa, although information from the three regional CF associations indicates that there are currently about 700 people with CF in SA. In the 1950s few children with CF lived to attend elementary school, but today advances in research and medical care have further enhanced and extended life expectation for people with CF who can now expect to live into their 30s, 40s and beyond (Cystic Fibrosis Foundation 2011). There are approximately a 1000 new cases diagnosed worldwide each year; more than 70% of patients are diagnosed by the age of two years; more than 45% of the CF patient population is older than 18 years and mid 30s is the predicted median age of survival for a person with CF (Cystic Fibrosis Foundation 2011; US Department of Health and Human Services 2011).

The relevant theoretical paradigm for this study is predominantly *Gestalt* Field theory (Kirchner 2000) with the assumption that everything is of a field (Woldt and Toman, 2005; Yontef, 1993; Perls, Hefferline and Goodman 1951) and that human beings

constantly configure their experiences within their environment. Conservation of Resources (COR) theory will also be incorporated because it offers a psychosocial approach to people exposed to continuous, repetitive stress (Van der Merwe and Kassan-Newton 2007). The interest of this study is the interplay of risk and protective variables in the internal and external fields of adolescents with CF. No literature was found linking CF with Gestalt field theory. This research should expand the existing knowledge on this link, thereby contributing to building a *Gestalt*-related theory related to a special area, namely CF. It is hoped that these research results will expand the knowledge regarding CF in adolescents within a Gestalt field perspective.

From a bio-psychosocial perspective, understanding the risk and protective factors in the fields of adolescents with CF is a first step in the appropriate management of this chronic disease. If adolescents with CF are not supported adequately, based on a solid understanding of the risk and protective variables in their field, they may fall into negative resource loss cycles (Van der Merwe and Kassan-Newton 2007; Hobfoll, Dunahoo and Monnier 1995:350-361) with non-adaptive or non-constructive coping efforts.

2. Method

2.1 Participants

Sampling was used to select a portion of the population for the study. Purposive sampling was employed, meaning that participants were selected because of a defining characteristic that makes them the holders of the data needed for the study (Maree and Van der Westhuizen 2009). The researcher interviewed adolescents in the middle and late adolescent years in the age group 15-22 years (Dumont and Provost 1999), living in Gauteng and sharing the defining characteristic, i.e. CF. This broad age group was selected because of the small numbers of people with CF. Participants were included until themes were repeated and it was deemed that data saturation was reached. Six participants were included, three female and three male, all at different stages of CF. Five participants were Afrikaans speaking and one was English speaking. Four of the interviews were conducted in a hospital and the other two at private homes.

2.2 Design

The research design was a case study (Fouché and Schurink 2011, Nieuwenhuis 2010b) and focused on exploration and description of risk and protective factors in the fields of adolescents with CF. This research was exploratory in nature in order to gain insight into a situation, phenomenon, community or individual (Fouché and De Vos 2011). It was also descriptive, as it provided specific detail of the unit of analysis (Fouché and Schurink 2011), outlined as themes emerged from the collected data.

2.3 Data collection

A literature review was conducted to scan the field of research in order to ensure that this research was feasible and would not duplicate previous efforts. Semi-structured interviews of about 90 minutes were conducted as method of collecting data. The questions asked was open-ended. During the interviews the risk and protective factors in the internal and external fields of participants were described by the participants themselves. Literature control, as a form of data triangulation, was done after themes were identified.

2.4 Data analysis

Videotape recordings of interviews were transcribed and subjected to thematic analysis as described by Whittaker (2009). Most of the identified themes can be categorized within the risk and protective continuum as will be described in the next section.

3. Results/key findings

3.1 Faith

3.1.1 Risk factors

Participants had questions about their medical condition linked to their faith, such as: Why me? These questions link with the search for meaning regarding suffering, which lies on the religious-existential level. Victor Frankl (1963) says: 'He who has a why to live for can bear with almost any how'. Despite the fact that some participants had the 'why me?' question, it was observed that other participants had an answer to this question, making the 'how' in other words the management of their illness, more bearable for themselves, thus proving Frankl's statement.

3.1.2 Protective variables

The polarity regarding the faith theme was that five of the participants indicated that while they had questions in the faith domain, faith was also a major protective variable, as indicated by the following statements:

'I would not have been able to do it without Him. He helps me so much.'

There are also indications of how participants could find meaning in their plight, as illustrated by the following:

People have asked me if my life would have been better without CF. No, because without CF I would not have been the person I am today. I think the Lord gave me a talent for sport and CF in order to use me one day on a bigger scale. I see CF as a challenge given to me by God.

The above is in line with Frankl's observation that the human spirit can transcend sickness in the body. Frankl also viewed a healthy spiritual core as a resource for healing (Frankl 1963). Clearly, faith offers a potential non-tangible resource on a

personal level and it may aid constructive coping (Pediatrics 2002). According to Corey (2005) faith fits in with the existential-phenomenological approach of Gestalt theory as it focuses on the individual's perception of reality. It was certainly part of the reality of research participants and offered support for Browell's (2002) observation that it is not possible to exclude the faith component from the Gestalt field.

3.2 Daily routine and time

3.2.1 Risk factors

Cystic fibrosis is a disease for which there is no known cure and the goals of treatment are to alleviate symptoms, slow the progress of the disease, prevent complications, and thereby increase the quality of life for the CF patient (Bilton 2008). One need of people with CF is to have time for rest and idleness. There is a sad contradiction in the group of participants where they are forced to be idle in order to undergo medical procedures, but where it is not connected to rest. They are in a sense trapped while linked to either oxygen machines, nebulizers or receiving physiotherapy. Hobfoll et al. (1995) outline four categories of resources of which energy resources include aspects such as time. It was clear that dealing with the medical aspects of CF is time-consuming. Four out of the six participants indicated that aspects such as nebulizing, exercising, physiotherapy, cleaning machines and taking medication (some take up to 12 pills with each meal) has an impact on their time. Participants indicated how the taking of medication during sport events and camps are difficult because of the perceptions of other people and also because of their own sensitivity concerning the amount of medication they have to take.

Monroe (2001) refers to aspects in the routines of adolescents with CF that impact their learning for example, missing school due to doctor's appointments and tiredness preventing them from engaging in school work. This tendency was also clear from the accounts of participants. Max-Neef (1991) refers to understanding as a fundamental human need that includes the need to learn and obtain a qualification. Medical care clearly impacted this human need of the participants since their learning was adversely affected by often having to spend time in hospital, or being caught up in medical

procedures. Participant 1 indicated how difficult it was to have to leave hospital for short periods to write matric examinations. Participant 3 had to start with home schooling due to the illness. Heather (1998:1) describes a 16-year old person's perception of the impact of her illness, which concurs with what was conveyed by the participants in this study: 'I don't go to school, I'm on homebound, due to all the sicknesses that goes around, so goodbye to socialization. I don't have many friends because people either see me as *nasty* or they just slowly leave my life'. Many people with CF are concerned about symptoms that affect their image, particularly during adolescence (Heather 1998). The danger is that they may start to isolate themselves and, in doing so, limit their access to the much needed social support that can potentially be offered by the peer group. It is clear that participants have to adhere to strict medical routines and procedures, but at the same time it is also clear that these interventions have a serious multi-dimensional impact on their functioning in the areas of learning, socialization and overall time allocation.

3.2.2 Protective variables

Participants also indicated how the medical procedures fitted in with their routines. It was obvious how early their days start in order to adhere to the medical procedures. Participant 5 gets up at 05h00 in the morning to start with medical care. A protective factor in his functioning is his engagement in positive self-talk:

'When I lie on my bed by the end of the day, thinking about all the things I had to do, I think to myself that I am awesome.'

Girlfriend (2005) agrees that positive self-talk can be a constructive coping skill with thoughts such as 'I am a bright and wonderful person, I bring good things to this world and good things come my way.' Internal dialogue refers to dialogue that takes place between aspects of the self (Mackewn 1997). It appears to be a process that helps to resolve contradictions between external demands and internal needs and can be helpful in supporting positive thinking in adolescents with CF. It was also clear how participants

managed their time in order to bring in synergic satisfiers (Max-Neef) where more than one need was satisfied at the same time, e.g. Participant 6 who watches television while nebulizing, thereby attending to the need for rest and idleness while also looking after her health.

The adolescent developmental stage can be one of the most difficult transitions of life when, according to Wright (2003), internal resources such as doubt of self and inferiority can be impacted negatively. Joyce and Sills (2010) describe the process of continuous contact between organisms and their field where there should be ongoing mutual regulation as the conditions in the field constantly change. Within this process people should, ideally, adjust to the challenges in the internal and external field in a creative manner. In the contact with the field there is constant configuration of experience and needs are met and managed in many different ways. Such responses may flow from awareness, be habitual and effective, or it can be a habitual response which has become outdated for particular situations. Within the Gestalt paradigm it was previously theorized that contact boundary disturbances may develop, such as introjections, where people incorporate contents from the environment without criticism or awareness (Joyce and Sills 2010, Blom 2004). According to Clarkson such introjections interfere with natural organismic self regulation and lead to the development of unfinished business (Clarkson 1989) or fixed Gestalts (Joyce and Sills 2010). Joyce and Sills (2010:113) refer to 'modifications to contact' as 'simply creative adjustments to the challenges of being in the world'. Clearly, adolescents with CF should ideally be aware of their own processes, be in contact with their internal and external field and how they regulate such contact with the challenges of their illness.

3.3 Emotions

3.3.1 Risk factors:

Various emotional reactions to the losses which are linked to CF were outlined by participants. CF is part of each participant's phenomenology, because having CF is part of their perception of reality (Corey 2005). Participant 1 said:

'You miss out on so much! Activities, social life, school. I tried to go to school with my drip and going out to the movies with oxygen, but people are funny– I did that once and never again.'

Participant 3 said:

'You need to adapt to get used to using oxygen. This also is time consuming: 24 hours a day, 7 days a week. You are uncomfortable to walk around with the oxygen and let others see you with it and know about your illness.'

Participants mentioned that they felt isolated and also tried to hide their illness from others in order to avoid rejection, sympathy and judgment. Participant 5 says:

'People don't think before they speak; the smallest thing they say can lead to self pity, because you take the smallest thing they say as directed at you.'

In Gestalt field theory human behavior is the function of the person and the environment. A person's behavior is related to personal characteristics and the social context (Yontef 1993). Adolescents' self-worth generally depends significantly on peer acceptance. They need self-image validation by others and their identities are shaped by how others see them (Wright, 2003). Participant 1 was falsely accused of using drugs at school when he took his Creon medication. (Creon is a medication used to replace enzymes when the body does not have enough of its own, as is typical with CF) (Drug.com 2011). Participant 5 elaborated on the impact of other people's reactions by pointing out that, apparently, adolescents with CF are not interesting enough for their peers because they cannot smoke or use alcohol. The impact from the field is clear and leads to various other emotions as described by participants, such as a feeling of powerlessness.

Loss was also part of their experience. Participant 1 indicated that he had almost all of his most important birthdays (16th, 18th, and 21st) in hospital. Participant 2 related how she missed out on so much due to frequent hospitalization, stating that having CF is

definitely not exciting and leads to feelings of discouragement. A sense of loss emerged when Participant 2 indicated that both her sisters will graduate next year and further saying that:

'It is not normal; you need support and it feels as if you have a bit of a disadvantage. It is give and take, compromise.'

Participant 3 said:

'I get cross when people tell you how sick they are, but then it's just a running nose; I can't even breathe normally without oxygen.'

Participant 4 indicated an awareness of the progression of the illness stating that the decline began after leaving school.

'Suddenly you are ill, you can't do much or anything anymore, you can't even do the things at home you're used to doing.'

Participants suffer bereavement when friends with CF die. Participant 4 indicated a need for a lung transplant and had an acute awareness that she could not lead a normal life:

'I am not scared of dying; but I am sad when I think how everybody staying behind is going to feel. I don't want to feel I can't do anything. There are days that's difficult: you feel down, asking why, how long, how much worse it's going to get.'

Participant 6 spoke about negative emotions, such as irritation, arising when people tell him what to do:

'My mom usually said I must...and then I am like, do I have to?'

Two participants also spoke of negative feelings about medical intervention when it seemingly does not help to improve the condition and feelings of guilt when treatment is neglected. Participant 5 indicated that he is prone to mood swings.

It is clear from the above that living with CF leads to many taxing emotions and Oaklander (2006) says that expression of emotions is not comfortable for many people. The illness seems to overwhelm the ordinary functioning and impacts on quality of life. This is in line with Monroe's (2001) observation that CF affects the emotional functioning with affect such as feeling anxious, sad, angry and scared.

3.3.2 Protective variables

It was clear during interviews that participants also experience positive emotions. They stated that laughter and humor is helpful. This is in line with Frankl's (1963:106) observation during his own suffering in a concentration camp when he stated that 'Humor was another of the soul's weapons in the fight for self-preservation.' When participants experience success, such as completing matric successfully, it leads to happiness and they find support for positive emotion from family, friends and religion. The benefits of humor were acknowledged as far back as the book of Proverbs in the Old Testament, in verses such as: Prov. 17:22: 'A cheerful heart is a good medicine...'

Participants expressed positive emotions such as acceptance of the fact that it is not their fault; and acknowledging that they have to learn to deal with it, implying that they must make the necessary mind shifts. Some took a philosophical stance and feel that such things happen to people and that they need to take responsibility for themselves. They also seem to realize the importance of health and body. Participant 5 proclaimed the importance of having mental toughness when dealing with CF. Monroe (2001) mentions that those affected by CF typically learn self-discipline and how to use humor and a positive attitude as coping mechanisms. This seems to be true of all participants.

