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PARENTAL PERCEPTIONS OF PROSOCIAL BEHAVIOUR IN CHILDREN WITH CANCER

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A research report submitted in fulfilment of the requirements for the degree of

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DECLARATION
OF ORIGINALITY

I hereby declare that this thesis is my own original work, and that it has not been submitted for any degree at another university.



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Submitted on 18th day of September 2009

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And to children afflicted with cancer

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CHAPTER 1: INTRODUCTION

This research sought to address the relatively under-researched area of the perceptions of parents of children with a chronic illness and their prosocial behaviour in specific. The problem outlined throughout the length of this report is whether parents indeed do see their children in a positive light because of the children's vulnerability in the face of harrowing illnesses like cancer and if so what are the dynamics at play in this process? The definition of prosocial behaviour then becomes a significant exercise in the analysis of the data obtained as well as the conceptualisation of the responses of the participants in the light of the body of literature reviewed.

1.1 Aim of the Research

This was an interpretive study on parents' perceptions of prosocial behaviour in children with chronic illness, specifically cancer. It especially targeted their experience of their children after hospitalisation and for a few, during hospitalisation. It aimed to address aspects of this topic such as perceived fluctuations in levels of prosocial behaviour of their children from when they became hospitalized and ill as viewed by their parents. In addition, it had the goal of looking at attributions for any possible prosocial or other behaviour as provided by the parents.

1.2 Rationale

Prosocial behaviour is an indication of a well-adjusted and socially adept child. The literature on the subject illustrates prosocial behaviour as being beneficial to society since helping, caring and sharing behaviour enhances the social fabric and provides supportive mechanisms to individuals (Mullis, Smith & Vollmers, 1983). There is an orientation towards the social good in children who exhibit prosocial behaviour. While there have been several studies on the factors that produce prosociality in the normal population, this same characteristic has not been sufficiently explored in other special populations such as abused children, or children with chronic illnesses and more specific to this research, how

the caregivers subjectively perceive the fluctuations in their children's prosocial behaviour after hospitalisation.

There have been local anecdotal reports of how children in hospital wards, or after discharge tend to exhibit higher levels of prosocial behaviour. This however, has not been substantiated on a large scale, or as it pertains to this particular research, even if on a smaller scale, has not gone through ample academic investigation. This research aims then to delve into areas of this field that may have been overlooked or not adequately exhausted. The only studies found by the researcher that focused on this subject more specifically were done by Seagle, Jessee and Nagy (2002), who found that chronically ill children tended to exhibit higher degrees of prosocial behaviour which is an aspect of prosociality, than healthy school children. The other was a review by Vollhardt (2009) which looked at 'Altruism born of suffering' and found that traumatic events, including chronic illness produced higher levels of prosocial behaviour.

While the effects of chronic illness like cancer is devastating to all concerned, the study may have demonstrated a positive outcome for chronic illness. Though this study focuses on children with cancer, the findings and conclusions may also be adapted to children with other chronic diseases including HIV/ AIDS, diabetics, asthma and others through further investigation.

There are several factors attributed to the development of prosocial behaviour in children, however, this study aims to uncover the specific nature of prosociality in children with cancer as perceived by their parents. If the parents report the children as possessing a particular prosocial inclination, it would be interesting to isolate the factors that incline them towards such behaviour and explore further possibilities of instilling them in the normal population through subsequent research studies of a quantitative nature that allows for generalisability. In addition, it is an aim to explore levels of idealisation in the parents with regards to their children due to their illness.

Furthermore, some of the literature such as Cook, (1974), has shown that extreme altruism and empathy which precedes altruism, may impact negatively on the child demonstrating it by causing distress and anxiety. Other literature has found that with some children, fear of impending death may cause them to have increased anxiety, regression to earlier forms of behaviour, clinginess and behaviour that is considered asocial, such as angry outbursts and non-cooperation (Cook, 1974). It would thus be interesting to study the particular nature of prosociality shown by children with cancer as perceived by their parents as well as their psychological responses to death and illness. This can provide understanding on the part of health care professionals as well as family. It can indeed also offer incentives for other researchers to investigate possibilities of the kind of support these children and parents require to contain their emotional state and create possibilities for their interactions with others to be expressed in a healthy manner.

1.3 Outline of the Research

This research report comprises of five chapters. This introductory chapter aimed to present and acquaint the reader with the aim and rationale of this research. It also provides an outline of the structure of the proceeding chapters.

Chapter Two will describe a review of the literature available around the different aspects of the topic. Debates around the difference between prosocial behaviour and altruism will be addressed. It sets out the decision made to then use prosocial behaviour as the desired and relevant term for the remainder of this report. Both foundational perspectives from earlier years as well as more contemporary views from recent studies were used. An overview of the factors in the development of prosocial behaviour will be provided and thereafter sections on paediatric cancer and their prosocial behaviour will be more specifically looked at. Finally the topic of parental experiences of their children's illness, as well as conceptualizations around the idea of subjectivity of the way parents view their children and the construct of the 'halo effect' will be explored.

In Chapter Three, the aims and research questions will be discussed and thereafter the method employed in this study will be addressed. This was an interpretive study which used a qualitative research design. What was required was not an empirical measure of

prosocial behaviour but to understand subjective experiences of the parents as they lived through and witnessed their children's illness and hospitalisation in relation to prosocial behaviour. Semi-structured interviews were used to obtain data then the transcriptions were analysed using thematic content analysis. No one particular theory was used to describe the content but a bottom-up approach was needed to explore the material and thereafter form patterns of meaning into themes.

Chapter Four will report the findings of the research. It first introduces and summarises the individual participants narratives and thereafter provides the themes gleaned from the obtained material and organises them into two categories with seven themes under the first category and two under the second.

Chapter Five will present a discussion of these results by integrating and providing an exploration of the findings against the literature reviewed in chapter two. The material will be broken down and discussed according to the outlined themes. As part of this final chapter, the research will be concluded through a presentation of the summary of the study, discussion of the limitations of the study and recommendations for future research as well as reflections from the researcher.

CHAPTER 2: LITERATURE REVIEW

Research linking prosocial behaviour and children with chronic illness is sparse. Attempts to substantiate anecdotal reports of how the prosocial behaviour of children with cancer increases during hospitalization with sound academic publications has been a challenging endeavour. There is even less research on parental perceptions on the topic. Therefore much of the review of the literature in this study will focus on different aspects of these concepts and the meagre publications available on the topic itself have been augmented by deductive links between different studies.

In the review that follows, definitions and theoretical underpinnings of prosocial behaviour will be explored. Comparisons to, and differentiations from, altruism and morality will be made. At the root of prosociality is the ability to emotionally connect to another and therefore the concept of empathy will be described. The history of the study of prosocial behaviour will also be looked at in light of the contexts that drove it. The sections that will follow will explore the different factors that assist in the development of prosocial behaviour and a special elaboration will be made in its relation to Kohlberg's theory of moral development. Thereafter, the specific population groups targeted within the parameters of this research paper which are children with cancer and their parents and families will be examined. Literature on prosocial behaviour with regards to the specific demographic of children with cancer will be looked at. Finally the concepts of perception and 'halo effect' will be expounded on as it pertains to how human beings tend to perceive a certain population group in particular ways. This last aspect is an important element of this study which provides a variety in the scope of studies done on the subject as it pertains to parental defences utilized to counteract the harrowing effects of their children's illness such as idealization.

2.1 The Definition, History and Theoretical Perspectives on Prosocial Behaviour

One of the features that define our social nature as humans is our ability to help, share, care for, and provide comfort to others. These types of acts are collectively termed "prosocial behaviour" (Mullis, Smith & Vollmers, 1983). They are seen as behaviours that are commonly beneficial to society. Prosociality was a relatively under-researched topic and there were reportedly 10 times more studies on anti-social behaviour (Bierhoff, 2002). There was however, an exponential increase of research in this field during the 1960's and 1970's. It was focused mainly around bystander assistance and spontaneous interpersonal helping (Dovidio, Piliavin, Schroeder & Penner, 2006). This interest was aroused after the case of the American Kitty Genovese who was murdered in 1964 in the street outside of her apartment. No one came to assist her even though 38 bystanders heard her plea for help. Latane and Darley (1970) did extensive research on this event and its connection with levels of prosocial behaviour and bystander apathy. Their work included creating a five step process of decision making that the individual goes through to decide if he or she is going to assist in a given situation. In fact the phrase 'prosocial behaviour' only began to be used in the 1970's as an opposite of the term 'antisocial behaviour'. Social psychology itself as a discipline emerged in the early 1900's. Much of its focus was on the social ills of the time which centred on the World Wars, the Nazi dispensation and racial discrimination.

Authors such as McDougall (cited in Dovidio et al, 2006) were initially at the forefront of the study of prosocial behaviour. The work of Nancy Eisenberg was important for the contribution of the concepts of prosocial behaviour especially in children. Daniel Batson, Latange and Mussen also contributed a great deal to the understanding of the prosocial behaviour of humans in various contexts. There was then an attempt to construct definitions of this type of behaviour.

The study of prosocial behaviour has grown in its complexity over the last few decades, moving from the social, to the interpersonal, or one on one helping behaviour pertaining

to emergencies, to spontaneous assistance, to voluntarism and philanthropy, and now to the political sphere related to the response to exigencies of national proportions.

Besides social psychologists, it was also developmental and personality psychologists who had an interest in the field. Beyond psychology, sociologists, anthropologists, biologists, economists as well as political scientists started gaining interest in prosocial studies (Dovidio et al, 2006).

To move towards the various definitions that have emerged, Eisenberg and Mussen (1989) state that it is a broad collection of actions that are promoting or enhancing the well-being of others, and stress that these actions are defined by society as being beneficial. They are voluntary and have the intention of enhancing another's wellbeing even if they are done for a variety of reasons, some of which may be self-serving. Prosocial behaviour is one of the primary characteristics reflective of social competence – a vital component for the development of positive, healthy social relationships (Eberly & Montemayor, 1998). Prosocial behaviour also includes the following: donating, acting charitably, rescuing, saving, volunteering and such philanthropic acts by the wealthy such that have helped thousands if not millions (Klein, 2003). However, one could question the motives of individuals and indeed corporations for the motives behind their social responsibility activities. There have been several debates on if one can call the action prosocial if the instigating spirit behind it is that of materialistic profit or is the very notion of prosociality dependent on the altruistic thought behind it?

While Bar-Tal (1976 p.4) stated that prosocial behaviour is a positive form of social behaviour and is defined as "voluntary behaviour that is carried out to benefit another without anticipation of external rewards and is performed when the behaviour is done for its own end". However, subsequent publications by Eisenberg et al (1989) stated that prosocial behaviour is any action that helps another but in its definition refers to the end result as being good not the motivation behind the action. This would seem to be an evolving conceptualization which further differentiates altruism and prosocial behaviour

and pegs it to the feeling or state of mind behind the action. The individual according to both definitions however, must have the freedom to choose to display such behaviour on his/her own accord rather than be coerced to act on it. What Bar-Tal (1976) does is include a sub-premise with regards to prosocial behaviour which is that of an act of restitution. This suggests that which is done to reciprocate what has previously been done for the individual or to compensate for any wrongdoing. Thus, Bar-Tal extends the definition of prosocial behaviour from pure altruism to include reparative or reciprocal exchange and so would encompass altruistic choices also. However, in both situations the condition of the act being performed without expectation of a reward is maintained.

Prosocial behaviour specifically in vulnerable populations like those with chronic illness then becomes an interesting subject. Questions such as what the motivation of these children may be in demonstrating such behaviour and what effects it has on others may be posed. Could they have feelings around the illness being a 'punishment' for their badness? Could they be compensating for this feeling through acts of benevolence? Might the behaviour be 'reparative altruism' that tries to abate any guilt the child may have? In these cases, can the reward of prosociality be life? These questions will be further explored in the section under 'Children with cancer and their prosocial behaviour'.

Before proceeding with the formative factors of prosocial behaviour, it would be pertinent to delineate the differences between prosocial behaviour, altruism, moral behaviour and empathy as these concepts are at times used interchangeably and indeed overlap. Eysenck (2004) provides an explanation by saying that prosocial behaviour is specifically intended to help another human being. Bierhoff (2002) states that it is any behaviour that is intended to assist others and strives to improve the position of the other. This behaviour may or may not be motivated by genuine concern for the second party and at times may be done with selfish reasons such as a child helping a peer with homework in order to get compliments from the teacher. However, Berk (2003 p.407)

defines it as “voluntary actions that benefit another person without expected rewards for the self.” Berk’s explanation contradicts several of the above authors.

Altruism is a type of prosocial behaviour that is mostly sacrificial at times which comes as a cost to the self (Ridley & Dawkins, 1981). For example, the attempt of someone to go into treacherous waters in order to save a drowning human being. It is a philosophical doctrine that propounds the moral imperative to assist others. According to Dovidio et al (2006) it is the quality of unselfish concern for the wellbeing of others. As was stated previously, Eisenberg et al (1989 p. 3) regarded it as “voluntary actions intended to benefit another that are intrinsically motivated – that is as motivated by internal motives such as concern and sympathy for others, or by values and self-rewards rather than personal gain.” Bierhoff (2002) emphasises that such acts are driven by a fundamental belief in the importance of others’ welfare. There is a focus on that person’s needs and a wish to remedy their plight due to the sense of empathy one has for them. As can be tracked, the various definitions of different authors yields at times overlapping and indistinct explanations of the concepts of altruism and prosocial behaviour (see Berk, 2003). However, for all intents and purposes the overall differentiation between the two constructs may be the motivation behind the act and whether a level of sacrifice is involved.

There are two reasons for the choice of the concept of prosociality rather than altruism in the context of this research: Firstly, it is difficult to measure motivation behind the action in the altruistic ethic (Eisenberg et al, 1989) and seems to be more of an abstract construct, whereas prosociality is an observable, concrete and behaviour-based concept that parents can see in their children and comment on. This is necessary in this type of research especially because it is the parents being interviewed and not their children. Having delineated these two concepts, it is however, important to reiterate that this is an interpretive qualitative study based on the *perceptions* of the parents of the children’s prosocial behaviour and their *fantasies* of the motivation behind the behaviour. Therefore, one could argue that term ‘altruism’ can also be used due to the phenomenological framework mentioned. Secondly, prosociality is a more encompassing

and broader concept that allows for a better inclusivity of sub-topics and varying motivations. Therefore it could be argued that altruism is a subset of prosociality. Thirdly, it would seem that there is greater ambiguity and conflicting arguments as to the definition of altruism than there is for prosocial behaviour (Bar-Tal vs. Berk vs. Eisenberg). In the interest of clarity and due to the scope of this research, it was deemed efficacious to rather use the concept that appears to elicit less contradiction.