Within the Gestalt theoretical paradigm it is believed that the self should be empowered to take self-care and also to gain emotional awareness. Yontef (1993:33-34) rightly states: 'Awareness is accompanied by *owning* the process of knowing and control over, choices and responsibility for one's behavior and feelings.' It was clear that the participants generally had awareness of how they regulated their contact with the illness and how they self-regulated. The essence of Gestalt Therapy is that people should take responsibility for their own lives (Clarkson 1989), like most of the CF participants have already done to a great extent. It is, however, important to take heed of the observation of Joyce and Sills (2010), namely that people can bury aspects in the 'ground structure' out of awareness. It can be of value to facilitate processes to help adolescents with CF to become more aware of the patterning and templates formed in their configuration of experience with CF.

Perls (Mackewn 1997) describe responsibility as the ability to respond. Participant 5 is aware of his condition, owning it and taking responsibility. He values positive actions such as exercising in order to excel in sport and also encouraging words, for instance when others tell him that he is an inspiration. He also finds it inspiring to see how other CF sufferers live successful lives. Monroe (2001) mentions that it is not uncommon for CF sufferers to try and live full lives. In this regard Participant 6 indicated that he deals with life as it goes and can then get excited about everyday life, going to school and to be with friends. This attitude is in line with Beisser's (1970) observation that change comes when the individual starts to accept his/her reality without trying to change it.

3.4 Hospitalization

3.4.1 Risk factors

Each year, one in three patients with CF is hospitalized, mostly for treatment of 'pulmonary exacerbations' caused by an infection requiring intravenous antibiotics (ATS- American Thoracic Society). Although there are obvious risk factors linked to hospitalization, it was apparent when interviewing four participants in hospital that they were mainly positive and tried to constructively deal with hospitalization. However, it

was clear from the discussions with participants that hospitalization was also difficult and taxing. The following aspects were especially prominent:

- Spending months in hospital and feeling as if they miss out on life
- Sorting out hospital accounts
- The financial burden on their families
- Medical procedures such as getting a drip fitted
- The quality of the food
- Hospital routine (e.g. having to wake up at about 04h00 in the morning)
- Medication which is seemingly not working
- Loneliness and boredom
- Uncertainty about time of release from hospital

It was evident that hospitalization entailed dynamics that was out of the participants' control, leading to a sense of powerlessness. In this regard Monroe (2001) refers to the importance of good communication between doctors and CF patients so that treatment protocols are understood by the patient and they know what to expect.

3.4.2 Protective variables

Participants also recognized the positives regarding hospitalization where hospital staff did their best to make them feel comfortable. They mentioned that they could foster good relationships with nursing staff that cared for them physically and also provided emotional support.

Participant 2 viewed hospitalization as an opportunity to talk to people about her religious beliefs. She mentioned activities that can be helpful during hospitalization, such as playing board games, reading, positive thoughts e.g. thinking about a lung transplant, having visitors, resting, engaging in crafts and selling those products for an income. This participant actually addressed many of the nine fundamental human needs

described by Max-Neef (1991), i.e. creativity, participation, spirituality, and also rest and idleness.

She refers to action which refers to creative adjustment in the cycle of awareness moving from conformity to healthy self-regulation (Woldt and Toman 2005).

It is clear that although hospitalization is necessary at times and adds to the medical care, it is often strenuous. Van Aalderen, Mannes, Bosma, Roorda and Heymans (1995) emphasize that an alternative such as home care can be as effective as hospital care and mentions that it is not all that difficult to put into practice. It is possible to apply intravenous antibiotics and enteral tube feeding at home for the treatment of pulmonary exacerbations and underweight conditions. Home care is less expensive and less intrusive. More research from a medical point of view is needed on home care in the context of CF, but also on the bio-psychosocial impact of such an intervention.

From the above it seems to be important to be aware of resource loss and gain spirals (Hobfoll et al. 1995) in the fields of adolescents with CF. When constantly monitoring the interplay of energy, object, personal and condition resources, also incorporating the fundamental human needs, it can be noted timeously when these adolescents slip into spirals of resource loss. Interventions such as home care can be an important impetus to facilitate gain spirals.

3.5 Health and body

3.5.1 Risk factors

There were many risk factors in terms of 'health and body' of participants. While there is no cure for CF, various treatments can help to improve breathing and digestive problems. The goal of treatment is to avoid lung and other body system damage. This slows the progress of the disease and helps the person lead a normal life (Monroe 2001). Participant 6 indicated the effect of CF over the life span. Ryan (2001) outlines the concept *chronosystem* as conceptualized by Bronfenbrenner. The *chronosystem* refers to the dimension of time as it relates to a person's environment. It can either be

external or internal; as people get older they react to environmental change differently and may be more aware of how change influences them. One participant was merely two months old when he had his first port put in (a port-a-cath is a small medical device inserted beneath the skin. It is connected to the vein via a catheter. Through a septum blood samples can be drawn and medications can be administered (<http://www.aboutcysticfibrosis.com/port-a-cath.htm>). This participant also stated that a blood clot passed through his brain due to the illness and certain medical procedures and that this affected the language part of his brain. From this it is clear that there will always be uncertainties and possible complications with medical procedures that are CF related. Such medical complications impact the life stories of participants and forms patterning in the *chronosystem*. If participants could talk through the lifetime of complicated medical procedures and the physical scars of such procedures a life narrative will possibly emerge, accompanied by affect and more risk and protective factors. More research can be done on embodiment, and of scars carrying information on the life narrative.

Struggling to breathe was another taxing symptom for participants and oxygen therapy is indicated. There are different degrees of oxygen therapy – some people need it when they exercise or when sleeping. Others need it almost constantly. Participants 1, 2, 3 and 4 had to be on oxygen almost constantly and mentioned intense tiredness. They described it as difficult to be on oxygen so often.

Some CF patients struggle to get their body weight up as CF negatively impacts absorption of nutrients. Patients would therefore need a high-calorie, high-protein and high-fat diet (Monroe 2001). Participant 3 mentioned that eating is a struggle. In order to support feeding a peg can be put in the stomach of a patient for feeding purposes, similar to intravenous feeding. The impact of CF on the body is clear, since medical procedures such as a peg or ports are invasive.

One symptom of CF is thick mucus in the lungs, obstructing the airways. Infection can be caused by bacteria that grow as the chronic lung condition develops (Kidshealth.org 2011). The impact of coughing was mentioned by participants. Sleeping can be problematic as indicated by some participants who mentioned interruptions to sleep due

to coughing or medical procedures. Coughing worsens when they have infections. Four participants indicated that they feel tired even when they had a good night's sleep. Exercise is an important part of-cystic-fibrosis-treatment because it may improve the breathing muscles and strengthen the heart, while also loosening mucus in the lungs (Monroe 2001). However, participants indicated that they were usually too ill to exercise or very tired after exercising.

Participant 5 mentioned the constant attention to the symptoms of CF:

'With CF, it's the smaller things; if you do the right things, you won't have a problem, but if you neglect it, you really struggle to get back.'

Self-image, an individual's perception of the self, becomes particularly important during the adolescent years and can be impacted negatively when the physical appearance is altered. According to Berk (2000) physical attractiveness is an important factor in adolescence, with strong links to self esteem. Further studies should be done on this particular impact of CF as the physical appearance of CF patients is impacted by the illness and/or medication (Boyse, Boujaoude and Laundry 2008).

It is clear from the above that CF severely impacts the body and that the medical and other interventions such as exercise are often so taxing that participants find it difficult to follow prescribed procedures and treatments. If they do not follow such treatments they end up in a negative downward spiral with serious implications for the management of CF. Van der Merwe and Kassan-Newton (2007) also talks about a downwards spiral, where exposure to continuous stress can lead to general interpersonal resources loss (Van der Merwe and Kassan-Newton 2007). Living with a chronic illness will also influence the other resource domains of condition, energy and object resources. It is crucial to also assess protective variables linked to health and body as these aspects can incorporate gains which can lead to resource gain spirals.

3.5.2 Protective variables

Lung transplants are a last resort for some people with cystic fibrosis (Monroe 2001) and although it has many benefits, it has psychological, social, medical, and financial implications. In discussing lung transplantation, Trulock states: 'Lung transplantation is a treatment, not a cure, and it is not panacea. Lung transplantation for CF patients involves trading part of one disease for an entire second disease.' (CHEST 1998:113). However, Participant 1 mentioned that a lung transplant had a remarkably positive effect, saying that he felt like a different person.

Participant 5's lung function is still 98%. He is doing very well, being active and trying to take control over his health. As mentioned, exercise can be an important protective factor. An exercise program should be well planned and supervised. People with CF usually are encouraged to choose exercises such as swimming, biking, running, weight training, and bouncing on a trampoline. Extra fluids and salt is needed when CF patients exercise (Monroe 2001).

Other helpful medical interventions that support the body are:

- Chest Physical Therapy (CPT). CPT is needed one to three times a day. CPT takes about 30 minutes to complete. It loosens and thins out the thick mucus in the airways.
- Many people with CF inhale different types of drugs by using a nebulizer. This machine turns liquid medicines into a mist. People breathe in the mist for about 15 to 20 minutes. The mist goes deep into the lungs (Monroe 2001).
- Physiotherapy can be helpful to manage mucus and the breathing cycle.
- The following will all support the body: yearly flu shots, more fluid intake, avoidance of smoking, yearly assessment for diabetes and taking vitamins and minerals (<http://www.aboutcysticfibrosis.com/port-a-cath.htm>).

Whereas the expected life span of CF patients was previously short, many more people with CF are currently living longer, fairly normal lives. (Monroe 2001). Perls (1967) states 'it is possible to discover means and ways whereby you can grow and develop

your potential and iron out difficulties in your life.’ CF patients also need to iron out the challenges of living with CF, and it seems as if the participants are finding many different ways to deal with the illness. In this regard, Participant 6 indicated that he took responsibility for the management of the illness ever since he was about ten years old. Obviously, these adolescents have to face serious responsibilities at a young age. Perls et al. (1951) said that a person’s behavior can be understood when all the dimensions of this person is taken into account. The whole-person concept implies a holistic outlook including feelings, behavior, body, dreams, thoughts and environment; in other words, the internal and external field.

3.6 Family, friends, support structure and socializing

3.6.1 Risk factors

It is important to assess the ways in which CF affects the lives of people in the field of adolescents with CF, such as family and friends, and to ensure that they get adequate support. It was clear from the discussions with participants that their illness has an impact on the time and other resources of family members. Sometimes families even needed to relocate to get better medical care for the family member with CF. Participants 1 and 5 mentioned that their family members spend a lot of time to help with medical procedures and to transport them to where they have to be. They also mentioned the financial implications of the illness. Participant 2 referred to the financial implications of obtaining good treatment which impacts negatively on the overall financial situation of the family.

There is clearly also an emotional impact on family members. Participant 6’s mother had a nervous breakdown because of the implications and challenges of CF on the family. It is clear that people with CF and their families often experience high levels of stress.

In field theory of Gestalt, human behavior is the function of the person and the environment (Yontef 1993). Parents are a significant part of the field of adolescents with

CF and as such they also form part of the micro system from where there are immediate and direct mutual interaction, influences and contact. The theoretical paradigm offered by the Bio-ecological Systems Theory of Bronfenbrenner (Christensen 2010) presents a framework to understand the interplay within the field of the adolescent with CF by looking at the complex dynamics in and between the different systems from micro level to macro level (Bronfenbrenner 1979).

3.6.2 Protective variables

Monroe (2001) mentions the value of support from parents, other family members and friends. From the information provided by participants it was evident that family offer support and motivation. Participant 2 expressed gratitude for the way her parents handled her illness. They mainly understood pressure from their parents to adhere to medical procedures, diets and other interventions as being 'for the better', although it caused irritation and frustration at times. The father of one of the participants was her ultimate motivator, and two other participants referred to the support of their mothers. The following statement by a participant indicated the value of family support:

'The time my father spends with me he has given fully. I appreciate him very much, because without him I wouldn't have been who I am today. My dad is the driving force behind me and my mother helps with things like food. My brother, with his positive words of how well I am doing is also helping a lot. I have a team behind me; without them nothing would have been possible.'

Although Monroe (2001) points out that siblings of patients with CF can easily feel left out and resent the attention given to the CF patient, participants mainly indicated that they receive good support from their siblings. Participant 2 said that her sisters support her, stating 'They got my back'. Another participant's brother motivates her and her sister is her best friend.

Participants indicated that it is helpful to have close friends. It seems that friends provide emotional and practical support.

Participant 1:

'Going to school and having friends keep your mind occupied and helps you think about other, more positive things.'

Participant 6:

'My friends know that they must slow down, they are all very understanding.'

Participant 5:

'You need friends to help you maintain a positive attitude.'

Participant 3:

'It helps when they ask questions like: How are you?'

Fortunately, according to Woldt and Toman (2005), adolescents move quickly past the egocentric self stage and learn to become aware of their strengths and weaknesses, thus they are more aware of when they need support and when not. Monroe (2001) cautions that not all friends will be able to cope with a condition like CF. Interventions with adolescents with CF will have to incorporate ways for them to cope with the influences from their field, especially regarding the significant peer group.