Most researchers and authors in the field suggested that prosocial behaviour is generally beneficial and it promotes or enhances society (Bar-Tal, 1974; Eysenk, 2004; Berk, 2003; Eisenberg, 1989 and Bierhoff, 2002). The very term 'pro' as a prefix to the term 'social' renders it 'good' or is defined as 'in favour of' society. It may seem redundant to dispute whether such acts then profit society or not. However, there have been critiques against the notion of prosocial behaviour and altruism by such philosophers and writers as Nietzsche (cited in Leiter, 2004) and Ayn Rand (cited in Rushton & Sorrentino, 1981) claiming that such acts demean the person who offers the service and is stifling of creativity, economic prosperity and socio-political progress. This is motivated by individualistically driven theories that place the welfare of the individual above the society. However, much more research has been found that show the benefits for the person enacting the prosocial behaviour as well as for society at large (Bierhoff, 2002).

To clarify and differentiate concepts further, the definition of morality and its relation to prosocial behaviour must be looked at. The latter is the concern with the distinction between good and evil or right and wrong. It is the motivation to do the right thing or the stimulus to perform acts based on ideas of right and wrong. Therefore a prosocial act may be given impetus by a moral motivation.

Empathy is the emotional ability to understand and feel the viewpoint as well as share in the emotions of another and usually have concern for others' well-being (Eisenberg et al, 1989). Thus empathy is an important indicator of, and precursor to prosocial behaviour. If we feel psychologically connected to another then we are more likely to extend a helping hand. The more empathy we feel towards the person, the more we may want to help them

and thus end the discomfort caused by seeing someone else in distress. Some individuals may feel that alleviating another's distress is a reward to themselves as well as to the other. Therefore that could be the benefit for the helping behaviour.

It should also be noted that the phenomena of prosocial behaviour is invariably an interactional one. There is at least a dyad involved and is therefore relational in its expression. There is always the one involved in providing the help and a beneficiary on the receiving end of the assistance. The benefactor can even be a collective and the beneficiaries likewise (Dovidio et al, 2006).

2.2 Factors in the Development of Prosocial Behaviour

Since the time when the study of prosocial behaviour accelerated in the 1960's there have been several enquiries as to the factors that produce prosocial behaviour in children and adults. The nature/nurture argument has been a fervent debate within the social sciences in the last century or more with regards to the emergence of behavioural phenomenon. Even though puritan, deterministic theories no longer hold sway, it is still the centre of social debate in terms of which orientation a theory may incline. Prosocial behaviour is a concept that has not escaped this debate. The causes may be laid out in a way that may seem to suggest that they are singular and separate, however it should be noted that the advancement and sophistication of the modern theory is in its multi-dimensional and multi-factorial stance. The bio-psycho-social formula takes the diverse developmental positions and integrates them into a holistic and encompassing theory.

The various factors have been roughly classified into the biological or genetic aspects, psychological factors which include the child's own temperament; cognitive capacities and developmental trajectory and finally, social dimensions under which fall socialisation both in the home and school and cultural and religious influences. In the following section these will be looked at in relation to the emergence of prosociality.

As stated prosocial behaviour and altruism has been used interchangeably in some literature, however, for the purpose of conceptual consistency, this research will use

prosocial behaviour throughout, except for instances where authors are quoted that use altruism.

2.2.1 Biological Factors

Biological Determinism

Genetic theory has had a profound impact on the study of behaviour in humans. Charles Darwin being among some prominent scientists who contributed evolutionary theory argued that humans evolved through a process of natural selection (Darwin, 1871). Thus, we inherit certain traits through the gene pool that guarantees survival of the fittest. At first glance, altruistic behaviour which at times is sacrificial and comes at a cost to the individual species may seem to go against this theory. If each species is programmed to survive at all costs and in that way ensure the survival of its gene lineage then why put one's self in the line of fire to help or rescue another? This phenomenon is seen in the animal kingdom when species such as worker bees will sting an intruder for the sake of protecting the queen bee and the colony. According to Berk (2003) several other animals such as apes have a tendency toward prosocial behaviour too. They exhibit it in the form of sharing food and adoption of orphaned apes. Subsequent and newer theories of evolution then modified Darwinian theory to and argued that altruism protects the survival of the collective species even if at the cost of the individual organism. Thus it ensures the perpetuation of the gene pool as a whole and not necessarily the unit within the species.

Newborn infants also display signs of empathy, which is the precursor to prosocial behaviour. It would stand to be inferred that if babies display empathic traits, that there is a biological dimension to this behaviour since they have not had a chance to be socialized yet. Already one and two day old babies respond by crying when they hear another baby crying. This strong experience of empathy is considered innate and a natural outcome of our genetic makeup as also observed through twin studies (Eisenberg & Fabes, 1998). Zahn-Waxler, Radke-Yarrow, Wagner and Chapman (1992), found that identical twins show greater similarity in prosocial behaviour at 14-20 months than fraternal twins. It

was also seen through a study cited in Dovidio et al (2006) that kinship also influences who one helps more. Identical twins tend to help and be cooperative to their other twin than to other family members. This may fall under the general term 'kin selection', where people of the same genetic material tend to display more prosocial behaviour to their own genetic counterparts so as to perpetuate the same strain. This also gives explanation to why people are more likely to help those who are similar to them. There may be a tendency to confuse similarity with kinship linkage (Zahn-Waxler et al, 1992).

It would stand to reason however, that there may be a biological tendency for empathy and altruism but that actual prosocial behaviour is generally learned. It should be stressed then that the impact of the environment either directly changes, influences or mitigates the extent of the genetic force in terms of shaping the behaviour of the individual.

2.2.2 Psychological Factors

Cognitive Development

Even though babies may show empathy when a few days old, it has been demonstrated from several empirical experiments done, that prosocial behaviour increases with age (Bar-Tal, 1976). In a particular study, children from infancy to adolescence demonstrated prosocial behaviour less than 9% of the time, whereas 13-15 year olds showed prosocial deeds 9% of the time, 18-20 year old showed it 21% and 23-25 year olds 49% of the time (Eysenck, 2004). After 2 years of age, the frequency and the type of prosocial behaviour depends on the situation and the other person involved. According to Hoffman (1987), empathy has different stages of development. In the first year of life, there is global empathy which is involuntary and is expressed in the child crying when another does as stated above. In the second year of life, there is egocentric empathy which is that the infant realises that the other person is distressed but is hard for it to separate from his/her own emotions. Between age 2 and 3, empathy for feelings develops where the child starts becoming aware of the various emotions that others express. Finally from late childhood

onwards, there is empathy for life conditions where the child is observant of different people's emotions, states of being and their experiences.

The reasons for the positive correlation between age and prosocial behaviour are due to several factors: as children grow older, their level of competence in interacting with their environment increases and becomes more sophisticated. They are more in tune with their external world and have the ability to gauge other children and adults' needs and requirements from them. Their level of responsibility then changes accordingly (Bar-Tal, 1976). The more reasoning skills children have, the more prosocial behaviour they are able to exhibit. Overall cognitive functioning is important for prosociality as is seen in its decrease in children who have experienced head injury or brain tumours as well as mentally disabled children. The other reason is their moral sensibilities become more refined.

The leading figures in the cognitive-developmental field who propounded that levels of moral judgment change with age are Piaget and Kohlberg (Berg, 2003). The type of moral reasoning used is dependent on the moral understanding and cognitive level of the child. Piaget stated that there are two stages that a child goes through, the first is called moral realism that a child has at an early age and then autonomous reality when the child starts getting older. The first stage is when the child obeys rules and performs moral acts as an obligation to authority and is related to concrete, egocentric thinking. Here children are self-centred. The second stage is related to a more abstract way of seeing the world. The morality that is demonstrated is more flexible since the child realizes that morality should be for the common good and do not simply obey it because it is a rule.

Kohlberg extended this further and divided these two stages into six main categories namely (Duska & Whelan, 1975 cited in Ronald, D. & Mariellen, W., 1975): heteronymous morality, which is obedience to the rules for fear of punishment; instrumental morality – following rules when it is in accordance with own interest; good-child morality- doing what is expected of one and keeping good relationships through trust and loyalty; law-and-order morality – obedience to the state law; social-construct

reasoning – the awareness that different individuals hold varying values and perspectives and lastly, universal ethical principles which is holding ethical beliefs that override rules and arbitrary agreements (Cole & Cole, 2001).

A more specific type of moral judgment called 'prosocial moral reasoning' refers to "the thinking that is involved in deciding whether to share with, help, or take care of other people when doing so many prove costly to oneself" (Cole & Cole, 2001: 563).

Attachment Theory

Attachment theory was developed by John Bowlby and its central theme is that there is a psychological and emotional connection that exists between people and the level and type of an infant's bond to its mother has vast implications for the general development of the child socially, psychologically, emotionally as well as cognitively (Bowlby, 1969). More than just a socialisation process, attachment to a parent who is available, responsive and in tune with the needs of a child can create the right set of emotional wiring that forms a sense of security. Secure attachment is the best form of attachment which is a concept further explored by Mary Ainsworth (Ainsworth, Blehar, Waters & Wall, 1978). It describes the child who has a dependable parent in its first few months of existence and who's parent establishes a safe and secure base that allows the child to explore the world and trust that the parent will be there. It impacts on the type of relationships one forms with those other than caregivers as well.

According to a study done with preschoolers (Elicker, Englund, & Sroufe, 1992), those who were securely attached displayed higher levels of social competence, self-esteem and empathy. In a subsequent longitudinal follow-up (Shulman, Elicker & Scroufe, 1994) of the same children when they reached the age of 11, the securely attached children had better relationships with their friends, closer, more trusting relationships with adults and better social skills. Securely attached children are much more prosocial (Waters, Wippman, & Sroufe, 1979; Eisenberg et al, 1989). Berk (2003) suggests that parents can encourage prosocial behaviour by giving unconditional acceptance and being positive to

reasonable demands as well as if they are perceived as sensitive and empathic by the child.

There is a better chance of a child modelling a parent if he/she has a good and trusting relationship with their parent. Parents that show a lot of support are inclined to have offspring that are securely attached to them. Nurturing parents who use effective parenting techniques like induction and modelling therefore are more likely to produce prosocial children (Eisenberg, 1992)

Psychodynamic Theory

This section briefly provides a psychodynamic view of prosocial behaviour. This is the type of model that postulates the relationship between different aspects of the psyche and the forces operating in the unconscious mind and how it manifests in behaviour (Ahles, 2004). Proponents of this theory argue that for actions that are exhibited in the outer form or thoughts that are in the conscious sphere, there are a myriad unconscious forces presiding and motivating below the surface. Therefore the question of 'what motivates prosocial behaviour' is then posed. What unconscious dynamics act in the unconscious realm that express themselves as acts of kindness, helpfulness and caring toward others? Psychodynamic theory not only attempts to posit debates around motivations but also looks at origins of moral behaviour which as was stated above can be a pre-curser to prosocial behaviour.

Freud's theory with regards to the structure of the psyche suggested that there were 3 parts to the personality: the id, which is the primal, instinct-based and impulsive part of us (Snowden, 2005). The ego, which is the second aspect of the psyche is that reason-based reality principle that is organised and rational. It acts as the mediator between the id and the world. Lastly, the superego is the moral voice of society and parental influences that have been internalised. It includes the ideals of the ego, spiritual ideals and conscience, also known as psychic agency and polices what it deems are unacceptable behaviours or thoughts. The super-ego is what is at play when making moral choices or prosocial actions (Eisenberg & Mussen, 1989). Its emergence according

to Freud, is linked to interactions with caregivers on a primal level. It is a product of the healthy resolution of the tensions between primitive impulses and social demands. The child then at age 5 or 6 internalises the parent's moral standards and values.

While this theory has contributed to and has become a foundation for the majority of psychological theories, it begs the question: is the moral inclination absent prior to the age of 5? What is to be interpreted of the behaviour of a 3 year old child's attempts at caring for, comforting and sharing with another?

As a return to dynamics behind behaviour, one of the central principles of psychodynamic theory is the use of defences against anxiety. What are collectively termed 'defence mechanisms' are used in the service of the psyche to protect it from the overwhelming forces of anxiety and aggressive impulses (Fonagy & Target, 2003). The defence mechanisms run on a continuum from the most primitive, such as splitting, denial and repression to more adaptive ones such as sublimation, reaction formation and relevant to this study, idealisation. According to Wikipedia (2009), the definition of idealisation is "Unconsciously choosing to perceive another individual as having more positive qualities than he or she may actually have".

As was stated in the preceding sections, parental apprehension and worry in the face of a crisis like their child being diagnosed with cancer can be exceedingly high (Parker & Mauger, 1979). To withstand and assuage the high levels of anxiety felt during such a traumatic experience, parents may use defence mechanisms, one of them being idealisation. As was also previously noted, parents may also go through Elizabeth Kubler-Ross's (1969) stages of processing such a crisis, including denial. These stages can therefore intersect with psychodynamic theory since aspects of the process are defensive in their nature.

Personality Type

Personality is a distinct contributor to the emergence of prosocial behaviour and its variations can likewise impact on its expression. According to Eisenberg et al. (1989)

personality types such as gregarious children and those who are verbally expressive of their feelings are more adept at connecting to and assisting others. These children performed more prosocial acts than their control group. Spontaneous sharing and cooperation with others was higher in sociable and extroverted children (Eisenberg et al (1989)

Assertiveness which is an important component of personality was another important element in the likelihood of children showing prosocial behaviour. It was argued by Midlarsky and Hannah (1985) that children may need to be assertive and daring to approach people who need help and the correlation may be due to this. A critique of this study is that there were variations in the level and type of prosocial behaviour presented. In the case of those who are expressive and assertive, their prosocial behaviour was high in relation to spontaneous acts but not in situations where they were asked for items. Those who are assertive and outgoing may have been more prosocial due to their likelihood of being in situations where they would be social. The quieter and less forthcoming children were rather the target of other children's requests for help than them spontaneously offering.