Social support is a well-known protective factor and five of the participants indicated the value of such support from other CF patients. Monroe (2001) agrees that such support from others with the same condition is helpful, as they share a special bond and have inside knowledge about living with CF. Support of this nature like this also fulfills a fundamental human need regarding understanding as pointed out by Max-Neef (1991).

Participant 5 used the metaphor of a survival chain incorporating faith, friends, family, sport and other activities, perseverance and positivity. He also referred to the valuable input of his doctor and that of other patients. From this it is clear that resources on personal and condition levels can support coping.

3.7 The subjective experience of CF

Participants are wondering what life would be like living as a normal person. Kirchner (2000) said: 'There is no self independent of field or contact; it is rather something given in contact that comes to life in the encounter with the world.' When CF patients compare their lives to others in the field around them or in the world, they feel different. One participant mentioned how people look at her when she is coughing. It is a sad reality that CF can impact negatively on the desire of adolescents to fit in and to be like their peers. Participants feel that cystic fibrosis makes them different from other adolescents as stated by Participants 4 and 2:

'There comes a time that you feel you don't have a normal life.'

'Using oxygen 24 hours a day reminds you of not being normal. This was something I needed to deal with' (Participant 2).

Individualization is an important principle when trying to understand the bio-psychosocial field of adolescents with CF. The personal experience of each participant came to the fore when they were asked what would, according to them, be an accurate comparison with CF. They generally used metaphorical comparison and their answers are given in Table 1 below:

Table 1: Metaphorical comparisons to CF according to the participants

| Participants | Comparison |
|---------------------|--|
| Participant 1 | It's like a lion and a lamb. You are the lamb, you need protection, you are fragile and CF is like the lion that wants to attack you. |
| Participant 2 | It's like a tumble-bug, you have this dung you need to roll, even if you don't want to, you need to, although it's dung, it's part of you. |
| Participant 4 | CF came like a natural disaster. I only learned of CF the past two years. |
| Participant 5 | It's like Mandela's life. He went through bad things, terrible things |

| | |
|---------------|--|
| | but he got through it. |
| Participant 6 | It's like a butterfly, colorful, each color represents a part of CF. There are lots of colors just like the plenty of division of CF. |

From the above, the different perceptions of participants emerged. It was also apparent how they succeeded in using metaphor to highlight positives and negatives of their illness. Participant 5 clearly tried to make meaning of the experience with CF and indicated that he does not want to be merely another statistic, but wanted to excel and thrive.

A risk factor of some CF patients mentioned by Participant 5 is that people with CF do not easily talk about their illness. They do not admit when it is not going well and will typically say things like: 'it's going awesome' and 'can't go better', while in actual fact it is the complete opposite. Participant 5 has a positive attitude towards CF and life, his motto is: "strewe vir die positiewe" which if directly translated to English means to strive for the positive. Participant 6 made comments along the same lines of those mentioned by Participant 5:

'...CF to me is not really something negative and it doesn't affect my whole life. CF is just like another part of my body. You have it for the rest of your life and now you'll have to deal with it.'

Participant 3 mentioned the following regarding the response to CF by people in their field: *'see a CF patient as you see other people, they just have an illness. Appreciate what you have! I don't want photo's to be send around where I need an oxygen machine...it's just temporary.'*

This last comment also illustrated her desire to be treated as a normal adolescent without stigmatization and without too much focus on the illness. An awareness of having CF is required to be able to take control to find organismic self regulation.

Awareness is defined as being in touch with your existence as individual (Yontef 1993). According to Perls (1976:33) awareness facilitates a state of organismic self regulation—a process whereby individuals self-regulates by recognizing their needs and identifying the manner in which such needs will be fulfilled, thus enabling people to resume control.

3.8 Future

3.8.1 Risk factors

Monroe (2001:36) mentions that people with CF typically worries about the future. They find it difficult to do educational and career planning as they never know when the illness will progress to the extent where their functioning is even more impaired. They also worry about the future of relationships and their ability to get married. Participants mentioned concerns about their futures stating that they think about dying and they articulated concern about those staying behind should they die. They mentioned that their dreams are compromised. Some of them place hope on a lung transplant, but also consider the risk factors of such severe medical intervention.

Despite the mentioned concerns about lung transplantation, participants generally placed considerable hope on this procedure. Shortly after completion of the empirical study one of the participants had a lung transplant. However, there are slight complications and she has been hospitalized in intensive care ever since. This shows the polarities involved in the medical procedures related to CF. Participants cannot survive without these interventions, but the interventions in itself seem to be intrusive, severely uncomfortable and at times overwhelming. Murphy (2002) refers to the positive effects of lung transplantation where people attested to the fact that it changed their lives for the better. More research is needed on the dynamics regarding lung transplants and especially the bio-psychosocial effects of waiting for such a transplant, the effect on future vision thereof and the implications of such a transplant. Despite the severity of their symptoms, participants still verbalized hope for the future and they had ambitions to achieve. Participant 6 indicated, for instance, that he wants to be a mechanical engineer. They also indicated that they are still hoping that a cure for CF will be found. It

emerged from the empirical research that the participants were brave and resilient despite the challenges of their illness.

4. Recommendations

4.1 From the above the following recommendations are relevant

Through all the themes discussed above the following recommendations in relation with risk factors and protective variables, were derived from the information gathered: CF impacts the whole life and field of an adolescent with this chronic illness. Living everyday life with this chronic illness is a challenge and managing CF overall is a difficult task. Patients need to take responsibility to be able to take sufficient care of themselves like taking medication, do daily treatments and maintaining body and health. These mentioned responsibilities are difficult to sustain, are very time consuming and affect the adolescent's daily program every day. It is recommended that their social support should be assessed and expanded. Their formal support system may be expanded to include not only medical professionals, but also life coaches and professionals who can render psychosocial support.

The impact of the medical procedures on their time was of special concern. This impacts the fundamental human needs such as the need to understand and to learn. It is recommended that more attention is given to synergic satisfiers where more than one need is met by the same satisfier. While they are undergoing medical treatments such as nebulizing, a volunteer can, for instance, read and discuss their school work with them. They can possibly recite the content of creative work such as essays while someone else writes it down for them. They need all possible assistance to support their learning.

As the impact of CF on general health becomes more severe, adolescents need to adapt to more intrusive medical procedures. It is recommended that they receive psycho-education on the nature and implications of such procedures. They can also be involved in participatory action research aimed at the development of educational

material for adolescents in their position. They can help with development of other therapeutic aids such as board games to explain the illness to younger family members. As the illness progresses, they need appropriate therapeutic intervention to facilitate processes of integration.

Participants mentioned internal dialogue and positive thinking as adaptive coping skills. More research should be focused on coping with CF. It can be useful to place such research within the structure of the Gestalt cycle of awareness, where those affected work towards completion of Gestalts which will lead to constructive self-regulation.

Williams and Poijula (2002) write about resourcefulness and refer to the classic work of Antonovsky on salutogenesis (wellness). These authors also cite the work of Dunning (1997) who expanded Antonovsky's work with a list of thirteen helpful characteristics; the thirteen C's of salutogenesis which supports coping and resilience. More research can be directed to these characteristics in adolescents with CF; i.e. congruence, control, communication, seeing the illness as a challenge, clarification, using ritual and commemoration, understanding the effect of culture and having connection with others. These characteristics can be expanded to use in assessment and intervention.

The competencies of emotional intelligence (Hughes, Patterson and Terrel 2005) such as personal awareness, problem-solving, impulse control, assertiveness, self-actualization, interpersonal relationships and stress tolerance seem to be valuable constructs that can be expanded in further research in the context of adolescents with CF. By focusing on emotional intelligence these vulnerable adolescents will be assisted to function more effectively in the interpersonal and intrapersonal fields.

It was obvious that risk and protective variables in this study often were on the extremes of the same continuum, i.e. faith being a major protective variable but also an area where questions arose, especially on the level of assumptions and meaning-making. Further research can focus on this interface between risk and protective variables and

explore how to turn resource loss in terms of such aspects into resource gain, e.g. by working through issues on faith level to enhance the supportive function of spirituality.

Hospitalization is an inevitable part of the overall medical care regarding CF. It does, however, have a considerable impact on time and it limits participation in ordinary life. Alternatives such as home-based care should be expanded, also supported by further research on the medical level and in the field of physiotherapy.

Social support is a protective variable and it was indicated as a strong asset by participants. Further research can focus on asset-mapping and Conservation of Resources in the context of CF to expand the interplay of resources in the field of adolescents with CF.

It is indicated that research should also focus on the bio-psychosocial impact of CF on other age groups such as very young children, pre-school children, those in primary school and young adults. CF is a serious challenging illness with possible negative impact on the completion of developmental tasks in the different life cycles. These processes should be better understood and managed.

Intervention research should be conducted to develop intervention strategies for adolescents with CF on individual and group level. Such programs should incorporate work on bereavement and loss. Intervention strategies should also be developed for siblings and parents.

In the school environment information on CF and other chronic illnesses should be incorporated more specifically into life skills programs to sensitize other learners to the challenges of living with such conditions. They can also receive guidance in terms of how to reach out appropriately to adolescents with CF.

In this study it was possible to hear the voices of a vulnerable and possibly neglected group of adolescents. More research should be conducted from a multidisciplinary perspective focused on the multidimensional impact of CF.

5. Conclusion

It is clear that having CF impacts all the resource categories mentioned by Hobfoll et al. (1995). Energy resources such as the financial situation of the families and time are negatively affected by the cost and time-consuming nature of medical care. Object resources such as place where they live are affected when they have to move to be closer to hospitals or medical care. It was, however, also clear that participants managed their internal resources such as sense of hope and optimism to support and strengthen their functioning. Social support is a major protective variable on the level of condition resources. In conclusion, it is apparent that CF influences the whole biopsychosocial field of adolescents with CF, as emerged from the themes described here. Interventions should be directed to all the complicated and diverse aspects of human functioning as they live and develop within their field.

6. References:

About Cystic fibrosis (2011) *What is a Port-a-cath?* Available at:

<http://www.aboutcysticfibrosis.com/port-a-cath.htm>. [Assessed 27 October 2011]

Barich J (2009) *A few thoughts on Martin Buber's I-Thou*. Available at:

http://www.choosingtolive.blogspot.com/2005/01/martin_buber.htm. [Assessed 20 January 2009]

Beisser A (1970) *Paradoxical Theory of change*. Available at:

www.gestalt.org/arnie.htm [Assessed 2 October 2011]

Berk LE (2000) *Child development 5th edition*. Massachusetts. Allyn and Bacon

Bilton D (2008) *Cystic fibrosis*. Medicine 36. pp 273 – 278.

Blom R (2004) *Handbook of Gestalt Play Therapy: Practical guidelines for child therapists*. London: Jessica Kingsley Publishers.

Boyse JRN, Boujaoude LMD and LaundryJMD (2008) Reviewed by faculty and staff at the University of Michigan: *Your child development and behavioral resources*. Updated June 2008. Available at: <http://www.med.umich.edu/yourchild/topics/chronic.htm>

Bronfenbrenner U (1979) *The Ecology of Human Development*. Cambridge: Harvard University Press

Browell P (2002) *Gestalt Global Corporation Gestalt*. Vol. 5:no.3. Retrieved from: <http://www.g-gej.org/5-3/introduction.html> [Assessed 4 January 2009]

CHEST. American College of Physicians (1998) *Lung Transplantation for COPD*
Truclock EP Available at:
http://chestjournal.chestpubs.org/content/113/4_Supplement/269S.full.pdf. [Assessed: November 2011]

Cristensen J (2010) Proposed enhancement of Bronfenbrenner's Development Ecology Model. *Education Inquiry Vol. 1, No.2, June 2010,pp.101-110*. Available at:<http://printfu.org/read/proposed-enhancement-of-bronfenbrenner-s-development-ecology-model-d1e5.html>

Clarkson P (1989) *Gestalt counseling in action*. Dryten ed. London: Sage publishers.

Corey,G (2005)*Theory and practice of counseling and psychotherapy*. United States of America. Brooks/Cole. Thomson learning. Crocker SF (1999) *A well-lived life*. Essays in Gestalt therapy Cleverland,OH: Gestalt Institute of Cleverland Press.

Cystic Fibrosis foundation (2011) Available at:

<http://www.cff.org/LivingWithCF/AtSchool/> [Retrieved: 20 September 2011]

Cystic fibrosis worldwide (2011) Available at: www.cfww.org or

http://en.wikipedia.org/wiki/Cystic_fibrosis. [Assessed 10 September 2011]

De Vos AS, Strydom H, Fouché CB and Delpont CSL (2011) *Research at Grass roots: For the Social Science and Human Services Professions (4th Ed)*. Pretoria: Van Schaik Publishers.

Drugs.com (2011) *Drug information online*. Available at:

<http://www.drugs.com/creon.html>. [Assessed 20 October 2011]

Dumont M and Provost MA (1999) Resilience in adolescents: protective role of social support, coping strategies, self esteem, and social activities on experience of stress and depression. *Journal of Youth and Adolescence* June 28 no.3pp344. Available at: <http://psycnet.apa.org/index.cfm?fa=search.searchResults>. [Assessed 14 September 2011]

Ekvall SW and Ekvall VK (2005) *Pediatric nutrition in chronic diseases and developmental disorders. Prevention, assessment and treatment*. Oxford University Press. United States of America. pp363-368

Fouché CB and Schurink W (2011) *Qualitative research designs*. In DE VOS AS, Strydom H, Fouché CB and Delpont CSL (Eds.) (2011) *Research at grass roots: For the social sciences and human service professions (4th Ed.)*. Pretoria: Van Schaik. pp320-323

Fouché, C.B. & De Vos, A.S., 2011, Formal formulations in De Vos, A. S., Strydom, H., Fouché, C. B. & Delpont, C. S. L., (Eds.) 2011, *Research at grass roots: For the social*

sciences and human service professions (4th Ed.). Pretoria: Van Schaik Publishers. pp89-100.