2.2.3 Social and Environmental Factors

Socialisation

Socialisation is the mechanism which allows the learning and internalization of culture, language, habits, manners and other social competencies in children (White, 1977). This is conveyed through intentional teaching and instruction but most often it is absorbed vicariously and comes as a by-product of being with others in the community. Socialisation is one of the primary ways that ensures the perpetuation of societies and as Wang and Wheeler (1961) stated, it is the process of becoming human. Values, morals and ways of living are transferred from one generation to the other.

Other agents of socialisation are peers, teachers, the media, religious institutions, extended family and neighbours. Through pressure from various means, the child then

learns to conform to the norms and behaviours and adapt one's thoughts to that of the accepted standard. One such 'mode of conduct' that the system of socialisation is used to transmit is prosocial behaviour. Most socialisation occurs first within the home and then in the external environment. Bandura's (cited in Berk, 2003) social learning theory states that moral learning and other prosocial behaviour acquisition is made like other types of behaviour, through reinforcement and modelling.

According to social learning theory, parenting style and sibling relations have a large influence on the development of prosocial behaviour. The more agreement and harmony there is among the socialisation agents, the more systematically and optimally the process will be absorbed by the child. If there are numerous adult models living in the household, as is at times the case in a South African household, the multiple and sometimes diverging information creates confusion for the child, and the socialisation process then becomes less effective. Grandparents and other extended family can confound the incoming feedback (White, 1977).

Different parenting styles yield corresponding outcomes in the development of prosocial behaviour. The different styles are authoritative, authoritarian and permissive parenting. Authoritative child-rearing is the most effective in developing prosociality (Penner, Dovidio, Piliavin & Schroeder, 2005). This approach is child centred, parents are sensitive to the child's needs, are involved with the child and are warm. This is different to authoritarian parenting which is controlling, restrictive and punitive and also to permissive parenting which is lax in discipline, over-indulgent, neglectful, inconsistent and uninvolved. It would seem that authoritative parenting is more conducive to healthy child development. Schaffer (1996) found 5 types of parenting behaviour that assists with prosocial behaviour: giving specific guidelines around the prosocial behaviour desired; transmitting their belief in the guidelines by providing emotional cues; perceiving the child as being prosocial; modelling the desired behaviour and lastly empathic and warm disposition displayed by the parent.

Reinforcements such as praising and rewarding the child for good behaviour like helping and sharing is an important factor. However, such reinforcement is not enough, it may increase the frequency of prosocial behaviours but not their initial emergence (Berk, 2003). Other studies by Fabes, Fultz, Eisenberg, May-Plumlee and Christopher, (1989) found that rewards may actually inhibit prosocial behaviour. As noted in Schaffer's (1996) list, modelling, whereby caregivers either deliberately or automatically exhibit prosocial acts has a much larger bearing on whether children will behave in a similar way (Berk, 2003). According to an experiment by Bar-Tal (1976), merely telling a child what to do in a situation has little effect on them exhibiting prosociality. It has been shown that children whose parents are prosocial also tend to be prosocial themselves (Papalia, Olds & Feldman, 1998). Besides modelling, prosocial behaviour can be taught more effectively if the child is guided to consider and understand the consequence and effect of their behaviour on others (Krevans & Gibbs, 1996).

Trommsdorff (1991) stated that mothers who know how to take perspective and reason with their children have a higher chance of having children who are emotionally responsive. When parents also provide boundaries and guide the child to use moral reasoning, the effects are longer lasting. For example, showing the child the consequences of his/her behaviour on others (you see how Sipho looks happy when you share your toys with him?) is more helpful because the child will remember and enact the principle of prosocial actions independently in the future without external encouragement. This is called induction (Cole & Cole, 2001).

The sibling relationship affords greater chances to develop prosociality than in single-child situations because the nature of the interactions demands it. The birth order also has a bearing on prosociality as older children tend to feel more responsible and therefore show more caring behaviours, especially in parentified children. These are children who meet the needs of the parent and a situation where a role-reversal takes place. This concept will be further talked about in proceeding sections. This opportunity is heightened when there is a conflict in the home. Children become more prosocial to the victimized parent and siblings in order to lessen the other's anguish, but if the situation is

too intense, it may cause the child to empathize to the point of distress to the self. This will actually result in decreased prosocial acts, as the focus will now be on the self (Eisenberg & Fabes, 1998).

The home is the most significant context for socialisation and for the development of prosociality, especially in the first 7 years of the child's life (Eisenberg and Fabes, 1998). The children's microsystem may at first consist mostly of the family, but as they grow and are exposed to school, neighbourhood friends and larger community, their context enlarges and becomes more complex. Children spend a large amount of their waking hours at school. Significant school experiences are imbedded both in structured learning and play activities as well as in unstructured relationships that children form with their friends. This provides a developmental thrust because the environment that they are exposed to and interact with impacts on the children and likewise the children impact on their environment (Papalia, Olds & Feldman, 1998).

Eisenberg and Fabes (1998) argue that children who have caring, supportive relationships with their teachers and a good working environment, such as collaboration of teachers and students, and a positive school environment where students feel safe and have a sense of belonging and integration within the school have been associated with greater levels of prosociality (Williams, 1999). In addition, schools which have community service programmes that teach children social responsibility have been shown to produce children who are more other-orientated and helpful (Papalia, Olds & Feldman, 1998).

The quality of peer relations is an important indicator of overall social functioning. Peer acceptance has been found to be directly related to prosocial behaviour and great emotional distress is experienced when this support from peers is perceived as lacking (Wentzel & McNamara, 1999). A deficiency in prosocial skills at the beginning of a school year predicted becoming rejected by peers. Rejection by peers and a feeling of isolation again reinforces the deficiencies in prosociality. Peer interaction that enhances prosociality can begin as young as infancy when a few days old babies have been shown to have more empathic regard for other babies more than they do for adults as shown

through crying (Eisenberg & Fabes, 1998). As was stated previously, empathy is a predictor of prosocial behaviour in many cases.

Besides socialisation in the home and relationships in school and with peers, the media also has an influence on children. Television programmes which show prosocial behaviour are shown to be beneficial for children (Friedrich & Stein, cited in Eysenck, 2004). However, studies have shown that the modern child who spend less time interacting with others and more time in front of the television, playing video-games or other gadgets such as cell-phones etc, may have a tendency towards being self-absorbed and to be less empathic to others as their social cues and connection is less refined and somewhat 'out of practice' (Browne & Hamilton-Giachritsis, 2005). In addition, while there are various thoughts on the effects of violent media on the child, most research seems to support that it may encourage more socially inappropriate behaviour (Konijn, Bijvank & Bushman, 2007). There as also been ample focus in recent years on publicised philanthropic efforts by celebrities in the media on issues around HIV/AIDS, cancer and refugees.

Culture and Religion

According to researchers, far more prosocial behaviour exists in community based, collectivist cultures than in individualistic societies. Whiting and Whiting (cited in Eysenck, 2004) found that 100% of the Kenyan children of ages 3-10 they studied exhibited altruistic and prosocial behaviour as opposed to 8% of the American children. Kenyan culture is known to be collectivist and American is considered to be individualistic. A study by Eisenberg and Mussen, (cited in Eisenberg & Fabes, 1998), made the same observation: that children from Western, urban environments tend to be less cooperative in their behaviour than those from traditional rural and agrarian communities. This is especially so in societies where help from the children is inculcated and demanded. Another example is that of the Kibbutz system in Israel where the communal setting purposefully is created to produce helpful and socially orientated children and adults (Papalia et al., 1998).

South Africa finds itself in a unique position that has its population sitting on the cusp of both realms. Due to its socio-political background, migration trends and economic process, South Africa has a diverse mix of cultures, socio-economic backgrounds and races. Post-apartheid, contemporary South Africans have more contact with people from backgrounds that are different from theirs and therefore it is difficult to attach a particular culture to a heterogeneous society. However, a significant component in the cultural ethos of the country is the concept of 'ubuntu' – "I am because you are". This construct of unity obligates individuals to help others in a spirit of fellowship at least on a theoretical realm (Ramose, 2003). The rising rate of criminal activity in the country that includes violent acts seems to be a contradiction to this concept.

Societies where there is a strong religious orientation have a strict approach to social responsibility and a sense of duty to others and are more likely to exhibit greater prosocial behaviour than less religious countries (Miller cited in Eisenberg & Fabes, 1998). Indeed the spiritual teachings of many religions propose the interconnectedness of all things and so the golden rule of "do unto others as you would have them do unto you" is a part of every major world religion. Since religious virtues of charity, generosity, helping and serving are acculturated as societal norms, this golden rule is a significant contributor to the emergence of prosocial capacities in religious communities and individuals (Penner et al, 2005). The major religions of the world including Christianity, Islam, Buddhism, Hinduism, Judaism as well as the Bahai Faith emphasise the moral imperative ordained by a Supreme Being to do good to others. In effect, according to the Bahai Faith, indeed this golden rule, along with other teachings which fall under spiritual principles are the part of all world religions that do not change. What is evolved and altered is the social guidance that is suited to the age in which the religion is revealed. Illustrated in the religious scriptures of these religions are numerous parables, stories, analogies and commands either emphatically stating or alluding to prosocial acts. In Judaism, the Jews were obliged to assist the poverty-stricken, in the Christian Bible, it is personified in the imagery of the 'good Samaritan', in the Islamic Quran, acting charitably is stated as being one of the five pillars of the religion (Pearson 1997;

Mcchesney, 1995). In the Bahai Faith, assistance to one's community and servitude is elevated to be the highest station that an individual can attain (Abbas, 1911).

According to research by Saroglou, Pichon, Trompette, Verschueren and Dernelle (2005), there is an impact of perceived religious adherence on prosocial behaviour and that it does not reflect self-delusion. Therefore, the research participants who were religious not only perceived themselves as being prosocial but were also perceived as such by their peers such as friends, siblings and colleagues.

2.2.4 Ecological Systems Theory of Development

An approach that looks at the various factors explored above and amalgamates them in a compact theory of human relations is Bronfenbrenner's (1979) Ecological Systems Theory. The main tenet of this theory is that different systems in the environment influence the development of the child and it is through the complex and dynamic feedback loops that the child's identity, behaviour and beliefs are moulded.

There are 5 main systems that Brofenbrenner has outlined and they are: the microsystem which is where the child lives and which has the most direct influence. It comprises of the child's family, friends, school and neighbourhood. The child is not just influenced however, but is an agent that in turn constructs this context. The Mesosystem is the links between the aspects of the microsystems. The Exosystem includes the connections between the social context where the child doesn't play a role and does not concern him/her and the child's own context. The fourth part is the Macrosystem which is the larger socio-cultural context in which the child lives and includes socioeconomic status, race, religion and ethnicity. Last is the aspect that Brofenbrenner added much later, and is the Chronosystem. This describes the series of events and transitions in the environment in the course of the child's lifetime as well as the evolution and historical context in which the child has come from and exists in.

With regards to the impact of Brofenbrenner's work on the study of prosocial behaviour, it has been increasingly clear that it is the influence of multiple systems and factors like

the individual, family, society, culture and religion as well as the socio-political environments that shape a child's prosocial behaviour.

Brofenbrenner's (1970) study on the prosocial behaviour of children living under the communist regime in the then Soviet Union outlined how the intricate layering and synergy between the systems outlined above is much more than combining various factors, but rather evinces an effect that indelibly moulds the child's very identity towards a strong prosocial disposition.

The preceding sections looked at the various factors in the development of prosocial behaviour. They interact in complex ways to bring out such aspects as helpfulness, consideration and sharing behaviour. In subsequent sections, the special population group that is children with cancer will be explored and studies around the prosocial behaviour of this demographic will be further expanded upon.

It would therefore seem that the most viable way of explaining prosocial behaviour (and by definition and nature of the concept) is through the bio-psycho-social perspective.

2.3 Paediatric Oncology

Cancer is one of the most devastating and mysterious of diseases. It is less common in children than in adults. There are approximately 700 children who get diagnosed with cancer every year in South Africa (CHOC, 2009). It is also rare to find the types of cancer that adults get experienced by children. The types of cancers that children mostly get are Leukaemia (cancer of the blood), Neuroblastoma (nervous system), Osteosarcoma (bone), Hodgkin's and Non-Hodgkin's lymphoma (lymph nodes) and Nephroblastoma (kidney) as well as types of cancers that involve other types of areas such as the brain and eyes. A third of all childhood cancers and therefore the most common, is Leukaemia (Parker et al, 1979). Much of the cancer in children forms when immature cells develop into abnormal cells in type, shape or size.

Oncology which is the study of cancer, has not yet found a definitive cure for all types of cancer. However, children's cancer are much more treatable and the resilience of children's bodies lend to a much better prognosis. In addition, treatments have progressed to such an extent that according to the American Cancer Society (2008), there has been a survival increase in children with cancer by about 45% since the 1960's. 77% of children treated for cancer survive 5 years or longer and according to the CHOC (Childhood Cancer Foundation of South Africa) (2009), about 70% of children who have been ill can be cured in South Africa. There are different treatments depending on the type of cancer it is: It can either be surgically removed if it is a tumour, and/or treated with chemotherapy or radiotherapy which is the use of chemicals or radiation to kill off cancer cells. These treatments may have adverse side-effects such as nausea, hair loss, fatigue, skin-rashes and mouth ulcers.

While children with a chronic illness like cancer may have some similar desires, developmental requirements and a need for nurturance to other children, their lives have very important differences too (Hobbs, 1985). These differences manifest themselves on various levels from emotional, physical, psychological, systemic and familial to practical aspects. Their illness not only becomes what they have but what they are as well, it morphs as part of their identity (Massie, cited in Hobbs,1985).

One of the main departures is around the experience of pain. Depending on what type of cancer the child has, pain may be part of his/her general life. Enduring it, bearing it, fearing its return, crying about it and accepting it (Hobbs, 1985). Even if there may not be pain caused by the cancer itself, the side-effects take a toll on their body. These treatments take create emotional rollercoaster rides. At times there may disfigurement from surgery or hair-loss, marks that make them feel different and embarrass them. Even if there may not be physical markers of illness, due to their absence or display of fatigue, they may be singled out and rejected by other children at times. According to a study by Alderfer, Wieber and Hartmann (2001) children with a chronic illness were less accepted in their peer groups than healthy children. The lengthy times they are separated from friends and at times family make them feel lonely and forlorn. Their lives are marked by

trips to the hospital and long stays which fill them with boredom and impatience. At times they get angry with the experience and lash out feeling like they are helpless and out of control. Children are also prone to confusion with regards to their diagnosis or treatment and may not comprehend their illness in the same way as an adult can. Besides the emotional impact of having a serious illness, the cancer and treatment itself can make the child tired. This can make him/her sad, having little energy or motivation for the things that he/she used to be excited about. This can make them anhedonic and depressed (Parker et al, 1979). Children sometimes express depression in the form of irritability and anger outbursts.

Children react to and comprehend their illness differently depending on their age (Parker et al, 1979) and emotional development (Perrin & Gerrity, 1984). Understanding of illness is tied to general milestones reached, for example, very small children's concrete stage corresponds to magical thinking and an ego-centric inclination. They may feel that the reason they have cancer is because they are being punished for something wrong they did, for being bad. Their understanding then moves to deductive reasoning that includes cause and consequence (Hobbs, 1985). At the same time the child's identity forms as they start getting older. The age group between 7 and 14 is a time of enquiry and questioning and the ability to understand by listening and going through experiences. Children in this group understand that one becomes sick from contamination and then you get better when you do what the doctor says (Hobbs, 1985). There is also an awareness at this age that one is different from other normal and healthy children. Some may regress and become infantile in their responses, others may become aggressive (Parker et al, 1979). They are able to listen to the truth of the diagnosis and have an opportunity to be a full participant in their management. However, whatever age the child is, cancer is a stressful experience and has similar effects to other types of traumas.

Hospital settings have also advanced and with the aid of such organizations like CHOC, they are now more patient-friendly. Such alterations to their experience such as allowing parents to stay over with the child, allowing games and other entertainment in the ward and providing simple, child-friendly explanations by specially trained nurses as to the

disease has allowed for better experiences of the management of cancer (CHOC - Childhood Cancer Foundation of South Africa, 2009).

2.4 Children with Cancer and their Prosocial Behaviour

"Those who learned to KNOW death (or come close to it), rather than to fear and fight it, become our teachers about LIFE" (Elizabeth Kübler-Ross, 1985 pp. 17)

There have been meagre publications in the study of prosociality in children with cancer or other chronic illnesses. It appears from some studies that children with chronic illness have more social and behavioural difficulties than other children (Fletcher, 1995; MacLean, 1992 and Mulhern, 1993 cited in Seagle, Jessee & Nagy, 2002). Other studies demonstrated that there are no significant differences between the behaviour of children with chronic illness and healthy children (Creer, 1992; Daltroy, 1992 cited in Seagle et al, 2002). Seagle et al (2002) argue that many of the studies focused on the negative results of chronic illness and stated that their study demonstrated that chronically ill children tended to exhibit higher degrees of altruistic behaviour than healthy school children. In their study they looked at "Chronic illness" as a term for illnesses or conditions that endure for more than 3 months. The study Seagle et al (2002) did, concentrated on paediatric cardiac patients more than half of whom were hospitalized at some point. The sample included children from ages 8 to 12 and were mostly white from middle-class backgrounds.

The factors they outlined for this increase in altruistic choices were two-fold: on the one hand, children who frequent hospitals have contact with other children who are ill and who they can connect to because of their similar circumstances. This interaction spurs on a concern and increased empathy for those who are vulnerable and are somewhat the 'under-dog', due to the understanding that they too are suffering. In addition, children who are constantly exposed to other sick people are afforded greater opportunity to exhibit and in a way 'practice' prosocial behaviour. The other factor is that ill children are in contact with people around them who constantly demonstrate prosocial behaviour

towards them. They care for them, help them and show love and consideration towards them. These behaviours of parents, doctors, nurses, relatives and friends are internalized and modelled by the children (Seagle et al., 2002).

The implications of this research for the further study of prosocial behaviour and health is indeed positive. Various studies have claimed that social skills which prosocial behaviour is a large component of, have direct correlations and a causative link to improvement in personal health and well being. Some journals in Health Canada (Benard, 1991) have asserted that a person's capacities and coping skills determines their health outcome. It was further found by Caprara and Cervone (2000) that the attitudes and skills (strategies, abilities) needed to get ahead in life comprise of cognitive, social and indeed emotional abilities such as sensitivity, empathy, warmth, and perspective taking (Caprara, 2000).

A recent publication by Vollhardt (2009) consolidated different studies around the topic of 'Altruism Born of Suffering and Prosocial Behavior Following Adverse Life Events'. It was found that for some who go through negative experiences such as violence, trauma and illness, become more altruistic and prosocial. This was not only 'despite' their trauma but also 'because of' it. Further research by Reiter-Purtill, Vannatta, Gerhardt, Correll and Noll (2003 cited in Vollhardt, 2009) found that long-term follow ups of chronically ill children showed that their prosociality endured and was more prominent than other children. Chronically ill children were also reported by their teachers as less aggressive and their self-reports were also prosocial. In the same review, research showed that those who were prosocial under traumatic circumstances enhanced their coping abilities and had positive benefits for the person exhibiting it, lowering their levels of depression and post-traumatic stress (Brown et al., 2008; Kishon-Barash et al., 1999; Midlarsky, 1991 cited in Vollhardt, 2009).

There has also been further evidence of a strong correlation between those who survive life-threatening illnesses like cancer and their level of resilience in other studies too (Phipps, 2007). According to Phipps (2007) children with cancer have generally been shown to flourish and cope well. They have lower levels of depression and have adapted

to the stress of treatment and illness. He also argued that this level of resilience and strength was not detrimental to their well-being but indeed served as adaptive defences against the perils of the illness and helped them survive. One can thus hypothesis through a summary of the findings of this type of research which link the resilience of cancer patients and a heightened sense of prosociality.

Therefore, while the effects of chronic illness like cancer is devastating, several studies mentioned above may indicate an outcome of illness that may have interesting implications for the study of prosocial behaviour, which is that prosocial acts may actually enhance wellbeing. While it may not explicitly state the connection in direct terms, however, there may be a possibility that children who are ill and who have better capacity to engage in prosocial activities may indeed have a higher survival rate, may stave off a recurrence after remission and may enjoy a better quality of life. Another rational of this study is to study the impact of cancer on children and whether their behaviour patterns, in specific relation to prosociality, has changed or remained the same. It is important to study how an illness impacts individuals and how they may make meaning of the outcome of the illness.

Another component of this subject is that of resilience. Resilience can be defined as “a tendency to return to a state” and “buoyancy, springing back and power of recovery” (Oxford English Dictionary, 2003). According to Eisenberg et al. (1989, p.63), children who had prosocial inclinations were more likely to be “well-adjusted, good at coping and self-controlled”. In a research by Block and Block (1973) that was conducted, children and adolescents who scored high on helpfulness, consideration for others and interested in ethical subjects scored high on ‘ego-resiliency’ which is “the ability to recover after stressful experiences”. Ego strength and coping skills earlier in life predicted increased prosocial behaviour later. Furthermore, pre-adolescents who were prosocial also scored higher in levels of ego-strength, confidence and self-esteem.

Overall it was observed through different studies that children with strong prosocial orientation “appear to be better adjusted, socially skilled, more expressive, more

gregarious, and somewhat aggressive or assertive" (Eisenberg et al.,1989, p.65). These studies however have not been consistently reliable and may have loose associations between the findings. There is also a question of valid causality. Is it because they are resilient that they are prosocial or has their resilience emerged because of their prosociality?

One can thus hypothesise through a summary of the findings of this type of research which link the resilience of cancer patients and a heightened sense of prosociality. A leap of tentative connections can then be made between the special resilience of cancer patients and a heightened sense of prosociality as per the studies cited in Eisenberg et al., 1989).

Other studies have however have not supported this explanation. According to Parker and Mauger (1979), some children with cancer have an inclination to regress emotionally and act in a manner that is much younger than their chronological age. This dependent, babyish behaviour is a way of eliciting greater care from those around them and is a cry for support by a child who is fearful, overwhelmed and confused. At times they may use their illness deliberately to harness attention and reassurance. It would be argued that a child's regression to an infantile state would make him/her more likely to be less resilient and thus illicit more support and care from others rather than providing similar care to others.

In addition, certain types of cancer treatment such as corticosteroid based chemotherapy such as prednisone and or decadron may cause mood swings and irritability (Hukovic & Brown, 2003). Chemotherapy suppresses the immune system which can have adverse effects on stress management and it can be debated that it may then decrease prosocial acts as well. Gailliot (2006) argued that prosocial behaviour can require effort and might be lowered by decreased levels of metabolic energy. As was discussed in the previous section, one of the symptoms of cancer or consequence of treatment is fatigue (Hobbs, 1985). It may be then, that a decrease in energy of cancer patients may well prevent them from showing behaviours like helping and caring, since the effort needed would be more

than that which they can muster. Another symptom of cancer which as been mentioned is pain. Approximately 60% of children with cancer have pain because of the illness itself or the treatment. Children experiencing pain may not be as compliant and cooperative or in general prosocial with the hospital staff or others (Pinkerton, Cushing & Sepion, 1994). Therefore, while there have been some studies that confirm the positive influences of life stressors such as chronic illness on the emergence of prosocial behaviour, there are other instances where they may decrease it.

In another study, it was indicated that one of the ways in which children face and accept stress is through altruistic behaviour. Thus children who have been diagnosed with cancer or other life threatening illnesses may use altruism as a mechanism to cope with the illness. (Vaillant, 1997). Altruism may be used as a defence whereby children use it to forego their own problems by helping others, especially parents and siblings (Fonagy & Target, 2003). They gain satisfaction from the helper role and from knowing that they are being useful. They therefore try to alleviate their own distress by doing good to others. The negative aspect is that they do not allow themselves to be carefree or irresponsible and grow up too quickly in a process termed 'adultification' by Maeder (1989). These children maturate and become older than their chronological age. They take on a parentified role of caring for their parents and others. Miller (1995) agreed with this take and added that parentification, especially to narcissistically needy parents may hamper normal psychological development. Freud (1923) likewise talked about the concept where other-directed libidinal investment may deplete one's own resources.

Socially, it has been shown that the more support the ill get, the better their prognosis. However, the study by Alderfer et al (2001) stated that ill children were less accepted by their peers as compared to a control group of healthy children. Having stated that, an interesting result of the study showed the following: that ill children who showed more altruistic or prosocial behaviour were more likely to be accepted by their peers than children who were not. Therefore as a worthwhile incentive, doing good earns them the reward of better assimilation post-hospitalisation, as they try return back to their everyday environment.

Further inferences can be made from research dealing with similar traits and factors relating to the general body of work on prosocial behaviour. In a study that looked at the social functioning of children with chronic illness, it was discovered that the children were more compliant and cooperative than the normal population (Meijer & Sinnema, 2000).

Prosocial behaviour can also be related to what stage of an illness the person may be in and whether they are closer to death. Furthermore, the setting in which the children with cancer are treated is also important. Children who are hospitalized see themselves as being closer to death since that is "where people go to die" (Bluebond-Langner, 1978:11). The saliency of their morbidity may is therefore stronger as in-patients rather than in the out-patient or clinic context. Their perception of time also changes. Unlike other children, especially those who are still concrete in their thinking, children who are chronically ill tend to see time as being finite even more so than peers of the same developmental level. Due to this they did not talk about what would happen of the future and felt time is not to be wasted and therefore are more likely to engage in behaviour that is beneficial to others.

Bluebond-Langner (1978) found that chronically ill children can change roles, act appropriately in different social settings and are attuned to their surroundings. They become highly perceptive also of what the other child patients in their ward are going through and whether or not they died. This brings their own death closer to reality. It is also interesting to note that terminally ill children come to see their role in life as supporting others and they can tend to become nurturers. This is especially so if the parents and those around them have high levels of anxiety about their illness (Cook, 1974). This gives such children a sense of self-worth and a hope that they will leave a legacy that is long-lasting. However, this only usually comes about when they have been told they are chronically ill and have come to accept their fate. In their initial stage when they first feel like they are dying, they may be silent, withdrawn, show regressive behaviour or may even display anger – which are opposing indicators of prosociality.

Their level of prosocial behaviour may also depend on which stage of Elizabeth Kübler-Ross's (1969) stage of death acceptance they are in: denial, anger, bargaining, depression or acceptance (Cook, 1974) Although there is some debate as to the validity of this framework, it would stand to reason that if the child is in the anger or depression stage, it may not be in a position to demonstrate prosociality whereas if they are in denial, bargaining or acceptance stage, they may indeed show increased levels of prosocial behaviour.

According to a study of patients who are terminally ill, there is a difference in attitudes and behaviours of patients who experience mortality saliency, which is the realization that death may be nigh. They tend to be more selfish and greedy than others, whereas the patient who has near-death feelings and finds a sense of transcendence and growth from the experience through death reflection has the perspective of this world that possessions are empty and meaningless and demonstrate unselfish behaviour. (Cozzolino, Staples, Meyers & Samboceti, 2004). It may be debated that even though this study was done particularly on material greed and its opposing quality of generosity, one may generalize this virtue to other types of prosocial behaviour such as sharing and helping behaviour of the non-material type. In another finding by Siegal (2005), there seemed to be much prosocial behaviour exhibited by what he termed "exceptional cancer patients". This is also due to their realization that this physical existence is indeed finite and there is more to life and existence than the self.