Frankl VE (1963) *Man's Search for Meaning: An Introduction to Logotherapy*. New York: Washington Square Press. (Earlier title, 1959: *From Death-Camp to Existentialism*. Originally published in 1946 as *Ein Psycholog erlebt das Konzentrationslager*).

Frankl V (1997) *Man's Search for Ultimate Meaning*. New York: Plenum Press.

Girlfriend (2005) *HealingWell.com: PSYCHOSOCIAL issues unique to Cystic Fibrosis*. Available at: <http://www.healingwell.com/community/default.aspx?f=18&m=103946>. [Assessed 11 October 2011]

Harris A and Super M (1991) *Cystic Fibrosis: The Facts*. Oxford university press: Great Britain. pp1-116.

Heather C (1998) *"Different but the same. Young people talk about living with serious illness."* Lothian, Port Melbourne. Available at: http://www.chronicillness.org.au/invisible/cf_b.htm. [Assessed 2 October 2011].

Hobfoll SE, Dunahoo CA and Monnier J (1995) *Conservation of resources and traumatic stress*. In: Freedy JR and Hobfoll SE (Eds.) *Traumatic stress. From theory to practice*. New York: Plenum Press. pp350-361.

Hughes M, Patterson LB and Terrel JB (2005) *Emotional intelligence in action. Training and coaching activities for leaders and managers*. San Francisco: Pfeiffer.

Joyce P and Sills C (2010) *Skills in Gestalt Counseling and Psychotherapy*. Londen: Sage Publishers Ltd.

Kidshealth.org (2011) From the health experts of Nemours. Available at: <http://kidshealth.org>

Kirchner M (2000) Gestalt therapy: An overview, viewed October 2011, from www.g.gej.org

Mackewn J (1997) *Developing Gestalt Counseling*. Londen: SAGE publications.

Maree K and Van der Westhuizen C (2009) *Head start in Designing research proposals in the social science*. Pretoria: Juta & company Ltd. pp79

Max-Neef MA (1991) *Human Scale development conception, application and further reflections*. New York: The Apex Press Council USA.

Monroe, J. 2001. Cystic Fibrosis: Perspective on disease and illness. Capstone Press, p.1-64

Murphy W (2002) *Orphan Diseases: New Hope for Rare Medical Conditions; -FIVE ROSES'*. pp81.

Nieuwenhuis J (2010b) *Qualitative research designs and data gathering techniques*. In Maree K (Ed.) (2010) *First steps in Research*. (5th Ed.) Pretoria: Van Schaik. pp75-76.

Oaklander V (2006) *Hidden treasure: a Map to the child's inner self*. Londen: KARNAC

Perls F, Hefferline R & Goodman P (1951/1994) *Gestalt therapy: Excitement and growth in the human personality*. Highland, NY: The Gestalt Journal Press.

Perls F (1969) *Gestalt Therapy Verbatim*. Real people press

Perls L (1976) Aspects of Gestalt therapy. Unpublished manuscript presented at the American Orthopsychiatric Association.

Powers SW (2008) *Introduction to the special series on cystic fibrosis: Viewpoints on clinical trials, genetic screening, and behavioural medicine*. Children's Health Care 2008 37. pp1-4.

Quittner A, Barker DH, Kristen K and Grimley ME (2009) *Cysticfibrosis: A model for drug discovery and patient care*. In Roberts MC and Steele RG (Eds.) (2009) *Handbook of pediatric psychology (4th Ed)*: New York: Guilford Press. pp271-286.

Ryan J (2001) *Dede Paquette-Bronfenbrenner's Ecological Systems Theory*. Available at: <http://printfu.org/bronfenbrenner>

US Department of Health and Human Services (2011) *National heart, lung and blood institute*, from www.nhlbi.nih.gov/.

Van der Merwe M and Kassan-Newton K (2007) *Conservation of Resources: A Primary intervention for continuous traumatic stress in South Africa*. Social Work/MaatskaplikeWerk, 43(4). pp350-361.

Williams MB and Poijula S (2002) *The PTSD Workbook*. Oakland, California: New Harbinger Publications

Whittaker A (2009) *Research skills for social work*. Glasgow: Learning Matters. pp89-97

Woldt AL and Toman SM (2005) *Gestalt therapy History, theory and Practice*. Sage publications. pp 41-78.

Wright NH (2003) *Crises and trauma counseling*. USA:regal

Yontef G (1993) *Awareness, dialogue and process*. The gestalt Journal Press. pp323.
New York:Highland

Section C: Conclusions and recommendations

1. Introduction

In the previous section (Section B) the themes that emerged during the interviews with participants were discussed in article format. This section provides conclusions and recommendations of this study. Heppner and Heppner (2004:329) recommend that in this final section of a research report the relevance of the study should be revisited. The research theme for the study was 'An exploration of risk and protective variables in the bio-psychosocial field of South African adolescents with cystic fibrosis'. It was found from a literature review and the researcher's own experience with her sister, who has CF, that the medical management of CF, probably rightly so, takes precedence in the management of this chronic illness. This was also true for previous research in this field. It was clear that the bio-psychosocial aspects of living with CF were a neglected focus in research. From the information provided by participants it was also clear that medical procedures can be overwhelming, especially when frequent hospitalization is necessary. It was, however, also evident that the illness had an impact on meeting fundamental human needs such as understanding within the full spectrum of multidimensional functioning. Furthermore, adolescents with CF constitute a vulnerable population due to overwhelming bio-psychosocial challenges and they are often marginalized in their peer group due to the interplay of symptoms and their management.

This study was mainly applied research, since it focused on gaining knowledge about a vulnerable population in order to inform practice. However, as stated by Fouché and De Vos (2011:95), applied research adds to the development of knowledge and therefore this study also had a basic research goal.

2. Research question

The research questions were based on the research theme mentioned above and are as follows:

What are the risk and protective variables in the bio-psychosocial field of adolescents with cystic fibrosis?

How do the risk and protective variables impact multi-dimensionally on adolescents with cystic fibrosis?

It is also important in this section to consider whether the aims and objectives of this research have been reached and if the research questions have been adequately answered. The general aim of this research was to explore and describe the risk and protective variables in the field of adolescents with CF and to describe how these variables have a multi-dimensional impact on such adolescents. To date this has not yet been researched adequately and through this research it is hoped that research results will expand the existing knowledge of CF in adolescents within a Gestalt field perspective.

3. Overview of the study

How the objectives were achieved:

- **An in depth literature study as background to the thesis was conducted** with the focus on the following aspects: Gestalt theory, Phenomenology and Field theory, Conservation of Resources theory and the adolescent life cycle.
- **Semi-structured interviews were conducted with adolescents with CF.** Sampling was used to collect a portion of the population for the study. Six participants were included in the study, at which point the revealed themes started to repeat and it was deemed that saturation of data was achieved. Semi-structured interviews of about 90 minutes were conducted as data collecting method. The questions asked were open-ended, and focused on the experiences of the participants living with CF, with the focus on risk and protective variables in their internal and external fields.
- **Themes were identified through the use of thematic analysis where patterns in the data were reported.** Eight themes emerged from the analysis, namely 'the impact of CF on':
 - Faith
 - Daily routine and time
 - Emotions
 - Hospitalization

- Health and body
- Family, friends, support structure and socializing
- The subjective experience of CF
- Future

- **The data obtained was reflected in an article as presented in Section B.**

The research questions were answered in the article where the risk and protective variables in the bio-psychosocial field of adolescents with cystic fibrosis came to the fore directly through the words of participants when they shared their personal experience. As the research developed it became clear how these risk and protective variables have a multi-dimensional impact on the field of these adolescents with cystic fibrosis. This was a research study of limited scope. It is the opinion of the researcher that, within this limited scope, the overall aim of this study was achieved.

Understanding the risk and protective factors in the bio-psychosocial fields of adolescents with CF is a first step in the appropriate management of this chronic health issue. If adolescents with CF are not supported adequately, based on a solid understanding of the risk and protective variables in their field, they can fall into negative resource loss cycles (Hobfoll, Dunahoo & Monnier, 1995; Van der Merwe & Kassan-Newton, 2007:350-361) with non-adaptive or non-constructive coping efforts. An exploration as intended in this study may form a basis for future intervention research to plan strategies to assist adolescents with CF and thereby enhancing multidisciplinary intervention for this target group.

4. Credibility issues

Reliability of qualitative research essentially refers to the evaluation of the quality of the research (Golafshani, 2003). It is important to be able to trust not only the findings of the research, but also the methods applied to obtain data (Delport & Fouché, 2011:353). The researcher is aware that in qualitative research there are subjective calls to make, such as when are themes truly repeating so that it can be decided that saturation of data has been achieved. Thematic analysis is reliant on the researcher's opinion of emerging themes after constant and thorough contact with the transcribed data. After writing up the themes and supporting it with the words of participants, the researcher is convinced that themes depict the reality of the

participants. In qualitative research, quality will refer to how the study fulfilled its purpose of 'generating understanding' (Golafshani, 2003:598). Therefore, reliability in qualitative research may refer to the reliability, credibility and dependability of the findings of a study. However, according to the classic literature by Lincoln and Guba (1999 as cited by Schurink, Fouché & De Vos, 2011), qualitative research suggests that consideration of quality and credibility are related because any judgments of quality becomes the foundation for how credibility is perceived—put together; they address the issue of trustworthiness. In this study an understanding of living a life with CF was aimed to be generated and by doing so reliability was achieved. Therefore, through the reliability of this study, reliability, credibility and dependability of the findings were attained. It is however important to note two more aspects. The first is that in qualitative research the aim is not to generalize findings to other contexts. The researcher can predict with some certainty that similar research will confirm many of the themes of this study, but aspects typical to the field of each adolescent with CF such as are they living in a rural or urban area, quality of familial support, access to medical services etc. will determine the reality of each individual. The second aspect that had to be managed is the researcher's personal experience of a sister with CF. Attitudes, previous knowledge, hunches and ideas had to be consciously bracketed to make sure that the voices of participants could be clearly heard. Bracketing is always a strategy to consider consciously in qualitative research in order to understand the participants' views of their reality (Heppner & Heppner, 2004:170).

5. Findings of the research

Based on the themes that were discussed in Section B, the following conclusions in relation to risk factors and protective variables were derived from the collected information:

The chronic illness CF raised questions in participants on an existential and spiritual level like wondering why they have this illness and how to deal with it. The whole fields of participants were impacted, e.g. self image due to altered appearance and being different from their peers, poor school attendance which impacted learning, losing friends with CF when they passed away, etc. The overall management of CF is a difficult and daunting task. Living everyday life with this chronic illness is challenging and patients need to take responsibility to take care of themselves, as in taking medication and adhering to daily treatments. The strong link between thoughts, affect and behaviour was clear, typically when they neglect to take care of

themselves, which resulted in feelings of guilt which negatively influence thought patterns and internal dialogue.

Within the theoretical framework of Conservation of Resources it was disconcerting to hear how much time needs to be allocated to medical procedures. Time is an energy resource, but when it is lacking or overused, it can impact on personal resources such as skills development and learning, as was the case with participants in this study. Participants constantly need to manage their eating patterns, a rigorous schedule in terms of medication and need to exercise, even when tired. Health wise it is crucial for them to stay in gain cycles. Should resource loss set in, in terms of health aspects, it is literally life threatening.

In terms of emotional experience it seems as if the illness evokes strong feelings of powerlessness in participants, especially when they have no other option but to be hospitalized for long periods. They typically experience loss on many levels. It was apparent that they miss out on the ordinary activities typical to the adolescent life stage such as going out with friends and having the opportunity to engage in learning. Even normal breathing is not something that they can take for granted. It was also clear from the information provided by participants that they feel isolated due to their illness. They do not always experience understanding from those around them.

From the above it is clear that living with CF seriously impacts the internal fields of participants, regarding their personal resources. Such resources as having hope can at times be depleted and at other times be a strong protective factor. The personal resources often seem to be on the extremes of a continuum with the capacity to aid resource gain at the one extreme and resource loss at the other. When adolescents with CF have a sense of control, it will be a protective factor, but when they do not feel in control, it becomes a risk factor. More research is needed on this interplay of risk and protective factors within loss and gain spirals.

The management of CF also has implications for family members in terms of energy resources such as finances and time. It is taxing on the emotional level and it was obvious that medical procedures and hospitalization can potentially facilitate loss spirals in all family members. On the other hand, participants expressed appreciation for the support of family and friends. As condition resource, social support is a major protective variable. More research is indicated on social support of adolescents in the context of CF.

Faith and positive thinking were two protective factors frequently pointed out by participants. Positive internal dialogue was also indicated as protective variable. In a now classic work, Lahad (1988) outlines the BASIC Ph coping and resilience model. This author explains the value of having a coping style which includes coping on the levels of beliefs, affect, social contact, creativity or imagery, cognition and physical activity. More research can be conducted on the particular coping styles of adolescents with CF. Research can also focus on how they can enrich their coping styles with a comprehensive coping strategy focusing on all the mentioned aspects.