For those who have spiritual beliefs, religion and faith in general provides several levels of benefits in times of stress such as being faced with illness. Cardella and Friedlander (2004) suggested that it provides support, as well as ways of explaining and making meaning of the illness. It also provides a sense of control especially when other measures have failed them. In the same article, a study by Kaplan and Blazer (1995 cited in Cardella & Friedlander, 2004)) stated that religion can help manage this type of crisis in several ways including involvement in the congregational aspect of worship to stay active and gain support from members; asking God to provide answers and to assist in the

coping process and existential meaning making to perceive the crisis in healthier ways. Thus, religion can play a strong part in the coping process and derive transcendental experiences that can elevate the victims of such tragedies from the rawness of the situation.

Therefore, while there have been some studies that confirm the positive influences of life stressors such as chronic illness on the emergence of prosocial behaviour, there are other instances where they may decrease it.

2.5 Parents of Children with Cancer

And a woman who held a babe against her bosom said, Speak to us of Children. And he said: Your children are not your children. They are the sons and daughters of Life's longing for itself. They come through you but not from you, And though they are with you, yet they belong not to you".

Khalil Gibran

As was noted in the previous sections, the rate of survival in children has increased exponentially in recent years and therefore parents and family members will take on the stress of caring for ill children and going through the emotional turmoil for longer periods (Cardella & Friedlander, 2004). The impact of cancer is not only on the afflicted but also on the somehow affected through their kinship and relational ties or emotional connection with the patient (Hogan, 1997). Thus the trauma that the diagnosis and treatment of cancer inflicts on the siblings, friends, relatives and most significantly, parents, cannot be underestimated (Pinkerton, Cushing & Sepion, 1994). Parents may go through similar stages of grief that Elizabeth Kübler-Ross (1969) outlined, not in terms of the death of the child but rather the diagnosis of an illness that is feared. Parents may go through the stages of denial, anger, bartering, depression and acceptance.

There is a similar model looking at reactions in the face of illness where at first there may also be a tendency to fall into a self-critical mode, where the caregiver may blame

themselves for not catching the illness earlier, for not being adequately observant, for failing in their protection of their child and other self-berating thoughts (Pinkerton et al, 1994). For parents, it is important to produce 'unimpaired offspring' and if there is illness in the child, the parent may experience inadequacy as a caregiver and may feel responsible for the illness no matter how irrational it may be (Cook, 1974). Their anxiety may be so high as to elicit in their children caring behaviour resulting in role reversal. At this point, children may become parentified where they start comforting and providing support to the parent instead of the other way around. After the feelings of guilt, there may be anger, hostility or bitterness may be felt at the doctors and at times toward the child itself (Cook, 1974). Anger can be energy-sapping, making the parent to feel spent until they move to the stage of demystification, where they become more proactive in investigating their child's condition and looking for information with regards to treatment. This is termed 'conditional acceptance' (cited in Pinkerton et al, 1994).

Faced with their child's illness and possible death, caregivers may feel confused, distraught and desperate. They are thrust into a juncture where they will have to negotiate overwhelming feelings in order to care for and be there for their sick child (Parker et al, 1979). There are also difference reactions to an adversity such as this and different caregivers have different reactions. Some parents at times pretend that nothing was wrong so as not to alarm their children because they perceived them as fragile (Cook, 1974). In a study by Meyler, Guerin, Kiernan and Breatnach (2006) found that parents talked about how important having a positive outlook was in assisting them get through their child's illness. Having the belief that the family can survive the onslaught was a significant coping mechanism. They also stated the function of faith and religion in this ability to go on.

Besides the emotional pain and fear it causes, cancer is also demanding in terms of time. There may be long periods where the parent will stay with the child in the hospital, take him/her to treatments and sit in waiting rooms (Parker et al, 1979). There is also the financial burden of medical expenses. When a parent is putting time, care and attention into the sick child, other siblings may feel neglected and may regress to gain attention.

Much of the earlier literature that concerned parents and children with cancer focused on parents' perceptions of and responses to their dying child as the mortality rate of cancer sufferers was much more pronounced than in recent times. With the advancement of oncology research, treatment and management, childhood cancer was no longer a portender of death and so parents had to start coping more with the symptomology, treatment and the anxiety caused by a possible terminal status rather than palliative caring for a dying child per se (Woodgate et al, 2003).

However, the most common reaction is that of care and tenderness toward the child and this loving behaviour toward the child would then be the factor that would increase the altruistic choices made by the child itself. As had been stated in previous sections, nurturing caregivers like parents and hospital staff like nurses provides the best model for the children to demonstrate increased prosociality themselves (Seagle et al, 2002).

2.6 Perception and Halo Effect

According to Hannig (2002), parents do tend to idealise their children. This is especially so for sick children. With regards to perception, there is a concept in marketing and previously in the personality theory of Harold Kelly (1955) termed 'the halo effect'. This describes a human bias whereby a person's interpretation of qualities of the overall person is influenced by the traits one observes at first glance (Kalick, 1988). Thus for example attractive people are perceived to be more intelligent and kinder than unattractive people, only from the first point of contact. There may be a possibility if further research confirmed it, that this same concept can be applied to those who are regarded as appealing to one's emotions because of their fragile state may be perceived as having qualities that, even if existing may be exaggerated.

With regards to the present study, it should be noted that the experience of parents is a fluid and ever-changing phenomenon. It transforms continuously and is a reflection of the

dynamics of a systemic influence (Woodgate et al, 2003). The more support the parent gets from other sources, the better the communication and care within the hospital and the more attuned the family is to each other's needs, the better the parents feel they can cope. In addition, what parents choose to focus on as they narrate their experiences of having a child with cancer is telling of their state of mind. In a study that Woodgate and Degner (2003) carried out, it was noted that in their interviews, parents continuously chose to speak about their experience as a whole even when questions targeted specific aspects such as the symptoms of the child.

CHAPTER 3: METHODS

3.1 Aim of the Research

As was mentioned in the introductory chapter, this was a study on parents' perceptions of the possible prosocial behaviour of their children who were either previously afflicted with or were presently undergoing treatment with cancer. The research attempted to explore several aspects of the topic: Firstly, it looked at the parents' experiences of their child and his/her behaviour in general. Secondly, it focused on the way they conceptualized and viewed their children's prosociality after their treatment and whether they saw fluctuations in the levels of prosocial behaviour. Thirdly, it aimed to explore the attributions provided by the parents as to what influenced this change.

3.2 Research Questions

This research addresses several levels of enquiry:

1. What are parental experiences of the general behaviour and specifically, of the prosocial behaviour of children who are ill with cancer?
2. Do the parents perceive that there have been changes in their child's prosocial behaviour after the treatment process?
3. If they do feel that their prosocial behaviour has changed, what are the attributions provided by the caregivers as to what influenced this change?

Supplementary questions:

- What are the salient narratives that parents speak about with regards to their child's illness?
- How do they respond to seemingly anxiety-provoking questions?
- What is silently communicated in their unanswered or evaded questions?

3.3 Research Design

The present study is a qualitative one which is the interpretive enquiry into a phenomenon. It attempts to capture and weave the insider narratives of participants and takes into account the role of the researcher in making sense of the material. It stems from the epistemological heritage of empathically observing the participants and relating to the material from an interactional position in that the relationship between the researcher and the participant is noted and deemed important (Terre Blanche & Durrheim, 1999). The ontological stand point is that of exploring the internal reality of the participants and eliciting their subjective experiences rather than empirically obtaining facts. Such an interpretive study is inductive in its reasoning because there is an immersion in the details of the data and thereafter the extraction of themes and patterns from within the vast content rather than attempting to prove or disprove an already existing hypothesis.

The term 'perceptions' of caregivers was added to the title and stated in the present research so as to emphasise the interpretive nature of the study. The fact of whether or not their children did have an increase in their prosocial behaviour in the external reality is not as important as what the caregivers' subjective view of the phenomenon under enquiry was. Therefore the qualitative framework and the instrument used were well suited to exploring the topic under investigation as it enabled a detailed analysis of the material and find nuances in both process and content (Patton, 2002). The research questions were open-ended and aimed to invite narratives and in-depth search for meanings. A critical approach is also taken to the data collected which looks at the information provided at face value but also under a 'hermeneutic of suspicion', in that what is omitted is seen as silently communicated and is given a voice through a commentary on the process (Strous, 2006). A hermeneutic circle is also a significant aspect of a qualitative research in that it allows the movement, back and forth between the parts of the whole and the text (Ormiston & Schrift, 1990) so as to decipher the links thereof.

Lastly a reflexive attitude toward qualitative research was required to respect and ensure the intersubjective nature of this model (Terre Blanche et al, 1999). Reflexivity requires a constant consciousness of the role of the researcher to the meaning making process and how it is not possible to remain objective when carrying out the study. In this process, the contribution of the researcher and the way it informs the final product is constantly reflected upon, hence the term 'reflexivity'. (Nightingale & Cromby, 1999). This kind of personal reflexivity allows introspection of the researcher's values, beliefs and worldviews around the topic of research and how this impacts on the way one conducts the study. The person of the researcher is therefore part and parcel of the material and one's input cannot be obviated but worked through on a continuous basis. Researcher bias then assists to enrich the material rather than subvert it.

3.4 Sample

A purposeful, non-randomised and non-probability research procedure was used for this research since it requires a specific group of people, relevant to the topic, to explore the constructs described. The sample consisted of 9 parents of chronically ill, 7-12 year old children with cancer, who have been in-patients at the Haematology-Oncology Ward at Johannesburg General for a week or more prior to the interviews and were at the time of the data-collection being treated as out-patients. This sample size was dependent on the availability of children at the ward. The sample number is sufficient as the study is qualitative and the data gathered is rich and descriptive and therefore does not require a large sample size. Even though it will not be a representative sample in the statistical sense and the stories are of a personal nature, it is hoped that the issues explored can provide insights and can shed light on the experiences of parents of children with cancer in general.

The participants of the study were the parents of the children. One parent per child was required and the parent chosen was the one who was the most involved in the child's hospitalisation or treatment process. They were termed 'caregivers' due to the fact that

the initial design of the research included both the parents of the children as well as the nurses engaged in taking care of the children while in hospital.

The data gleaned from the nurses' questionnaire and behaviour scale was to be used as supplementary information to the parental interviews so as to get a holistic sense of those collectively named 'caregivers'. However, there were certain challenges faced in using nurses as part of the sample, such as the transitional nature of the staffing turnover, the self-reported inadequacy on the part of the nurses to be able to report on the prosocial behaviour of the children they encountered and other logistical matters. Therefore this part of the design was modified from using the nurses, to using volunteers instead. These volunteers do art, beading and baking with the children. However, once again, the volunteers did not feel that they were able to provide a checklist of behaviours because they did not have ample chances on a one-on-one basis to know the children in question adequately. One of the volunteers who did, knew only 3 children out of the 9 children. It was then decided to solely use the parental information and pursue an analysis of both content and process so as to add depth to the data. Therefore the title of the thesis was changed to 'Parental Perceptions of the Prosocial Behaviour of Children with Cancer.'

3.5 Instruments

The research instrument used was a self-devised, semi-structured interview schedule for the parents. The questions were formulated to include aspects of prosocial behaviour that were operationalised as expressions of helping, sharing and caring behaviour. However, other questions were open ended and as general as possible so as to illicit the type of information they are comfortable in providing as well as to get a sense of the salient features of their experiences as reflected in their narrative (see below and in appendix A). Due to the reflexive nature of the paradigm and the hermeneutic circle of enquiry, some interview questions were added at later stages in the data collection process. It was more of a spontaneous enhancement of the interview repertoire than an officially added segment. This was due to the growth of the researcher within the process of the data collection and having purviews of how the procedure can be enhanced for optimum gathering of material.

Additional material was obtained from a part-time nurse that works at the Oncology-Haematology unit in the capacity of nursing counsellor by helping parents and children understand the illness and providing psycho-social support. This supplementary data was information regarding the length of stay in the hospital of the child and other such information which can aid in the interpretation of the interviews (see appendix B). These questions looked at information regarding the length of stay in hospital by the child, the type of cancer the child had and what their general mood was like after hospitalisation in her experience of them. One of the questions that tried to gain the prognosis of the illness was not permitted by the Oncology ward because it was deemed irrelevant. The rationale behind the decision to include it in the initial set of questions was because the knowledge of prognosis is an important determinant of the parent's state of emotional wellbeing at the time of the interview as well as their perceptions and views with regards to their child's behaviour and their level of idealisation. This question was however removed so as to adhere to the wishes of the ward.

The following were the questions asked to the parents:

1. How has your child differed in their behaviour in general since they have been at the hospital?
2. Have you noticed any changes in their behaviour regarding sharing and if so, in what ways?
3. Have you noticed any changes in their behaviour regarding helping and if so, in what ways?
4. Have you noticed any changes in their behaviour regarding caring and if so, in what ways?
5. What are the possible reasons for the change?
6. How does your child talk about and make sense of his/her illness?

7.What has your child's experience been like since hospitalization?

8.What has your child been talking about since hospitalization?

9.What has been the general mood of your child like since hospitalization?

3.6 Procedure

The head of the Haematology-Oncology Ward at Johannesburg General granted written permission (see appendix G) and the resident social worker gave verbal consent to conduct the study in the ward after meeting with the researcher, consultations with ward management, perusal of the research proposal and upon provision of an ethics clearance. An internal Ethics Committee provided a clearance certificate from the University of the Witwatersrand (see appendix F). The aforementioned nursing counsellor was instrumental in providing a list of patients and their parents' contact details after she gained permission from them. The parents were then contacted by the researcher, asked for verbal consent to participate in the interview and thereafter arrange an appointment to conduct the interview. The interviews were carried out at various venues depending on the location of the participants and treatment schedule. Some were conducted at the Oncology ward, others at the CHOC House, a house sponsored by CHOC (Childhood Cancer Foundation of South Africa) where parents who do not live in close proximity to the Johannesburg Hospital are able to stay for the duration of the outpatient treatments or before and after hospitalisation. Still others were conducted at the residences of the participants.

3.7 Data Analysis

The data obtained from the interviews was processed and broken down using thematic content analysis. This type of analysis is what is required to examine the qualitative material drawn from the participants' interviews and to peer into their perceptions, experiences and worldview with regards to their children who are afflicted with cancer and more specifically to their prosocial behaviour.

Thematic content analysis helps the researcher to find patterns within the material then shape them into themes and thereafter report on them in discrete units of meaning (Braun & Clarke, 2006). The reason this type of technique was used was firstly, because it was the best way of organising a large amount of material from the transcribed interviews, into more manageable data. Secondly an important rationale was that it assists in the interpretation of the narratives as was explained in the research design section. By virtue of this research being qualitative, the method of analysing it needs to correlate with the ontological underpinnings of this type of study. This method can be used across different theoretical frameworks and models. Braun and Clarke (2006) provided five useful steps the researcher would follow in order to analyse the material using this system:

Step one involves the researcher getting familiarised with the data set by firstly transcribing the interviews then reading it several times. Secondly, it requires generating codes, which are data bits of meaning that can stand alone. These codes are then collated into potential themes. The fourth phase is when the themes are reviewed and checked back to the codes. The fifth step is to refine the themes and build them up. Lastly, the material is reported in the results section by providing quotations and extracts from the data itself.

Further analysis techniques were used beyond Braun and Clarke (2006), such as summarising each of the participant's accounts and de-bulking the extensive transcripts through finding points of relevance. Thereafter doing horizontal comparisons of the points in cross-case analyses where the researcher created matrices of the data sets. This reduces the data further so as to draw further themes and conclusions (Miles & Huberman, 1994).

3.8 Ethical Considerations

Cancer is a serious life-threatening disease which can cause much suffering not only physically but also psychologically. This emotional suffering is not confined only to the patients themselves but to loved ones as well. The fear of death of their children, confusion of one's state of being and the uncertainty of the prognosis can make the

parents of ill children sensitive to certain interview questions. Therefore the questions have been selected carefully and delicate questions excluded from the interviews. The more sensitive topics around the medical issues were deferred to the aforementioned nurse. In addition, it was incumbent upon the research to be in tune with the participant's state so as to listen out for moments when he/she was emotionally aroused and uncomfortable to go on. However, while it may be that some questions may stir up emotional reactions, it should also be noted that the opportunity for the parents to talk to someone other than a medical practitioner or family member about their child's condition may even be beneficial in a cathartic sense.

Information sheets were given to the participants prior to each interview (see appendix C). Permission to conduct and record the interviews was also obtained (see appendix D and E). Confidentiality forms that were included in the consent forms were also signed by the researcher due to the sensitive nature of the study (appendix D and E). Confidentiality was further ensured by omitting the names of both the children and parents from the report and transcripts of the recordings and instead utilising participant numbers.

If in the event that the participants required counselling subsequent to the interview, this was prearranged with the resident ward social worker to provide. The participants were informed at the start of the interview that if they experienced distress, such a service was available for them. They were also informed through the information letter as well as at times verbally when the situation demanded it, that there would be no negative consequences to them not taking part in the study. It was communicated to them that they were free to withdraw for any reason at anytime during the interview or the study in general without any adverse implications, if they feel it is causing them discomfort or if they experience any negative effects.

All raw data from the recordings, as well as the tapes is to be destroyed after the study is completed. All the transcribed material was kept out of reach of any other parties apart from the researcher and supervisor so as to maintain confidentiality. A summary of the results of the study can be made available to the hospital and parents on request.

CHAPTER 4: RESULTS

The data discussed in the Results Chapter comes from the participants' responses. These parents shared their experiences, feelings and perceptions about their child in different ways, varying in levels of depth, disclosure, detail and emphasis. However, the responses can be grouped into two main categories: i) behavioural and character attributes in the first category and ii) process of the illness itself. From these two streams, distinct patterns of meaning were gleaned and these can be grouped into seven main themes under the first category and two within the second. While several of the themes were as a response to the questions asked in the interview, still others spontaneously emerged beyond the scope of the structured questions and the significance of this will be explored further in the discussions chapter. Finally, a salient thread that interweaves throughout the responses of the participants will be presented. A summary of the individual participants' accounts has been provided so as to familiarise the reader with what the researcher perceived as salient aspects of the interviews. The themes that follow are presented in no particular order of prominence, emphasis or chronology. While some of the themes may overlap, it was felt prudent to retain them as independent themes due to the nuanced variations in tone and meaning beyond the semantic expression. For the function of clarity and to assist with the audit trail, a table of the themes and frequency of respondents is presented below:

Table 4.1: Demographic Table of Participants

Parent	Relation	Child	Age	Sex	Type of Cancer	**Duration of Illness	Race
*Participant 1	mother	Child 1	12	Female	Ewings Sarcoma	03/03 to 2004	White
Participant 2	mother	Child 2	9	Male	Fibrillary Astrocytoma of spinal cord	7/12/08 to present	Black
Participant 3	mother	Child 3	11	Male	Non- Hodgskins Lymphoma	11/07 to 07/08	Indian
Participant 4	mother	Child 4	7	Female	Acute Lymphoblastic Leukemia	03/08 to 08/08	Indian
Participant 5	mother	Child 5	11	Male	Medullablastoma	25/09/08 to present	Coloured
Participant 6	mother	Child 6	10	Female	Alveolar Rhabdomyosarcoma	4/07 to 09/07	Black
Participant 7	mother	Child 7	13	Female	Rhabdomyosarcoma	05/05 to 2006	Black
Participant 8	mother	Child 8	10	Female	Rhabdomyosarcoma	08/03 to 2004	Black
Participant 9	father	Child 9	8	Female	Acute Lymphoblastic Leukemia	10/06 to present	Coloured

***** Participant 1 will be referred to as P1 and Child 1 will be C1. Same trend will apply to all the participants.
** Duration of illness is relative as some come for maintenance treatment even if not acutely ill and in remission.

4.1 Summary of Participants' Accounts

The participants can be grouped together according to what they expressed about their children's behaviour and how they talked about them. Their accounts have been specifically grouped around more concise themes as will be provided in the next section of this chapter. With regards to their individual reports however, the following provides a summary of what they said and the process of how it was related:

P1 had an overall air of love and good feelings as she spoke about C1. She spent over an hour talking about her child and related details about the process of the diagnosis, symptoms and the treatment that C1 underwent. She explained that C1 went through a horrific time but came out of it with many attributes. She described C1 as being a very lively child and due to her experiences, C1 became vocal about the plight of children with cancer and became an advocate by shareing her knowledge about it so as to be a motivation and inspiration to others. P1 verbalised that C1 is very positive and optimistic

and how she played a role in protecting her mother from worrying and comforting the family.

While P1 spoke much about C1 achievements and attributes, P2 spoke briefly and mostly spoke about the diagnosis process and the confusion and uncertainty that went with it. She emphasised her anxiety at the time and felt her family was instrumental in supporting her both in terms of material resources with regards to finding a hospital as well as emotionally. P2 spoke of how C2 did not experience or complain about pain and how he was a healthy child before the diagnosis. She describes him as a cooperative and easy going child but that she had a role in this. She related that he was very considerate and understanding in the way he responded and was a very caring child. P2 describes C2 as being a playful and happy.

P3’s interview was the longest out of the nine participants. She spoke in detail about all aspects of her child and the illness. P3 described C3 as very pleasant and happy-go-lucky. She further explained that at the time of his admission into the hospital, C3 was in a lot of pain and he was irritable and ill-tempered. Once he was over this phase, he improved rapidly and was a strong and enduring patient whose attitude lessened the burden and anxiety of the family. He was inquisitive and wanted to understand his illness and treatment. She further said that he is a considerate and understanding child who is thoughtful about the well-being of his family. P3 stated that he is sharing, unselfish and helpful and attributed aspects of his prosocial behaviour to his illness.

Like P2, P4's initial comments were about the confusion they felt as parents in the wake of the diagnosis of C4's illness and the sense of helplessness they experienced in not being able to explain the illness to C4. A good portion of her narrative was in describing how much she feels C4 has grown into a mature girl since her experiences at the hospital. She describes her as being more confident, outspoken and assertive when it comes to her dealings with peers as well as the doctors. She has become more communicative and expressive and describes her daughter as being a teacher and advisor, wanting to talk about her illness and sharing her experiences with others.

As can be discerned, comments about lengthy hospitalisation and treatment regimes have been common among the participants as it was with P5. The initial confusions about C5's symptoms and diagnosis concerned P5 as did not realise that they were serious and caused by a life-threatening illness. She was emotionally sensitive during the interview and broke down in tears intermittently. She described C5 as an active child who used to play a lot and was a normal child. However, once he became ill she felt that things decelerated and he became very different, as though he was a stranger. She therefore had a firm belief in God and her narrative was strewn by this kind of discourse. She felt that she needed to be patient and have a sense of hope that he will be healthy again. P5 expressed that at times C5 would become short-tempered and angry, demanding, irritable and discourteous but attributed this to the treatment regime as well as the disappointments he had about his illness.

In a similar vein as P5, P6 explained that C6 was a sweet, patient and forbearing girl but that during her treatment, she became short-tempered and rude. The doctor had explained that it may be the chemotherapy and P6 felt that it changed her at the time. Now she is friendly, outgoing, confident and talkative child who is able to explain the illness well to others. P6 feels that she has grown up more and is more perceptive and capable of understanding a lot more than she was able to. She is a teacher and likes to instruct others in class even while the teacher is explaining. She has said to her mother that she wants to be a social worker so that she can help the children that are suffering. According to P6, she is attentive to the needs of others and wants to help and care for them.

P7 did not speak much and language may have been one of the problems. She explained that C7 was hospitalised 4 years ago and that she had a short-temper and attributed it to the illness. She was in much pain and because there was nothing she could do about it, she took it out on others, getting angry. Her short-temper started when she was undergoing the chemotherapy treatments and P7 explained that before her cancer experience *"she was a normal kid*". P7 described her personality as a child who talks a lot and who likes to play. She likes being with small children and to play with them. She is a helpful child and likes to assist P7 when she is doing the housework. She feels that

she has become more helpful now and the reasons she gives is because she has grown and has become more capable of helping. P7 stated that she likes sharing money, food and clothes. When she was in hospital C7 started saying that she dreamt of God. Thereafter she started to pray every night which is not something she used to do before.

P8 spoke of how C8 was in a lot of pain at the time of hospitalisation and she used to moan a lot as an expression of her pain. She stated that she was talkative and spoke of her hopes of the future. P8 felt that C8 is sociable and that she shares experiences with others. P8 emphasised that C8 likes helping and caring for children that are younger than her and is very maternal towards them. Possible reasons she thought of are that she has an increased sense of empathy for other children because of what she went though and P8 regards this quality as being one of her primary strengths.

Lastly, P9 was the only male participant and father of C9. He described C9 as moody and aggressive when she undergoes chemotherapy and after she takes Cortisone. He felt that when she was hospitalised they experienced difficulties. P9 stated that she was always a positive, talkative and friendly child. P9 described C9 as a sharing person who has always been that way but because of her experiences and because she went through what she did, she became even more sharing. She is very caring, considerate and feels for other people and her compassion and empathy for others has increased since her illness and the process she went through. He feels that she has become more concerned about people and how they feel and is a warm person. He attributes this increase in prosocial behaviour to her difficult experiences during the treatment, where she felt uncomfortable, invaded and beleaguered but came out of it with a renewed empathy for others.

4.2 Emerging Themes

Table 4.2: Categories and themes from interviews

CATEGORY 1: BEHAVIOURAL AND CHARACTER ATTRIBUTES	
1. 'The Old Child': maturation of child	P1, P2, P3, P4, P5, P6, P7, P8

and their desire to educate and advise.	
2. 'The Outgoing, Confident Child': level of assertiveness and gregariousness.	P1, P3, P4, P6, P7, P8, P9
3. 'The Jovial and Resilient Child': positivity and inner strength	P1,P2, P3, P4, P6, P8, P9
4. 'Transcendence': ability to rise above the suffering and gain spiritual insights and gratitude.	P1, P3, P4, P5, P7, P8
5. 'The Cancer Made Them Bad': Treatment and illness as attributive factor for negative behaviour	P1, P3, P5, P6, P7, P8, P9
6. 'Concern': ability to empathise and care for others.	P1, P2, P3, P4, P6, P7, P8
7. 'I taught her': Parental role in the instilling of prosocial behaviour in child	P1, P3, P4, P5, P6, P7, P8
CATEGORY 2: PROCESS OF ILLNESS	
1. 'The long beginning': Arduous and lengthy process of diagnosis	P1, P2, P3, P4, P5
2. 'My child's harrowing illness': Parental experiences and feelings around the illness and treatment	P1, P3, P4, P5, P6, P7, P8
Overarching theme: Idealisation of the child by the parent.	

4.2.1 Category 1: Behavioural and Character Attributes

'The Old Child'

The accounts of most of the parents emphasised the phenomenon whereby their child became a teacher and an educator of others after their experience of their illness. They recounted in differing discourse and explanation, the central concept of which can be summed up as their child having grown beyond their years. Many of the parents

portrayed their child as mature and inclined to care for younger children and even have maternal or paternal attitudes towards them. Others dwelt on the child's ability to ameliorate the suffering of the parent by their stoic attitude. These different expressions of the quality described in this theme was appreciated by the parents and considered to be praiseworthy. This was mentioned by 8 out of the 9 participants.

Furthermore, the participants described how their children sought out and cared for those younger than them and provided advice to adults and children alike. There were also instances where parentification or role-inversion occurred in the parent-child dyad, where the child takes on more responsibility than is age-appropriate. This can be in the form of emotional responsibility where the child manages their own anxiety in order to contain the distress of the parent. It may also manifest instrumentally where the child worries about the impact of the illness on finances and job situation of the parent. For the majority of the participants, the qualities described in this section emerged mostly after the experience of the illness.