It was noted that support from other adolescents with CF was especially valuable. Participants also found it inspiring to see how other adolescents with CF cope. They were heartened by cases where successful lung transplants lead to better quality of life. Improvements in medical care have already improved their life expectancy and they expressed hope for more such medical advances. They were all hoping that a cure may be found.

Overall, it was noted that although CF and its management is a constant challenge, the participants showed resilience and received strong support from their external field.

6. Recommendations from themes

- The impact of the medical procedures on the time of participants was of special concern. This impacts the fundamental human needs such as the need to understand and to learn. It is recommended that more attention be given to synergic satisfiers where more than one need is met by the same satisfier. While they are undergoing medical treatments such as nebulizing, a volunteer can, for instance, read and discuss their school work with them. They can possibly recite the content of creative work such as essays while someone else writes it down for them. They need all possible assistance to support their learning.
- As the impact of CF on general health becomes more severe, adolescents need to adapt to more intrusive medical procedures. It is recommended that they receive psycho-education on the nature and implications of such procedures. They can also be involved in participatory action research aimed at the development of educational material for

adolescents in their position. They can help with development of other therapeutic aids such as board games to explain the illness to younger family members. As the illness progresses, they need appropriate therapeutic intervention to facilitate processes of integration.

- Participants mentioned internal dialogue and positive thinking as adaptive coping skills. More research should be focused on coping with CF. It can be useful to place such research within the structure of the Gestalt cycle of awareness, where those affected work towards the completion of Gestalts which will lead to constructive self-regulation.
- Williams and Poijula (2002) write about resourcefulness and refer to the classic work of Antonovsky on salutogenesis (wellness). These authors also cite the work of Dunning (1997) who expanded Antonovsky's work with a list 13 helpful characteristics i.e. the thirteen Cs of salutogenesis which support coping and resilience. More research can be directed to these characteristics in adolescents with CF; i.e. congruence, control, communication, seeing the illness as a challenge, clarification, using ritual and commemoration, understanding the effect of culture and being connected to others. These characteristics can be expanded to use in assessment and intervention.
- The effect of facilitating emotional intelligence should be addressed through research. The competencies of emotional intelligence (Hughes, Patterson & Terrel, 2005) such as personal awareness, problem-solving, impulse control, assertiveness, self-actualization, interpersonal relationships and stress tolerance seem to be valuable constructs that can be expanded in the context of adolescents with CF. By focusing on emotional intelligence these vulnerable adolescents will be assisted in functioning more effectively in the interpersonal and intrapersonal fields.
- It was obvious that risk and protective variables in this study often were at the extremes of the same continuum, e.g. faith being a major protective variable but also an area where questions arose, especially on the level of assumptions and meaning-making. Further research can focus on this interface between risk and protective variables and explore how to turn resource loss in terms of such aspects into resource gain, e.g. by

working through issues on the faith level to enhance the supportive function of spirituality.

- Hospitalization is an inevitable part of the overall medical care regarding CF. It does, however, have a considerable impact on time and it limits participation in ordinary life. Alternatives such as home-based care should be expanded and also supported by further research on the medical level and in the field of physiotherapy.
- Social support is a protective variable and participants indicated it as a strong asset. Further research can focus on asset-mapping and Conservation of Resources in the context of CF to expand the interplay of resources in the field of adolescents with CF.
- It is indicated that research should also focus on the bio-psychosocial impact of CF on other age groups such as very young children, pre-school children, those in primary school and young adults. CF is a serious challenging illness with a potential negative impact on the completion of developmental tasks in the different phases of life. These processes should be better understood and managed.
- Intervention research on individual and group level should be conducted to develop intervention strategies for adolescents with CF. Such programs should incorporate work on bereavement and loss. Intervention strategies should also be developed for siblings and parents.
- In the school environment information on CF and other chronic illnesses should be incorporated more specifically into life skills programs to sensitize other learners to the challenges of living with such conditions. They can also receive guidance in terms of how to reach out appropriately to adolescents with CF.
- In this study it was possible to hear the voices of a vulnerable and possibly neglected group of adolescents. More research should be conducted from a multidisciplinary perspective focused on the multidimensional impact of CF.

7. Limitations

This research had a limited scope as part of a master degree with course work and practical work. It is seen as a preliminary study aimed at hearing the voices of a vulnerable group. More research is needed on the experiences of adolescents with CF and on possible interventions.

The themes that arose correlated with each other and with the literature, but are not necessarily the only risk factors and protective variables they face each day. Further studies may reveal more risk and protective variables. It should also be noted that data reflected the realities of participants at a particular point in time. If they were asked the same questions in a different time span, their answers may differ as new realities come to the fore.

The research study applied Gestalt terminology as foundation for understanding the unit of analysis. These terms only provide basic background information on Gestalt. It was not possible within the scope of this research to unpack the foundations of Gestalt; this terminology may be difficult to be understood by someone who has never been introduced to these terms and may therefore not be applicable to everyone.

The number of participants and also the race and language of participants used for this research study was limited; therefore the generalization of the findings will be limited as well. If there were more participants of various races it would have made the study more applicable to different race groups. There were only a limited number of participants involved in the semi-structured interviews because themes started to become repetitive. All the participants belonged to one specific race and most participants that took part were Afrikaans speaking; only one participant was English speaking. Another possible avenue of research would be to include participants from different religions, since the sample group in this study consisted of mainly Christians. Different age groups may also be researched; the primary focus of this research was middle and late adolescence.

Greef (2011:360) outlines the strengths and limitations of using one-to-one interviews as a strategy for data collection. While it is true that interviews may be used to obtain rich data in a cost-effective way, as was true for this research, it is also true that those interviewed may not be fully responsive. The wrong questions may be asked and responses may not be true. In the case of this research, it might have occurred that respondents wanted to impress the researcher

by showing more resilience than they really had. Welman, Kruger and Mitchell (2005:116) describe the so-called subject effect, also known as the Hawthorne effect, where participants react differently merely because they know that they take part in research. As far back as 1982 Bailey (1982:166) outlined participant bias, implying that the answers of participants could be affected by their reaction to the interviewer's gender, race, social class, age, dress, physical appearance or accent. However, the themes were supported by information from literature and the researcher is confident that the themes described in this study reflect the reality of the participants credibly.

A further possible limitation is that the interpretations of the participants' experiences were influenced by the researcher's phenomenology referring to her own values and viewpoints. In the process of engaging with the participants the researcher would have reflected these views in the manner in which she commented, structured and interacted in the interviews. Therefore the themes that emerged from the interviews in this study were co-constructions between the worlds of the participants and the researcher. The researcher was passionate about the research topic as it was of personal interest and was motivated by her own personal experience. Therefore, the researcher acknowledges that the findings of this study could have been coloured by the lens through which she looked at the particular point in time. This almost inevitable subjectivity, which is very much part of qualitative research, was moderated by frequent discussions with the study supervisor and conscious bracketing by the researcher.

8. Recommendations for further research

The principal aim of this study was to gather information on the identified research theme. It is indicated in this thesis that these questions were in fact answered and other significant aspects were noted that can be regarded as recommended fields for further studies.

- A fuller extent or further aspects of cystic fibrosis as it applies to adolescent developmental years can be researched.
- More focus could be placed on the application of Gestalt as meta-theory and Gestalt therapy theory in the context of intervention with adolescents with CF. Gestalt concepts such as self-regulation, movement through the Gestalt cycle of awareness in the continuous journey to find homeostasis and creative adjustment could be of value. It can

also add value to the holistic management of CF to include Gestalt-related mediums and techniques when intervening with this target group. Intervention research on these aspects is recommended.

- This research study was of limited scope which necessitated a strict focus. Further research can include persons from other developmental stages, other cultures and geographical areas to enhance the credibility of the findings.
- More information needs to be given to the meso-system of the CF patients, including family, religion and school. It is important that teachers, students, friends and parents work together as a team to promote the best possible support for the CF patient. The CF Organization developed a pamphlet that explains the laws that allow students to have their medical needs met when they attend day care, elementary and high school, college and university (CF Foundation). It is important to study the impact of this pamphlet by critically looking at aspects such as:

'Is the pamphlet circulated effectively so that families affected by CF take note of it; and does it provide affected families and the broader public with adequate and reliable information?

More research needs to be done on this aspect to be able to provide sufficient information to the public to be able to deal with CF appropriately. The researcher hopes that this study stimulates more qualitative inquiries into the chronic illness, cystic fibrosis, since it is perceived as an area that has mostly been ignored.

- The importance of taking care of oneself when suffering from CF needs to be highlighted medically, but certainly emotionally as well. Strategies need to be devised to assist adolescents with CF to enhance multidisciplinary intervention.

9. Conclusions from the research

The researcher has concluded that living a life with cystic fibrosis makes the patient feel different from their peers as clearly indicated by participants with CF. To help them conquer these feelings of being different they can be assisted by external intervention strategies. CF patients need people and there are many people in the CF patient's field such as family, friends, peers, and other CF patients, who can form the much needed support network. Participants were generally very positive, but special care needs to be taken to ensure that they have outlets for negative emotions and cognitive strategies in place in order to maintain some level of positive thinking. Through an internal locus of control and help from their field they can extend their lives, enabling them to have dreams for the future and live life to the fullest in the here and now.

10. Conclusive summary

This study explored and described the risk factors and protective variables of the adolescent with CF. The experiences of the participants were summarized into themes and discussed in Section B.

An adolescent with CF is faced with immense adversity. Facing a chronic illness and the intensive treatment required is a harsh reality that confronts the entire field of a chronically ill adolescent.

The need to assist adolescents with CF with all their emotions and the importance of obtaining inner peace became evident in this study. The researcher proposes that adolescents should, under all circumstances, be provided with maximal support and assisted in all ways possible to have an optimal life experience. CF patients can be regarded as fighters because every day of life is an added gift and every breath is a privilege. They fight to survive and they fight to breathe. In this context the participants in this study are saluted for their braveness and their willingness to expand knowledge in a neglected area.

11. References

Bailey, K.D. 1982. *Methods in social research*. London: The press.

Blacksher, Erika, Stone & John R. eds. 2002. Introduction to "Vulnerability" Issues of The retical [sic] Medicine and Bioethics. *Theoretical Medicine and Bioethics* 23 (6): 421-24.

Delpont, C.S.L. & Fouché, C.B. 2011. The qualitative research report. (*In De Vos, A.S., Strydom, H., Fouche, C.B & Delpont,C.S.L., 2011, Research at Grass roots: For the Social Science and Human Services Professions*. (4th Ed). Van Schaik publishers, p. 350-354.)

Fouché, C.B. & De Vos, A.S. 2011. Formal formulations. (*In De Vos, A. S., Strydom, H., Fouché, C. B. & Delpont, C. S. L. (Eds.) 2011. Research at grass roots: For the social sciences and human service professions (4th Ed.)*. Pretoria: Van Schaik, p. 89-100.)

Golafshani, N. 2003. *Understanding Reliability and Validity in Qualitative Research*. *The Qualitative Report*, 8(4): 597-607.

Greef, M. 2011. *Information collection: Interviewing*. (*In De Vos, A.S., Strydom, H., Fouche, C.B & Delpont,C.S.L. 2011. Research at grass roots: for the social sciences and human services professions*. Pretoria: Van Schaik publishers, p. 376-388.)

Heppner, P.P. & Heppner, M.J. 2004. *Writing and publishing your thesis, dissertation & research*. Belmont: Brooks Cole.

Hobfoll, S.E., Dunahoo, C.A. & Monnier, J. 1995. *Conservation as strategy of resources and traumatic stress*. (*In Freedy, J.R & Hobfoll, S.E.(eds)*. *Traumatic stress: From theory to practice*. New York: Plenum Press, p. 29-47.)

Hughes, M., Patterson, L.B. & Terrel, J.B. 2005. *Emotional intelligence in action. Training and coaching activities for leaders and managers*. San Francisco: Pfeiffer.

Lahad, M. 1988. (Ed). *Community stress prevention*. Kiriat Shmona: CSPC.

Schurink, W., Fouché, C.B. & De Vos, A.S. 2011. Qualitative data analysis and interpretation in. (In De Vos, A.S., Strydom, H., Fouche, C.B & Delpont, C.S.L. 2011. *Research at Grass roots: For the Social Science and Human Services Professions*. (4th Ed). Pretoria: Van Schaik publishers, p. 397-423.)

Van der Merwe, M. & Kassan-Newton, K. 2007. *Conservation of Resources: A Primary intervention for continuous traumatic stress in South Africa*. *Social Work*, 43(4): 350-365.

Welman, C., Kruger, F. & Mitchell, B. 2005. *Research methodology*. Cape Town: Oxford University Press.

Williams, M.B. & Poijula, S. 2002. *The PTSD workbook: Simple, effective techniques for overcoming traumatic stress*. Oakland CA: New Harbinger.

All references

About Cystic Fibrosis, 2011, what is a Port-a-cath? <http://www.aboutcysticfibrosis.com/port-a-cath.htm>. Date of access: 27 October 2011

Arbor, A. 2010. 'The Gestalt Counseling and Training Institute of Ann Arbor 2010 – Holistic Therapy for mind, body and soul 2010'- *Gestalt Counseling & Training*. <http://www.gestalt-annarbor.org>. Date of access: October 2011.

Bailey, K.D. 1982. *Methods in social research*. London: The press.

Blacksher, Erika, Stone & John R. eds. 2002. Introduction to "Vulnerability" Issues of The retical [sic] Medicine and Bioethics. *Theoretical Medicine and Bioethics* 23 (6): 421-24.

Barich, J. 2009. *A few thoughts on Martin Buber's I-Thou*.

http://www.choosingtolive.blogspot.com/2005/01/martin_buber.htm Date of access: 20 January 2009.

Beisser, A. 1970. *Paradoxical Theory of change*. www.gestalt.org/arnie.htm Date of access: 2 October 2011.

Berk, L.E. 2000. *Child development 5th edition*. Massachusetts: Allyn and Bacon

Bilton, D. 2008. *Cystic fibrosis*. *Medicine* 36: 273 – 278.

Blom, R. 2004. *Handbook of Gestalt Play Therapy*. Practical guidelines for child therapists. Bloemfontein: Druforma.

Borrell-Carrió, F., Suchman, A.L & Epstein, R.M. 2004. *The Bio-psychosocial Model 25 Years Later: Principles, Practice and Scientific, Inquiry* Annals of Family Medicine, Inc.

Boyse, J.R.N., Boujaoude, L.M.D. & Laundry, J.M.D. 2008. Reviewed by faculty and staff at the University of Michigan: *Your child development and behavioral resources*. Updated June 2008. <http://www.med.umich.edu/yourchild/topics/chronic.htm>

Bronfenbrenner, U. 1979. *The Ecology of Human Development*. Cambridge: Harvard University Press

Browell, P. 2002. *Gestalt Global Corporation Gestalt*. Vol. 5(3). <http://www.g-gej.org/5-3/introduction.html> Date of access: 4 January 2009.

CHEST. American College of Physicians. 1998. *Lung Transplantation for COPD* Truclock EP. http://chestjournal.chestpubs.org/content/113/4_Supplement/269S.full.pdf Date of access: November 2011.

Clarkson, P. 1989. *Gestalt counselling in action*. Dryden ed. London: Sage publishers.

Corey, G. 2005. *Theory and practice of counseling and psychotherapy*, United States of America: Brooks/Cole.

Cristensen, J. 2010. Proposed enhancement of Bronfenbrenner's Development Ecology Model. *Education Inquiry Vol.1(2) June 2010:101-110*. <http://printfu.org/read/proposed-enhancement-of-bronfenbrenner-s-development-ecology-model-d1e5.html>

Crocker, S.F. 1999. *A well-lived life*. Essays in Gestalt therapy. Cleverland: Gestalt Institute of Cleverland Press.

Cystic Fibrosis Foundation. 2011. *About Cystic fibrosis*. www.cff.org/AboutCF/index.cfm&www.cff.org/LivingWithCF/AtSchool/. Date of access: September 2011.

Cystic Fibrosis Worldwide. 2011. www.cfww.org or http://en.wikipedia.org/wiki/Cystic_fibrosis. Date of access: October 2011.

De Vos, A.S., Strydom, H., Fouché, C.B. & Delpont, C.S.L. 2011. *Research at Grass roots: For the Social Science and Human Services Professions*. 4th Ed. Pretoria: Van Schaik Publishers, p. 89-99.

Delpont, C.S.L. & Fouché, C.B. 2011. The qualitative research report. (In De Vos, A.S., Strydom, H., Fouché, C.B & Delpont, C.S.L., 2011, *Research at Grass roots: For the Social Science and Human Services Professions*. (4th Ed). Van Schaik publishers, p. 350-354.)

Drugs.com . 2011. *Drug information online*. <http://www.drugs.com/creon.html>. Date of access: 20 October 2011.

Dumont, M. & Provost, M.A. 1999. 'Resilience in adolescents: protective role of social support, coping strategies, self esteem, and social activities on experience of stress and depression', *Journal of Youth and Adolescence*, June 28 no.3.
<http://psycnet.apa.org/index.cfm?fa=search.searchResults>.

Ekvall, S.W. & Ekvall, V.K. 2005. *Pediatric nutrition in chronic diseases and developmental disorders. Prevention, assessment and treatment*. United States of America: Oxford University Press, p. 363-368.

Eve, J. 2008. *Writing a research proposal: planning and communicating your research ideas effectively*. *Library and information research*, 32(102):18-28.

Fouché, C.B. & De Vos, A.S. 2011. Formal formulations. (In De Vos, A. S., Strydom, H., Fouché, C. B. & Delpont, C. S. L. (Eds.) 2011. *Research at grass roots: For the social sciences and human service professions* (4th Ed.). Pretoria: Van Schaik, p. 89-100.)

Fouché, C. B. & Schurink, W. 2011. Qualitative research designs. (In De Vos, A.S., Strydom, H., Fouché, C. B. & Delpont, C. S. L. (Eds.) 2011. *Research at grass roots: For the social sciences and human service professions* (4th Ed.) Pretoria: Van Schaik, p. 307-327.)

Frankl, V.E. 1963. *Man's Search for Meaning: An Introduction to Logotherapy*. New York: Washington Square Press.

Frankl, V. 1997. *Man's Search for Ultimate Meaning*. New York: Plenum Press.

Girlfriend. 2005. *HealingWell.com:PSYCHOSOCIAL issues unique to Cystic Fibrosis* .
<http://www.healingwell.com/community/default.aspx?f=18&m=103946> Date of access: 11
October 2011.

Golafshani, N. 2003. *Understanding Reliability and Validity in Qualitative Research*. *The Qualitative Report*, 8(4): 597-607.

Greef, M. 2011. *Information collection: Interviewing*. (In De Vos, A.S., Strydom, H., Fouche, C.B & Delpont, C.S.L. 2011. *Research at grass roots: for the social sciences and human services professions*. Pretoria: Van Schaik publishers, p. 376-388.)

Harris, A. & Super, M. 1991. *Cystic Fibrosis: The Facts*. Oxford university press: Great Britain, p. 1-116.

Heather, C. 1998. "Different but the same. Young people talk about living with serious illness." Lothian, Port Melbourne. http://www.chronicillness.org.au/invisible/cf_b.htm Date of access: 2
October 2011

Heppner, P.P. & Heppner, M.J. 2004. *Writing and publishing your thesis, dissertation & research*. Belmont: Brooks Cole.

Hobfoll, S.E. & Lilly, R.S. 1993. *Resource Conservation as strategy for community psychology*, *Journal of Community Psychology* 21: 128-148.

Hobfoll, S.E., Dunahoo, C.A. & Monnier, J. 1995. *Conservation of resources and traumatic stress*. (In Freedy, J.R. & Hobfoll, S.E. (Eds.) *Traumatic stress. From theory to practice*. New York: Plenum Press, p. 29-47.)

Hughes, M., Patterson, L.B. & Terrel, J.B. 2005. *Emotional intelligence in action. Training and coaching activities for leaders and managers*. San Francisco: Pfeiffer.

Joyce, P. & Sills, C. 2010. *Skills in Gestalt Counseling and Psychotherapy*. Londen: Sage Publishers Ltd. p. 107

Kidshealth.org. 2011. From the health experts of Nemours. [http:// kidshealth.org](http://kidshealth.org)

Kirchner, M. 2000. Gestalt therapy: An overview. www.g.gej.org. Date of access: October 2011.

Lahad, M. 1988. (Ed). *Community stress prevention*. Kiriath Shmona: CSPC.

Lakhan, S.E. 2006. *The Bio-psychosocial Model of Health and Illness*.
<http://cnx.org/content/m13589/latest/>. Date of access: September 2011.

Lewin, K. 1951. *Field theory in social science; selected theoretical papers*. D. Cartwright (ed.). New York: Harper & Row.

Louw, D.A., Van Ede, D.M. & Louw, A.E. 2002. *Menslike ontwikkeling. 4de uitgawe*. Kaapstad: Kagiso Tersiër.

Mackewn, J. 1997. *Developing Gestalt Counselling: A field theoretical and relational model of contemporary Gestalt counselling and psychotherapy*. Londen: Sage publications.

Mackewn, J. 2007. *Developing Gestalt counselling: A field theoretical and relational model of contemporary Gestalt counselling and psychotherapy*. Londen: Sage publications Ltd.

Maree, K. & Van der Westhuizen, C. 2009. *Head start in Designing research proposals in the social science*. South-Africa: Juta & company Ltd.

Maree, K. & Pietersen, J. 2010. Sampling. (In Maree, K. (Ed.) 2010. *First steps in Research* (5th Ed.). Pretoria: Van Schaik, p. 172-180.)

Max-Neef, M.A. 1991. *Human Scale development conception, application and further reflections*. New York: The Apex Press Council USA, p. 91-127.

Mwamwenda, T.S. 2004. *Educational Psychology: An African perspective*. Heinemann Higher and Further Education Ltd.

Monroe, J. 2001. *Cystic Fibrosis: Perspective on disease and illness*. Capstone Press, p.1-64

Mouton, J. 2005. *How to succeed in your master's & doctoral studies*. Pretoria: Van Schaik.

Murphy, W. 2002. *Orphan Diseases: New Hope for Rare Medical Conditions; -FIVE ROSES'*, p. 81.

National Heart lung and blood institute. Disease and conditions index.

http://www.nhlbi.nih.gov/health/dci/Diseases/cf/cf_what.html. Date of access: 4 July 2011.

Nieuwenhuis, J. 2010a. *Introducing qualitative research*. (In Maree, K. (Ed.). 2010. *First steps in Research* (5th Ed.). Pretoria: Van Schaik, p. 47-66.)

Nieuwenhuis, J. 2010b. *Qualitative research designs and data gathering techniques*. (In Maree, K. (Ed.) 2010. *First steps in Research* (5th Ed.). Pretoria: Van Schaik, p. 70-92.)

Oaklander, V. 2006. *Hidden treasure: a Map to the child's inner self*. Londen: KARNAC

Park, A. 2004. 'What makes teens tick?'. *Time Magazine*, 7 June, p. 50-60.

Parlett, M. & Lee, R.G. 2005. *Contemporary Gestalt therapy: Field theory*. (In Woldt, AL & Toman, SM. 2005. *Gestalt therapy History, theory and Practice*. Sage publications.)

Perls, F., Hefferline, R., & Goodman, P. 1951/1994. *Gestalt therapy: Excitement and growth in the human personality*. Highland, NY: The Gestalt Journal Press.

Perls, F. S. 1969. *Gestalt Therapy Verbatim*. California: Real people press.

Perls, L. 1976. *Aspects of Gestalt therapy*. Unpublished manuscript presented at the American Orthopsychiatric Association

Powers, S.W. 2008. Introduction to the special series on cystic fibrosis: Viewpoints on clinical trials, genetic screening, and behavioural medicine, *Children's Health Care* 37: 1-4.

Quittner, A., Barker, D.H., Kristen, K. & Grimley, M.E. 2009. *Cysticfibrosis: A model for drug discovery and patient care.* (In Roberts, M.C. & Steele, R.G. (Eds.) 2009. *Handbook of pediatric psychology* (4th Ed). New York: Guilford Press, p. 271-286.)

Quittner, A. 2010. *CF Research Shows Importance of Mental Health*, September 2010, p. 1-2.

Reber, A.S & Reber, E.S. 2001. *The penguin dictionary of psychology*, (3rd Ed), wik.ed.uiuc.edu/index.php/schemas. England: Penguin.

Roberts, M.C. & Steele, R.G. (Eds.) 2009. *Handbook of pediatric psychology* (4th Ed). New York: Guilford Press.

Ryan, J. 2001. *Dede Paquette-Bronfenbrenner's Ecological Systems Theory*. <http://printfu.org/bronfenbrenner>.

Schrurink, W., Fouche, C.B. & De Vos, A.S. 2011. Qualitative data analysis and interpretation. (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delpont, C.S.L. 2011. *Research at grass roots: For the social sciences and human service professions* (4th Ed.). Pretoria: Van Schaik, p. 397-423.)

Strydom, H. 2000. *Maatskaplike navorsing diktaat vir MWKG 321-411*. Potchefstroom: Universiteit vir Christelik Hoëronderwys.

Strydom, H. 2011. *Ethical aspects of research in the social sciences and human services professions.* (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delpont, C.S.L. 2011. *Research at grass roots: For the social sciences and human service professions* (4th Ed.). Pretoria: Van Schaik, p.113-129.)

The South African Cystic Fibrosis Association. www.sacfa.org

University of Michigan Health System. 2008. *Children with Chronic Conditions*.
<http://www.med.umich.edu/yourchild/topics/chronic.htm>.

US Department of Health and Human Services. 2011, *National heart, lung and blood institute*.
www.nhlbi.nih.gov/.

Van Aalderen, W.M., Mannes, G.P., Bosma, E.S., Roorda, R.J. & Heymans, H.S. 1995. Home care in cystic fibrosis patients. PubMed PMID: 8526136. 20 p. 378 & 535-537.
<http://www.ersj.org.uk/content/8/1/172.full.pdf>

Van der Merwe, M., & Kassan-Newton, K. 2007. *Conservation of Resources: A Primary intervention for continuous traumatic stress in South Africa*. *Social Work*, 43(4): 350-365.

Welman, C., Kruger, F. & Mitchell, B. 2005. *Research methodology*. Cape Town: Oxford University Press.

Whittaker, A. 2009. *Research skills in social work*, Glasgow: Learning Matters.

Wikipedia. 2011. Spiegelberg, H. 1975. *Doing Phenomenology: Essays on and in Phenomenology*. en.wikipedia.org/wiki/Herbert_Spiegelberg. The Hague: Nijhoff, p. 1-290.