P4 felt that "*For a 7 year old she is actually a very grown up little child. She understands more than you think. Even in a conversation, she likes to be with, she enjoys being in the company of adults and she will have that kind of a conversation where they will be interested to hear what she's got to say*[1]*……. has that grown-up way of talking.*" P6 expressed similar thoughts saying *"I can say she's more grown up, matured ne, mentally. I can see some changes."* P3 felt that C3 had grown through the experience and stated *"that's why he carries on (before) like a baby. But now, he's gone so responsible suddenly. I noticed when he started school, he came home the first day, he took out his work, he started doing his homework and I ask "is there anything I can do?", "no don't worry, I know what I'm doing, and I'm managing"*

P1 stated how proud of C1 she was for being so empowering and of advising others and explained that she is not like other 12 year-olds. Similar observations were made by P3 who said *"he gives everybody motivational talks now when he comes here and*

[1] Broken lines denote parts of the phrase or statement removed to maintain relevance.

encourages them not to cry when they have to be dripped or any such things." P4 felt that "*she (C4) actually advises, she likes to be the adviser all the children on what they should be doing, on what they shouldn't be doing"*. P6 related *"her (C6) teacher call me one day said "P6 when I'm teaching, she is having her class outside". Because she's caring for those who don't understand so she is trying to show them. The teacher said you don't understand? You see? So she is a teacher herself. The teacher was complaining, "C6 doesn't listen, I teach, she teaches". So I ask her "why do you do this?". "Oh mamma, others they don't even know, they don't even understand English. So I am trying to explain some things to them"*. She added*, "even those younger children, 1 year, she can understand them, she knows how to communicate with the young kids. She knows how to accommodate them."* Similar sentiments were related by P8 saying "*she likes playing with kids, like teaching them and becoming a teacher"*.

There was a subtle sense of the participant's being comforted or helped to contain their parents' anxieties. In a sense there were instances of role inversion, where it was the child who comforted the parent instead of vice-versa. P1 illustrated her daughter's response to her distress: "*she was wheeled off to the operating room to have the tumour cut out, I was obviously in a state.."* Having witnessed this, C1 reacted in the following manner: *"she had this big grin on her face and she said to me, "mummy what are you crying for" and I said "you know I'm really worried about you". She grabbed my hand and told me "I'm going to be fine. You mustn't worry, I'll be fine."* P9 added "*sometimes they say it affects the parents more than the child."* P3 felt that C3 *"make everything easy", "makes things good for us", "he will say I'll be ok and make it easier"* and "*he made this whole thing easier for us with his attitude"*. In the same vein, P3 was touched by her child's ability to comfort her *"when I used to cry and I used to worry he said to me "mummy you mustn't cry because you must accept whatever God gave us."*

With regards to the child feeling burdened with the worries of the parent P5 explained: *"he (C5) was asking me "will I go work again", and I said "why?" and he said "because I know you want to work, because I'm sick you cant go work"* P6 felt that *"Maybe sometimes she (C6) thinks too much, my mother is not working and I am sick, ya*

bona? Those things, because now she's 10 years and she understand everything. She can see the situation." She further added*: "to me, she's always saying "mammy, you must do something, don't get stressed all the time. Do some applications, look for jobs". I say "how can I look for jobs because I'm a caregiver, you see when I leave you alone, who will look after you?" You see? So she is very focused on the future and life and those things. Because really, I'm a single mother, but I was having his father too, but we separated so I'm alone you see? So she always observe everything I do, "oh mummy is suffering", like that, but she's always positive. She's by me, by my side all the time."*

'The Outgoing, Confident Child'

Another salient theme that emerged from the narratives of the participants is the confidence of their children and in their talkative nature (7 out of 9). While some of them were described as being sociable and outgoing prior to the experience of illness, many perceived either an emergence in the level of assertiveness or an increase in their confidence and gregariousness. Furthermore, the traits of increased extroversion and self-assurance were noted as commendable and at times their garrulousness was related in a humorous manner.

Their willingness to share their illness and experiences with others was emphasised in a few of the participants especially in P1. While this characteristic may overlap somewhat with the previously described theme, there is a subtle difference in the tone of the description between the act of educating and advising others about the illness, treatment or other general subjects from a position of knowledge and hierarchical expertise on the one hand and the sharing of lived experience from a more equal stance through an interaction of care and connectedness on the other. In some of the instances, parents depicted an image that seemed to speak of an 'unfolding' or a blooming of the child or a 'coming out'.

P1 spoke much about courage and how her daughter demonstrated bravery and a desire to be an advocate for the fight against cancer. She explained that C1 became a public speaker and a fearless exponent of the cause at a tender age: *"C1 got up on stage and she*

was little, she was only, she was about 9 and a half, she got up and she spoke to all these women and she said you know this is what I've been through. And she's actually got that thing where she wants to talk". P1 goes on to acknowledge how much she values it and how she perceives it to be a therapeutic process: *"……which I think is great, I think that's also that's also been helping her with her own thing you know."* She adds *"it (cancer) has given her a tool which she can use to help other people. Whereas before she was always an outgoing child, but she didn't have something which she could help other people with, like a concrete thing she can help with. Now that she's been through that experience and she's happy to share that."* P6 portrayed C6 saying "*she loves everybody"* and "*she is always open*".

Talkativeness was one of the qualities that most of the parents mentioned (8 out of 9) and which was seen as a pre-existing trait afore hospitalisation. P9 verbalised, *"She calls herself a chatterbox because she chats about everything. She just talks and talks about every little thing."* P3 accounted of the situation when C3 was back at school and how he kept raising his hands to talk "*he has a lot of things he wants to say and speak about, he wants to speak constantly to everybody"*. P6 felt this way about C6: *"she's friendly and open and she can present herself about cancer. She is free….," " She is talking a lot. Even if you can interview her, she can tell you better"* and she describes C6's affable nature endearingly saying: *"even if she got friends, she invite some friends, sleep here……. even the parents say "we don't know….but our children are crying about C6. So she is just like that, she is a social people, she socialise."* She further states: "*She is very very very good. Even she's having friendship with the caregivers. When she just enters ward 294, they said oooh, all the staff, all the nurses, "C6 is here". Really she is like that."* The salient aspect of P7 daughter's personality for her was that "*she likes to talk. She talks a lot."* Similarly for P8, C8: *"talks a lot" and "she likes to go out, like to go with friends, you know like visiting mostly."*

With regards to confidence, P4 described her child as being "*more confident*" and " *her way of thinking, she is more open with the doctors in telling them what is wrong with her now, before it was always having to hide*". P4 attributes this to her role in it: "*I would say*

this is not how it should be, you must tell the doctors if there is something wrong because they can help you, they are here to look after you. So in that sense that fear has come out." P6 stated *"she knows, even to express her doctor, her feelings to her doctor. Even if I'm not there, even if she got sick, at the hospital during the school hours, she just go to the doctor and negotiate to the doctor".*

'The Jovial and Resilient Child'

Almost all the participants (8 out of 9) emphasised the trait of a positive disposition in their children. They described them as having the pervasive quality of happiness both before and after hospitalisation. Some may have accounted for the period during the treatment phase where their joyful attitude was lacking, however, they resumed back to this state once the cancer was managed.

Most of the participants who fell in this description perceived this state of being as ideal and was treated as being unique and awe-inspiring especially due to the circumstances in which the child was enshrouded. The attribute of hopefulness despite the illness was talked about frequently where the child would talk about his/her future prospects and dreams. Some of the children were felt to be resilient and strong, capable of enduring great suffering and pain – both physical and emotional.

P1 described these qualities frequently and made an emphasis an incident where a woman who C1 was encouraging stated *"your child is amazing, she said she has such an inner strength.* Again, *" And she just had this knowledge, she was going to make it and she was so positive. So that I think has really carried her through. She is desperate to share this positivity with others. You know what I mean, just fight, no matter what you do, just fight. That's helped us in the home situation as well. Because you do get worried and you do wonder gosh, where is this going to end up. And she was so positive and so enthusiastic about everything. And you can't help but be that way yourself. And you just know this kid is, she just knows something, she's going to be cool, which helped us tremendously."* She talked about another example: *"she'd give me this big smile and say Mummy I'm fine. And I was just like you know what this kid can't be fine. She must be feeling*

horrible. She would climb back into bed cos obviously she'd be standing over the basin and she would say to me, mummy lets go Barbies again. And she had such an inner strength. I would look at this and think wow this kid is amazing. Absolutely incredible and even with the radiation, she went through a terrible time with that, she was badly burnt and that to me was one of the most difficult times. And she was still so strong through that, and she would say to me, mummy you mustn't worry, I'll be fine. That was just so incredible to, it was almost an insight that she had. And I felt you know what, she knows she's going to be ok. And that was amazing." She further reiterated her resilience by saying: *" when she puts her mind on something and she excels at it. You know, she's such a fighter in all respects, she's not going to get anything get her down." "She just had this, its an ever, a never-ending spark almost. And it's unbelievable. That fight and positivity is just, it's just something she got. And I don't think it was an act or anything like that."* P2 only mentioned briefly: *"I know it is hard for him but he is a strong boy."*

P3 emphasised that: *"he's a very pleasant child.……if you ask anyone around here, they will tell you he is very pleasant, he is happy, go-lucky. He made this whole thing very easy for us with his attitude. He is a very happy child."* She had the perception that *"he hasn't been affected, he's not afraid of anything. Ok he is in remission now but he wasn't one day afraid of what's going to happen, what could happen, I don't know, he's very positive, my son. He looks at everything in a good way, he doesn't have any bad feelings. Ya, that makes things good for us."* One of the reasons she attributes for him being this way is: *"he is always laughing and joking and that so I don't know if…because he was like that even here, maybe its also him being the youngest, he was always spoiled and he always got a lot of attention and then after he got diagnosed again so obviously our whole lives revolved around him so maybe that also kept him so happy knowing that everybody is just willing to do everything and anything for him because it was myself, my husband, the whole family actually, they were so supportive.....I guess that's what kept him so happy and supported just knowing that everyone is just there and that they would do anything in the world to just keep him smiling and happy."*

P4 felt that C4 became more positive than she was before *"she will talk about about just doing things in her life when she grows older. Going to [2]???? Just depends on the conversation we're having but it's never "if I make it". She hasn't got that. She's got a very positive drive to go forward. "* On the other hand, P6 felt she had a role in cheering and distracting C6 when she was feeling low *"Even if I can see today he is very very upset, I try to collect her and show her and do some things so that you can forget everything."* She also mentioned "she's very focused about future" and *"She is talking most of the time, like when she grow up she want to be you know to work, go to school, work, so she can buy whatever she wants. Live a lively life".*

P9 illustrated her resilience and ability to bounce back when he spoke of the time when C9 had to have her hair shaved: *"She just enjoyed it. She was always a fun person and making jokes about it"* And he further adds: *"She's always been a positive person ya, like my wife always says, she is a morning person. When she wakes up in the morning, she's always friendly and so on. So ya that is how she normally goes through life, always being positive, ya. That's actually what we do appreciate about her. "* C9 also talks about *"what she would like to be one day."*

'Transcendence'

While the concept of resilience may describe the pervasive attribute that many of the children possessed as perceived by their parents, this next theme goes beyond the ability to bounce back. It has the additive quality of overcoming the horror of what transpired during the course of the illness and thereafter transcend the mundane trappings of the experience and find meaning in surmounting the unthinkable. It is going beyond the make-up of the character to transforming into a new kind of insight that lends itself to spirituality and faith. Part of this theme is the process of gratitude not only 'despite' the trauma they went through but for some, as it will be seen through some of the quotes, 'because of' of the distress they went through. This overall quality was perceived in 7 of the 9 participants.

[2] Multiple question marks denote segments of the interview such as a word or phrase that was not audible for transcription.

P1 found that C1 "*would have this almost aura around her*" and felt it was *"great"….."because a lot of kids I think almost block it off, they don't want to ever talk about it. Once they're in remission or they're cured they want to block of that part of their life completely, don't ever remind them again, they're over it and that's fine. Whereas she doesn't, she actually wants to go out there and talk."* She added *"I think this whole cancer experience has actually increased that in a way (positivity). She knows that she can almost look at death in the face and just carry on, it's amazing."* Furthermore: *"by going through the whole experience and knowing that like some days she wasn't feeling well. The days when she is well, to be so grateful for that. ……she said she gets so cross with normal people, you know they moan about a little flu or something. They don't actually know what illness really is.…… She's made me realize that there is so much to be grateful for. ……. She knows so many things in life and she's so very grateful for them. Even being alive. She said to me, I am so grateful I'm alive. And she almost lives every moment of her life to the maximum. She doesn't stop for a minute. She's like a jack in the box. And that's almost like an inner wisdom that she's got, that even if it's a bad situation, turn it around and look for the good in it. And she said to me, if she hadn't gone through the cancer story, she would never have been able to be so grateful for it. Because she can look back on it and just realize how lucky she is."*

P3 understood the process in this way: *"Somehow we got strength, God gave us strength and I suppose when you're in such a situation you just need to make the best of every single day and I think you know being so focused on what was happening with him and keeping him happy and that, we didn't have time to be unhappy, to feel sorry for yourself that you, to even think what am I feeling about what's happening."* Again she said*: "maybe sometimes God has a reason for things that happen and He knows best. Obviously initially you feel why, and why is this happening to me and why my child and that but maybe God knows best why it was He chose him, maybe he was strong enough to go through something like this because I cant think of many children that can go through this. There is just few children here and they somehow get through it and each and everyone of them are just so wonderful."*

A part of this quote was mentioned under the first theme 'the old child' due to its relevance to the quality of maturity and parentification. It is once again placed here and extended since it pertains to the attribute of faith and spiritual transcendence as well: *"he (C3) said to me "mummy you mustn't cry because you must accept whatever God gave us. Whatever's gonna happen. And I'm not afraid for what's gonna happen." And I said and I thought why is this child saying this to me? And I said "you not afraid of anything? You not afraid because I mean something could happen, I could lose you. I cry because I could lose you. You not afraid that something happens to you?" And he said "no mummy, I'm not afraid if something happens to me."*

P4 compared C4 with the other children in the hospital: *"in a situation where she was better off…… I said to her I said "this is where you have to see you're better and you must be grateful". So her views have changed a little bit more on that. Realising that she is, she looks after her body but the control is not hers, the control is His from the above. So appreciate and be grateful for that. For everyday, thank God that you've got today. Ya, it's it's, the level is actually very very spiritual. I'm trying to get that into her system, so it has changed with her as well."* With regards to the possibilities of death P4 said *"she's having to go in for check ups so often. So yes in that sense she knows that where it is but not the depth of you know that the possibilities of this could be death. We do explain to her that everyone has to die one day. How we go and when we go is not in our hands."*

P5's narrative was punctuated by numerous remarks about reliance on God and the need to have faith. She would say *"but there is hope and I know the Almighty will help us succeed."* To encourage C5 in his times of darkness and lethargy, she would say to him: *"there is no such word as people feeling you sorry and you can not feel sorry for yourself, it is a gift of life and you've got to accept what the Almighty has given you ……. you've got to fight this thing, forget about what happened and just look front, look to the future"*. Like P4, P5 used the other patients in the hospital and disclosed: *"when I saw those kids in the hospital they were very very sick children and would the doctors help*

and Almighty they are recovering, these kids were worse that you and they put an effort and they tried and they tried so you must also do it you know…We don't want to force, force you you know but slowly slowly you will be there…That's all I can think of."