Williams, M.B. & Poijula, S. 2002. *The PTSD workbook: Simple, effective techniques for overcoming traumatic stress*. Oakland CA: New Harbinger.

Woldt, A.L. & Toman, S.M. 2005. *Gestalt therapy: History, theory and practice*. USA: sage publishers, p. 41-78.

Wright, N.H. 2003. *Crises and trauma counseling*. USA: regal.

Yontef, G. 1993. *Awareness Dialogue and process: Essays on Gestalt Therapy*.
www.gestalt.org/yontef.htm. Highland New York: The Gestalt journal press.

Appendix A : Example of consent form

Dear potential participant

I am a postgraduate student who is currently studying for my Master Degree in Gestalt Play Therapy through NWU. I would like to invite you to participate in this study that aims to explore the risk and protective variables of adolescents in their middle and late adolescent years from the age group 15-22 years in South-Africa having Cystic Fibrosis.

The research is a requirement for my degree and a dissertation of limited scope will be written on this topic. Your participation will include being interviewed for approximately 90 minutes and you will be required to share your experience of having Cystic Fibrosis specifically in this age group.

Once the data has been collected, analyzed and conclusions made you will receive feedback, through a copy of my dissertation, with regards to the research. The interview will be recorded on videotape that will be kept in a safe place and will only be used by the interviewer for transcribing and extracting themes for qualitative results. Your identity will be protected and you will remain anonymous. There might be some of the questions that may touch on sensitive areas. However, every effort will be made by the researcher to minimize your discomfort. There are no financial costs directly associated with participation in this project. 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. This study will be shared with my supervisor as she will also have access to the data. The dissertation that results from this work will be published on hard copy, which will be housed in the Library of NWU University.

You have the right to withdraw from the study at anytime, and are free to ask any questions and clarify any issues regarding the study and the interview anytime. You may discontinue your participation at any time without prejudice. If you discontinue participation in this project you may request that the researcher do not use the information already given to her.

Your participation in this study would be highly appreciated.

Participation in this research project is entirely voluntary and you may choose not to participate. If you have any questions pertaining to your participation in this research study, you may contact the researcher at any time:

Carina Hugo 082 484 5902 or the study supervisor Dr M. Van der Merwe 082 964 6697.

Thank You very much

Carina Hugo

Please sign the consent form below if you are willing to participate in the dissertation research outlined above.

CONSENT FORM

1) If the participant is younger than 18 years:

Signed at _____ on this _____ day
of _____.

Signature of parent /
guardian: _____ Date: _____

2) If the participant is older than 18 years:

Signed at _____ on this _____ day
of _____.

Signature of participant: _____
Age: _____ Date: _____

Researcher's signature
Date

Appendix B: Interview transcribed

Onderhoud 2:

C: OK, aangename kennis. Ek is Carina.

N: (Lag.)En ek is deelnemer 2

C: OK, laat ek jou so bietjie van myself vertel. Ek is 'n kleuterskool juffrou, so ek werk met die klein kindertjies van 4-5 jarige ouderdom ek het onderwys geswot en my passie was kindertjies met leerprobleme. Toe doen ek honeurs in spesiale onderwys-behoeftes en toe gaan ek verder en toe besef ek kindertjies met leerprobleme het eintlik emosioneel altyd ietsie wat hulle pla, dis baie keer hoekom hulle skoolprobleme het, dis omdat daar emosioneel ietsie nie reg is nie, toe wil ek verder gaan en doen nou my M in speltherapie, weet nie of jy al gehoor het van speltherapie nie.

N: Nee.

C: Dis eintlik vir kleiner kindertjies, sê nou maar kleuterskool en laerskool kindertjies, wat soos sukkel om te slaap, nagmerries kry of ouers wat skei, of 'bullying' by die skool en sulke goeters, so ek wil graag daarmee werk. Ek wil graag my eie plekkie begin of so, maar nou wil ek by die navorsing uitkom. Ons is drie kinders, my boetie is 30, ek is 28 en my sussie is nou 22, en sy het ook nou CF enmm... Ja, ek het maar net gevoel dis iets waarin ek belangstel, waaroor ek nog altyd gewonder het en dit sal vir my lekker wees in hoe julle voel, 'n meer emosionele kant van CF in te gaan en ja...

N: OK

C: En dalk so 'n verskil te maak in die toekoms as mens meer verstaan oor hoe iemand voel en wat aangaan binne, kan mens dalk voorkomend help. Om dalk vir mensê te kan help, of so.

So dit is my hele storie. So die hele dingetjie gaan, as mens jou nou hier teken as mens. Ons kan jou nou jousêlf noem of ons kan vir jou 'n naam gee. So wil jy jou eie naam gebruik of 'n skuilnaam?

N: Ahmm....

C: Ek weet nou nie of ek dit reg gespel het nie, OK? Nou jy bestaan uit klomp deeltjies, en dit is partykeer wat jy voel, almal nie sien nie. 'n Klein deeltjie daarvan is dan nou CF. En as ons nou moet dink aan my navorsingsvraag sê "the risk factors" en "protective variables". So wat die "risk factors" is die amper negatiewe goed wat in CF is en wat is die goed wat help, wat die "protective variables", wat help om, wat help hierdie deeltjie CF binne jou. So ja. As jy nou vir

my enige plek kan begin, jy kan daar begin, as jy net vir my jou ervaring kan vertel van hierdie deeltjie in jou wat deel is van jou...

N: Jis dis nogals moeilik. Ek is nie eintlik 'n baie emosionele persoon nie, want ek is baie kunstig en so, so ek het baie uitlating en so, so ek is, ja. Vir my om, ek gaan nou nie voor jou sit en snot en trane huil nie...(Lag.)

C: Nee, nee, jy hoef nie..

N: Ek dink daar is baie ouens wat vrae het oor hoekom en so aan, veral in hulle geloof ook. Dis soos dit is baie maklik om iemand te blameer daarvoor, omdat jy gebore is daarmee en dit is nie regtig jou skuld nie, so ahm. Ek dink daar is baie ouens wat vrae het en dit baie negatief ervaar omdat dit is onregverdig en ahm, hoe kan ek dit sê: hoekom ek, tipe ding, daai vrae, maar ek sien dit half anders. Die ander ding is ek het 'n redelike "support structure" agter my en my gesin is baie ondersteunend en so. Hulle is ook my motiveerders en so.

C: Hoor hier, ek gaan hierdie afhaal (masker), ek voel te onpersoonlik saam met jou?

N: (Lag.) Dis reg, ek wou sê ek kan nie jou mond sien nie.

C: En dis nie lekker nie, dit voel net vir my ek "connect" nie met jou nie, want ek is hierdie masker. Nou kan jy my mond sien en sien wat is my emosie. OK"yes", jy het 'n goeie "support structure".

N: Wil jy weet, ahm, wat, soos wat is goeie goed om te hê vir 'n CF pasient.

C: Enige iets wat jou help? Wat help jou met CF?

N: Dis verseker, 'n gesin wat ondersteun en ouers wat ja, wat die geld het, wat kan bekostig om die beste vir my te gee, wat hulle vir my kan gee, dit help baie en ahm ek dink my sussies.(Lag.) Ons is soos beste vriendinne, so ahm, dit help. Ek dink geloof, help vir my, ek weet nie hoe ander mense dit sien nie, maar ek het 'n redelike verhouding met Hom. En ons stap al 'n hele pad saam en ek sou dit nie sonder Hom kon doen nie, so Hy help my baie.. Ahm, ja vriende, speel 'n groot rol om jou positief te hou en jou te motiveer.Ek dink dis wat my help...(Lag.)

C: OK.

N: En dan uitlating en ander goed wat jou aandag kan aftrek en waarmee jy jouself kan besig hou, veral as jy lang tye hier is in die hospital, dan help dit nogal. So...baie. Ahm. Ja dit is partymaal bietjie moeilik om fokus te verloor, veral as jy so lank hier is, want my sussies kry altwee volgende jaar graad en so aan en dan voel jy half bietjie agter, want jy werk nou nie en dan vra mensê: Wat doen jy? Ek is meeste van die tyd in die hospitaal, weet jy? So jy voel half, jy weet, 'n bietjie van 'n agterstand, maar aan die anderkant weet jy ek kan sê ek het gaan swot ek was eerste jaar op PUK en ek het ondervinding opgedoen wat niemand ooit van my kan

wegvat nie. Ek gaan nou nie wegstap met 'n graad nie, maar daar is ander maniere hoe jy dit kan doen. Dit is “give” en “take”. Partymaal moet jy “compromise”, veral met CF.

C: Is dit partymaal “compromise”? Is dit nie nogals baie “compromise” nie?

N: Ja dit is baie “compromise”, partykeer, van dit is lewensdrome wat jy “compromise”, so ja. Daai is nogals sleg, “compromise” is “suppose” om soos in “give” en “take” te wees, jy is “suppose” om goeie goeters daaruit te kry, hierdie is half lewensdrome.OK, wat kry ek nou weer hiervoor terug?Joe, so dis ja...

C: Dis nie maklik nie...

N: Maar daar is maniere om dit te “bypass”. Jy weet om op ander maniere dit reg te kry en dit is om dit raak te sien en daarvoor te gaan, wat jy weet wat jy die “support” nodig het, wat mense jou kop optel en vir jou sê kyk daar is ander goed waarop jy kan fokus, so ek kan...

C: Waste ander goeters help jou, waarop jy fokus?

N: Ahm wel, korttermyngoed, soos baie keer as ek hier is, beplan ek waarnatoe ek wil gaan, soos vakansies en goed, wat ek nog wil doen en so. Doen net die navorsing, gaan kyk op die internet, kies waarnatoe jy wil gaan en so aan. Ja ahm...ja en ander soos maniere om soos graad te kry, as ek hier uitkom gaan ek nog skilderye verf - jy weet ek dink dis vir almal maar belangstelling en “hobbies”...

C: “Yes”, waarmee jy jou besig hou. So jou “hobbies” is kuns?

N: Ja. (Lag.)

C: En teken, en skilder en kreatiewe goeters?

N: Ja , nogal, as ek hier is sien die naaimasjien.

C: (Verbaas.) Ek het dit nie eers gesien nie!

N: Ja, dit is wat ek maak, daai sakkies daar agter die zipsakkies.

C: (Verbaas.) OK (Kyk.)

N: En dan verkoop ek hulle. En dit is goed vir my besigheid, want hier kom baie verpleegsters hier in.

C:Jaaa. En hulle almal het so pennesakkie nodig...

N: Ja, en hulle kinders en daar is kinders by die skool hulle almal moet een hê.

C: Dit is “nice”...want hier is baie hier, so hierdie moet maar jou besigheidsplek wees, dit is baie slim...

N: Ja want hier is baie voete, so.

C: Dis “nice”, 'n Bernina.

N: Dis my ouma s'n, my ma het ons s'n opgeblaas, letterlik! (Lag.)

C:

N: Rook en alles, ek belowe jou, sy het gordyne gemaak.(Lag.)

C: (Lag.)

N: Ons hoop ouma s'n hou.

C: Ja nee, hy lyk sterk. Die ou goed is mos sterker.

N: Ja kwaliteit. Dis ook een van die goeters wat my aandag aftrek as jy besig kan bly, veral as dit iets so kleins is, soos jou eie besigheid, jy weet...(Lag.) iets anders om op te fokus, iets "exciting!"

C: En soos finansieel is dit ook seker lekker om 'n geldjie te hê?

N: Ja jy voel nie "useless" nie. Want...

C:Want as jy nie geld het nie, jis dis moeilik as mens nie geld het nie.

N: Ja

C: Ek...ja...

N: En al die ander mensê wat nou al 22 is werk al, of kry op 'n ander manier geld, so jy voel nie te uit nie...(Lag.) want jy het jou eie besigheid. Dit is wat ek bedoel het met die maniere om dit te "bypass", as jy nou nie werk nie, kry 'n ander manier...

C: Sou jy dit aanbeveel, sê nou maar iemand met CF wil eerste jaar iets gaan doen? Sal jy sê "go for it"?

N: Ja, vir seker! Ek dink so, veral as hulle nog gesond genoeg is om dit te doen, doen dit "by all means", want dis 'n ervaring vir enige jongmens is dit ervaring wat jy moet opdoen, daai ervaring...

C: Ja-ja.

N: Op jou eie wees, jy moet dit ervaar. Maar vir nog meer vir 'n CF pasiënt, daar kom dalk nog 'n later stadium wat jy dit nie kan doen nie, dalk maak jy nie eers jou studies klaar nie, daai ervaring en ondervinding. Die vriende wat ek daar gemaak het, is meer is nog meer deel van my "support structure..."

C: Is dit – is hulle nogsteeds deel van jou...

N: Ja, ek is nog baie in kontak met hulle en ons wou, ons wou ek en deelnemer een wou 2 weke terug. Hy het die Maandag ingekom, ons wou daai week Potch toe gegaan het om vir hulle te gaan kuier het, maar toe is ons nou hier...(Lag.)

C: Toe werk dit nou nie so uit nie.

N: Ja

C: Toe is julle hier, wat sê hy, "back in paradise"?

N: Ja (Lag.) Nee vir seker enige jongmens, en ahm juis omdat jy nie weet, jy weet wat vorentoe kom, en veral meisies as jy jou 20 slat dan raak dit moeilik, maar dis vinniger agteruit gaan, maar as jy kan, doen dit... "go for it!"

N: Ek sal dit defnitief aanbeveel. (Lag.)

C: OK, jou hoërskooltyd in vergelyking met nou, na skool. Hoe was jou hoërskooltyd vir jou, as jy bietjie vir my van dit kan vertel.

N: Hoërskooltyd het ek min maatjies gehad, maar ahm nog steeds my familie "structure" was daar gewees. Ek was nie so siek nie, soos ek het eers na my eerste jaar baie begin inkom. So dit was redelik, baie "normal" gewees. So "normal" soos wat dit kan wees, met pille en daai tiep van goed by. Daar was nie suurstofmasjiene toe nie, jy weet, en daai goed was nog nie ter sprake nie. Dit het stelselmatig begin erger raak agteruit begin raak Gr.11 en matriek, maar dit was nog nie so erg soos wat dit naskool was nie, toe het dit begin erg raak. Hoërskool was maar "normal", ek kon al my vakke deurkom, als, niks herre of gedop of so nie. So ek was redelik, ek kon by hou met alles. Maar ek was nou nie...

C: Moegheid?

N:Ja klasse, partymaal, 2de verdiepings en so was 'n bietjie ... (Lag.)Vyf minute, twee minute laat vir klas, dit was...(Lag.) Maar die juffrouens het dit verstaan.

C:So almal het dit geweet?

N: Nie almal nie, baie min het dit geweet, ahm wat vir my nogals lekker was, want ek kan wegstap en wees soos, ek was dan redelik"normal"want baie van hulle het niks geweet nie en niks agter gekom nie.

C:Dit was lekker, dit was beter, jy het dit so verkies!

N: Ja, die juffrouens wat nodig gehad het om te weet, het geweet...

C: Ooh

N:Ja

C:En laerskooltyd?

N: Laerskooltyd was ook "normal" gewees. Ek kon redelik, ek was, toe ek kleiner was het ek elke maand die dokter gaan sien, dan was daar dae wat ek nie by die skool was nie en dan het die maatjies geweet sy is nie by die skool nie. Maar hulle het ook geweet ek is siek, want ek het met die ""drip"" skool toe gegaan, maar so die wat moes geweet het, het geweet. En die ander maatjies het gesê: julle hoef nie te weet nie, (Lag.)so ja ek dink... (hoes) ek dink ek is dankbaar daarvoor, my ma'le het my, daar was nie"laps" gewees nie, as jy nou nie, ek voel nie lekker nie, so jy daar was nie gewees, ek voel nie lekker nie, so dan bly ek by die huis, maar as ek gesê het ek voel nie lekker nie, dan het sy gesê ek gaan jou dokter toe vat...

Dan's dit ek voel eintlik "fine". Ek wil nie dokter toe gaan nie. In daai opsig is ek bly, want as hulle vir my "gaps" gegee het, dan sou ek vir seker 'n jaar of twee moes oordoën, so daarvoor is ek dankbaar ek het geslaag en so, en ek was nie, daar, hulle het "grace" vir my gehad as dit regtig nodig was en die ander tye het ons gedoen wat ons moes doen. Ons het gewerk, en skool toe gegaan, al was dit nie lekker nie. Partykeer weg gekom, as ons hospitaal toe gegaan het, en ons was vroeg klaar by die dokter dan nie teruggegaan het skool toe ... (Lag.) Ek meen daar moet "perks" wees, komaan, regtig?!

C: Ag "shame".

N: So hier en daar, maar oor die algemeen, is ek dankbaar my ouers het dit hanteer soos wat hulle dit hanteer het.

C: OOK, so hulle het dit goed hanteer?

N: Ja

C: Is daar iets wat hulle gedoen het wat jy nie van gehou het nie?

N: Nee, ek dink nie so nie... hulle het partymaal het hulle nie vir my gesê wanneer ek 'n "drip" gaan kry nie, en dan het hulle my net gevat en dan was ek negatief, want dan was ek ook nie... ek het nodig gehad om myself emosioneel te...

C: Voor te berei.

N: Voor te berei, vir "drip"s en sulke goeters omdat dit is seer en daar is 'n kans dat dit "tissue" en daar is baie stres en so aan, so daarvan het ek nie gehou nie, maar hulle het my redelik baie gesê, OK hulle het my die oggend gesê OK, ons gaan hospitaal toe en jy gaan 'n "drip" kry en dis baie tyd. Dan het ek in die kar tyd gehad of die aand voor die tyd gesê. Dan het ek tyd gehad om daaraan te dink en dan daar gekom en dan was dit "fine", toe kon ek dit "handle", maar moenie my gooi daarmee nie, dit het nie gewerk nie.

C: So jy het tyd nodig gehad, voorbereidingstyd, net om jouself reg te kry.

N: Ja.

C: So die "drip"s" wat jy nou sê, dit is 'n slegte ding.

N: Ja ek dink dit vat baie weg, baie tyd weg. As jy hospitale sien, maar selfs toe ek klein was, daar was baie ouens wat vroeë gevra het op skool, en dit maak dit moeilik, want dadelik staan jy uit, en dit is 'n verband so dis nie gips nie, so jy kan nie sê jy het jou arm gebreek nie, alhoewel ek al daai verskoning gebruik het. Maar dit het nie gewerk nie...

C: (Lag.)

N: Maar dit maak dit moeilik want wat sê jy vir die maatjies? En... hulle gaan nie verstaan nie. Hulle weet nie wat dit is nie. Jy is siek, maar mens word mos dan gesond as jy op antibiotika gaan, en nou hoekom is jy dan so baie daarop en jy word nooit gesond nie, so gaan jy ooit

gesond wees, tipe ding. In daai opsig is dit nie lekker nie, maar ek was een van die mense wat wil wegkruip ek wil nie raakgesien word nie, ander mense kan die “spotlight” kry, ek wil regtig nie raakgesien word nie en dit het “sort” van die “spotlight” presies op my gesit en dit was nie lekker nie.

C: So los my net, gaan net aan met julle goed, ek wil net lewe.

N: Ja presies dit, ek sal my ding doen, ek sal hierdie hanteer en my lewe voluit lewe, doen julle dieselfde, maar fokus op julle goeters.

C: Ja, ja.

N: Maar ek dink daarmee was my sussies ‘n groot hulp, want hulle het baie keer vir my ingestaan, en dan vir mense gesê, los haar uit, sy is doodnormaal, los haar uit.

C: Wat is julle ouderdomme?

N: Ek is 22, my oudste sussie is 3 jaar ouer as ek, 25 en my jongste sussie is 2 jaar jonger as ek, sy is 20.

C: OK

N: So ons is redelik naby aan mekaar, maar nie te ver nie...

C: Dis goed, so jy sê hulle was ondersteunend vir jou? Hoe het hulle jou gehelp? In watse opsig?

N: Hulle het my baie gemotiveer en soos ek nou sê as daar mense was wat probeer het om “insults” te gooi of enige so iets het hulle gesê julle weet nie eintlik waarvan julle praat nie en of (hoes) en as daar mense was wat “insults” gegooi het, terwyl hulle nie by my was nie, het hulle altyd vir my kom sê wie is hulle...(Lag.)

C: So hulle het saam met jou die “battle” ge-“fight” amper, hulle het jou ondersteun in dit?

N: Ja. En gesprekke as ek nie by is nie het ek geweet, hulle sal....“they got my back” tipe ding.

C:OK. En soos by die huis. Het hulle jou by die huis op maniere gehelp?

N: Ja...veral nou toe dit erger begin raak het, daar is baie goed wat hulle vir my moes begin gedoen het (lag), nie altyd met ‘n “smile” nie...(lag), maar hulle doen dit en hospitaal kuiertjies. My sussie haat die hospitaal, maar sy kom kuier nog steeds.

C: Maar ek dink dis vir niemand lekker nie, so , dis ook nie vir julle lekker nie, niemand hou van die hospitaal nie, maar dit is maar so.

N: Ja, maar maak die beste daarvan.

C: So goedjies doen by die huis en so. En hoëskooltyd is daar nie regtig iets nie.

N: Daar is nie iets spesifiek wat uitstaan nie, omdat hulle dit so gereeld gedoen het, my baie gedra en ondersteun het. Ek kan nie spesifiek vir jou...

C: Het jy in die hoërskool gevoel jy het meer ondersteuning nodig as laerskooltyd, wat betref, hulle wat jou “back” en ouderdom en ahm, daai hele jy weet hoërskooltyd is maar ‘n moeilike groepsdruktyd.

N: Ja.

C: Wat het jou gehelp deur daai groepsdruktyd?

N: In laerskool dink ek het ek meer ondersteuning gehad as in die hoërskool. Want toe ek hoërskool kom het ek meer my eie...ahm hoe kan ek sê...Nie vir myself opgestaan nie, want ek het dit baie gedoen, maar meer die “guts” gehad om vir mense te sê: dit het niks met jou uit te waai nie. Ons is altwee grootmense of ja hoërskool so hanteer, ja. So ek hoef nie vir jou te sê nie, tipe ding. Laerskool was bietjie meer onder druk, ja, want ek was klein gewees, jy is nie altyd die grootste nie.

C: Ja nee ek weet, my sussie ook nie.

N: En ek was maar baie jy weet, nie meer gemanupileer nie, meer beïnvloedbaar. As mense iets wou weet of my vra dan het ek vir hulle gesê, jy weet (lag). Al wou ek nie regtig nie. Maar hoërskool het ek gesê: Nee, dit het niks met jou uit te waai nie. So in daai opsig dink ek het my sussies my gehelp laerskool. Groepsdruk was nie regtig vir my so groot “problem” nie, maar dit is as gevolg van my geloof en goeters, dit is net “solid” en standvastig. Daar is sekere goeters wat ek sal doen en sekere goeters wat ek nie sal doen nie. En ek “compromise” nie.

C: Jy skuif nie jou “boundaries” nie.

N: Ja, ja, so. In daai opsig was groepsdruk nie vir my so moeilik nie. In standerd 6 het ek soos koor gesing. En die koor was soos ‘n hele familie gewees, so dit was nog “support” gewees, ahm. So ek dink ook baie mense het my uitgelos in hoërskool, want hulle geweet daar is ‘n hele...en die koor mense het verstaan, hulle het geweet wat aangaan. So hulle het nie nodig gehad om vrae te vra nie...

C: Het hulle geweet van jou siekte? Geweet van CF?

N: Hulle het geweet ek is siek en ek kry gereeld “drip”s en so.

C: En dit is wat hulle geweet het.

N: En dit was wat hulle geweet het en dit was “fine”...

C: Dink jy ‘n mens skram ook weg dit is makliker om, minder te sê en minder mense weet, as wat jy alles moet verduidelik?

N: Ja maar ek dink dit hang af van persoonlikhede. As jy iemand is ,wat ahm... baie ekstrovert is, dan gaan dit vir jou bietjie moeiliker wees om niks te sê daarvoor nie, waar as jy ‘n introvert is, dan is dit maklik,want jy ... dit is jou persoonlikheid, so ek dink dit speel wel ‘n rol, soos ja in laerskool was ek baie meer van ‘n introvert as hoërskool, alhoewel dit vir my moeilik was, want

nou vra almal vrae daaroor en jy is redelik uitgesproke so hulle verwag jy gaan vir hulle sê, omdat jy uitgesproke is kan jy vir hulle sê nee. So, dit het ook gehelp...ja.

C: Jou pad met die Here. Wanneer het jy, het jy 'n dag of 'n datum nie?

N: Daar is nie 'n dag of datum nie, so groot geword, maar is 2 jaar terug gedoop, ahm en nog redelik ja baie baie sterk. My ouers het vandat ons baie klein was - het hulle in die kinderkerk gewerk en ahm vir klomp ouens opgelei in die kerk, so ons het basies in die kinderkerk grootgeword. Ons lag nou die dag, want ons kyk van die familievideos weer en my sussie sê ons was nie geleer om die eerste woorde 'mamma' en 'papa' te sê nie, ons was geleer "bless you" en "hallelujah"...(lag).

C: (Lag.)

N: Dit was die eerste woorde.

C: Ag "sweet" dis oulik. OK, so julle is mooi groot gemaak.

N: So ja, en dit is, ahm ek dink nie ek sou sonder dit of my ouers en my sussies, sou die "support" kon gee, wat hulle gee, sonder God se krag nie en ek dink dieselfde vir my, ek sou dit nie kon maak sonder Hom nie. Daar is al wonderwerke ook, ek sou nie hier kon sit, as dit nie vir Hom was nie. So.

C: Is dit in jou lewe gesondheidsgewys?

N: Ja ons was eenkeer, ons het gaan kamp ek dink dit was... kan nie onthou nie. Ek was baie siek gewees toe ek klein was en ek was baie koorsig gewees en die hospitaal was baie ver gewees en toe sê my ouma, maar Jesus het vir haar gesê hulle moet net daai tyd kom en hulle hande op my lê, niks sê nie, net hulle hande op my lê. En hulle het dit toe gedoen en my koors was weg en so, maar ek sou dit nie gemaak het daai aand, as dit nie daarvoor was nie, so ja.

C: "Wow!"

N: En klomp goed soos die dokters het gesê soos 7 jaar, maar ek dink baie CF pasiënte kan dit vir jou sê. Hulle dokters gee vir hulle 'n sekere jaar.

C: Ja, 'n sekere tyd.

N: Maar hier sit ons 3 sewes en nog 'n jaar by...(lag).

C: Ag...dis oulik "wow" (lag).

N: (Lag)...ja.

C: Jy sê dit so mooi. 3 sewes en nog 'n jaar by.