C6 was likewise encouraged by her mother, P6 in this way by referring to divine assistance: *"ok ma, you'll study, you'll get a better education, God will help you, you'll be alright"*. To portray C6's ability to overcome she expressed: *"Maybe I can say, maybe she believe she's a survivor I can say. Because she has so many many children who were dying before her. She lost many many friends, you see. But she can see now, "I'm a survivor and I'm only left with one month to finish my treatment. Really, we can see she's a survivor really."*

P7 illustrated C7's sudden inclination towards spirituality: *"when C7 was in hospital she changes like that, like believing in God. I didn't, she was like, she even said to me "I dream about God, He told me I'm going to be ok". And every night in hospital, she will say "let's pray". It was something that was new to me because she never does that before. So in hospital we pray and I dream I am going to be ok. Or sometimes she just say "I don't know why God choose me to be sick". So it's something that I don't know, I also don't know. Why me. ……No like its something we don't know, God, ya. Just like we have to pray you get better, that's all ya. And then she was like ok. So she got into that habit, we pray. Every time we always pray."*

While P8 described C8 as being irritable when she was on treatment, she said she is mostly happy now and perceived her as having overcome it "*she has accepted her illness now, she has accepted her illness. When she tell herself that she's healed, she's healed."* And P9 mentioned *"She somehow found a way to understand it and to bear with it. That she has to come here and she has to bear with it. But I suppose children have their own way of coping with things also."*

'The Cancer Made Them Bad'

As many as 7 out of the 9 participants commented on their children's behaviour that they considered 'bad' or negative. They observed attitudes or moods that were undesirable and concerning. What all but 1 had in common was that they attributed their 'badness' either directly to their treatment or to the process of the illness itself and the losses and disappointment associated with it. Most reported that this was behaviour that emerged as a result of the treatment process and not as part of the personality or character of the child him/herself.

For P1, it was the process of being ostracised at school due to the illness as well as the fatigue associated with frequenting the hospital that caused the difficulties *"So she was sick and tired of hospitals, she hated every minute of it, she was a horrible patient. She fought them every minute she got. When they told her they were going to get a drip in, they literally had to pin her down. It was so embarrassing for me because I just knew that my kid was gonna fight. It was really really difficult so she was, she got a lot of anger being at school and being in a situation where no one fully understood what she was going through".*

P3 warned *"Ok if you see him now, he's a little moody because he is under anaesthetic but generally if you ask anyone around here, they will tell you he is very pleasant."* She further explained: *"When we came in here he was in a lot of pain. His leg was sore. He wouldn't allow anyone to touch it. He wouldn't trust anyone to touch his leg at that time. So obviously he was very, I would say…I wouldn't say rude. It was because of his pain……If anyone would come into the room he would scream. "get out of here, go off from here". It was a different child. This was another child, not the child that I brought up. Overnight he changed. He would scream, he would swear."*

P4 focused more on the effect of the medication itself: *"You know with this medication as well, she gets irritated she gets to a point were everything snaps……Sometimes she speaks out of line which I think that also is due to the fact that we first left this medication, it was because of the medicine. You know the medicine would then have these*

funny moods". She therefore exhorted her *"At this present time, we know that yes the medicine does make you feel like that but that's not a reason that you have to be that way. So we also had to pull our ranks and get her into a routine with that too. So her mood swings sometimes, she does tend to go out of line but we do trim her down. We do talk about it and get her to understand."*

P5 attributed the misbehaviour to the disappointment of getting sick: *"And sometimes he is very short tempered you know. He gets cross very quickly now. And if he wants something, it must be there. He's very, how can I say….everything irritates him. He doesn't want noise or he doesn't want things that aren't suitable for him. He says to me the other day "if I said no, its no" and "don't force me", that's the first word from his mouth."* She added: *"From my point of view I think he is disappointed to see himself…He hasn't seen himself properly from the time he was diagnosed*".

P6 described how short-tempered C6 became: *"it has changed a little bit, C6 is a sweet girl….. But now after the treatment, she is very very very rude. If you say something she is just go, lashing and she is very very wild you know. One day I told the doctor and the doctor told me that ya, maybe it's the treatment."* Again she stated *"she was a kind girl you see, but since she was, she she got this chemotherapy and everything treatment, she is not no more C6 completely. She's a new person."* P6 made a reference to the pervasive aspect of her personality being prosocial versus the fleeting fluctuations in mood which she had associated with her medication: *"it's a gift I can say (C6's ability to share). It's a gift. Because it doesn't change. But even if this thing of being wild, sometimes I don't know, I can say wild, but she quickly cool up and she became fine again yes."*

P7 explained: *"I think they have a temper, I think it's from the sickness. When they were ill, there was nothing they could do. Its like that, because she got temper, she get angry, she force the things, she's like that.……...It's since she's been hospitalised. She is like that now. That time she wasn't, she is like that now. …..Moody ya.…..If she wants something, she wants something. If you say "no", she gets so angry. But at the same time, after a while she cools off she will be just ok."* Her reasoning was that the temper was more due

to a defence mechanism to abate the anxiety around her illness *"From when she was having chemotherapy in hospital. It started like then. If I don't want, I want, then I don't want, for me it's the thing…..I was thinking that when she was very sick, there was like nothing…, there was nothing she can do. She was like sick. I think when something, she can control of something, she say I want this, I want to eat this, she just want to eat that. You have to give it to her that thing. It's something she can control that. She can't control her sickness. That's what I was seeing when I was seeing like that, losing temper like that.* Then she reverts back to attributing it to the treatment*: "She was like that but temper no. Temper it was after. All those chemotherapies"*.

P9 mostly described how difficult the experience was *"with her I think it's quite difficult because obviously with the chemo treatment, at times she becomes very moody. Very moody, very aggressive with the brother and at times even with us as the parents. And I suppose here and there she also like make use situation for her own advantages. So ya. I must say that has been quite challenging, especially with her having to take I think, she has to take the cortisone tablets, I think every beginning of the month they give her a dose of cortisone for a whole week. Like now she's taking 8 tablets for a whole week everyday. The week after that then yassi, she becomes very difficult because of the steroids. It becomes quite challenging."* He then outlines how different she is from before the treatment *"That was a difficult time also because she was just not herself….with chemo I mean, if it is so difficult for adults, how much more for children? It just throws the mood swings completely off hey."*

'Concern '

One of the outstanding virtues that many of the parents talked about is that of empathy or the ability to put themselves in others' shoes, worry about them and show concern for them. More than the remarks on individual prosocial behaviour such as sharing and helpfulness, they dwelt rather on the broader ability to have concern about others and act on that concern. Many commented on how remarkable this was and saw it as a positive contribution that was special to their child. Some saw their child as selfless and almost self-sacrificial in their caring of others.

P1 discovered in her child a thoughtfulness for others that she was amazed by *"her (C1) aim in life is to go and help other kids because she knew, she could fully understand where they're coming from. Where they sit on that hospital bed and they are trying to insert a drip and the kid is screaming, C1 actually goes around, when we go for checkups, she actually goes around, she will sit with the kids and she will say to them, "I know exactly what you're going through."* She gives other examples: *"she'll go around and say you know mummy there's actually a lady that's crying, don't you want to go and talk to her? You know so she actually goes."* She explains this level of empathy *"because she's gone through it, she's able to actually link with other people. Like a normal person, you actually have no idea what a cancer person goes through until you've walked that road yourself. That's her willingness to share that whole experience" and "she's been through it and she's experienced it. It's given her that total understanding that she can care for somebody no matter what they've gone through. Because she's been through a broad spectrum of things. She can really empathise and sympathise with those people. Which is great for a kid to go and do that lot and she's said to me, she wants this to become her thing in life."* Furthermore *"Seeing all these kids around her not being well. I would sort of say to her how are you feeling and she says no I'm fine. I would say are you sure? And she would say yes, look at these kids, they're not doing well."*

P2 mentioned briefly that C2 is a sweet child who shares and says "*he is so caring*". P3 spoke more and felt that C3 is a very understanding child. She explained and gave reasons for his ability to give *"he doesn't have a single selfish bone in his body this child of mine and he would give everything of his away and I think by carrying a sickness like that you start realising you mustn't attach importance to little little things because you don't know for how long you gonna use it or what's gonna happen tomorrow and that. So with him it's only about giving things. If he eats, he would never eat alone, everybody had to eat with him. No matter what he does, if I'm cooking, he wants to help me cook, if I just say my back is sore, he wants to rub my back for me. My mother has osteoporosis and all the time that he was sick, he would need us to go to the toilet and that and he would never allow my mother to carry him, yet he would allow her to do everything else*

and she would say to him, "I can do anything, you mustn't worry, I can even put you on the toilet". But he would say no ma, what about your back? And what if something happens to your back and she would try to convince him. But because he knew from the time he was a child that her back is not too good, he wouldn't allow her to carry him or do anything that would be difficult. He worries about everybody, he cares about everybody." She makes further attributions: *"when you come so close to losing somebody so close to you, obviously you start realising what's important in life. And you start realising what you can lose so easily also." "He's not a difficult child and he doesn't demand attention. I don't know if it's because he gets attention all the time or what but he makes things so easy for us".* She continued to talk about an incident where he wanted to mend the contention between two boys at school by intervening with negotiations: *"they are going to make peace between these two boys because I think when he went to school he just felt that everybody needs to play with everybody and everybody needs to be everyone's friend. So he had to do that. So he said "mummy I need to fix it and they need to be buddies again."* She added *"maybe he's just being kind. Maybe because of what he went through and coming here obviously you start realising that you're not the only person in this world because you see so many children…..And maybe going through that and so now he feels everybody needs to be friends with everybody.……..…* and he wants to look after anyone suddenly*."*

P4 identified the attribute of concern in C4 saying: *"She (C4) tends to ask, how are they (the other children in the ward) coping? I mean just the kids here, every morning when she wakes up she'll ask "how's he feeling", if she saw the child wasn't feeling well the night before. Or when we go to hospital and she sees a child that is not looking so well that she knows of, she will always ask you know, how is that person?"* An interesting variation in P4's account from the other participants is that in her change towards a more assertive stance, her need to make others happy has not been at the cost of her own happiness *"she was always one to make everybody happy and not herself (but that this has shifted."* P4 goes on saying: *"She loves everything. She loves to give. You know, she would think of everyone in her life. It's not just about her. Like when she's praying she would say "look after me and look after the rest of the children." You know, that is to,*

it's not just about herself." One of the reasons she provides for this is her encouragement of C4 to *"Care for others like the care she got."*

P6 stated briefly that she was *"a sweet.....and kind girl"* (before she started becoming short-tempered – see above). She continues to say *"She is helpful and she wants to participate. Even if I'm cooking in the kitchen she will say mamma please I want to help you"*. For the quality of concern, P6 depicted a more serious and far-reaching gesture by quoting C6's intention: *"mamma I want to be a social worker, I want to do. I can see children are suffering, oooh pain, chemotherapy, I want to do this and this in the hospital."* She gives further examples saying: *"even if she see a person with something "mamma, you see that lady, maybe it's cancer, I want to help him, let me tell him that Johannesburg Hospital is healing. He can be alright". I say ok my dear. She is very sympathetic."* P6 felt that this is a pervasive aspect of her character *"She is more caring because since she was born, and watching her growing up, I saw this lady, maybe she can be somebody else, because, she's very very very caring, she is a loving girl. She loves everybody.....she is very kind I can say, she loves to share, sympathetic, a good girl."*

P9 stated that C9 *"was always caring and she was always sharing and so on. She was diagnosed at a very early age. I mean she was 6 years old when she was diagnosed with it. I think with every child, there is some selfishness initially but I think as things have progressed in her life, I think she is becoming more of a sharing kind of person now."* He added *"she doesn't really like to see people struggle. I don't know if it is because of what she has been going through. Because I remember, it was 2007 when she had an infection somehow in the blood system or whatever. Then she had to be hospitalised at Donald Gordon Hospital. That was a difficult time also because she was just not herself. But ever since that time, what I can see from her, she is, she just doesn't like other people in discomfort or people who are helpless and so on. She has become more of a ???? person.....You know if she sees people asking for food on the road, she would always want us to help them. If she find out that people aren't having food you know people are struggling, she would always want us to do something for them."* He differentiated it from before the illness saying *"her behaviour has really changed I mean, she is more*

concerned about the people…… She is a very warm person". He attributes this to an increase in her levels of empathy *"For me the only thing I can ascribe it to is the fact that she herself has been going though quite a difficult time…….…… I think all those things make her not to like to see other people struggling or in discomfort or whatever you know."*

Two other participants somewhat mentioned aspects of this theme but did not elaborate further: P7 felt that C7 is helpful but attributed it to her growing up and that she was cared for in terms of modelling and P8 briefly stated "*she's (C8) caring, she can feel for other people."*

'I taught her'

This theme was not a prominent one but nevertheless was found in some of the parent's accounts. It was especially emphasised by P4 and P5 and somewhat mentioned by others like P1. It appeared that some of the parents felt that they had a hand in the inculcation of prosocial behaviour in the broad and strict sense in their children. This was either by instruction and deliberate teaching or through modelling. This was at times conscious and other times less deliberate attempts on their part to shape not only worthy behaviour but also a desirable attitude such as gratefulness, cooperation, courage and spiritual sensibilities. They therefore use it as one of the attributions for the development of prosocial behaviour in their children.

P1 mentioned her encouragement of C1 to help others, *"And I actually said to C1 you know, go and talk to this lady it turned out that this lady didn't want to carry on with the treatment."* P2 spoke about how she had to encourage C2 to cooperate and comply with the rigors of treatment, *"I talk to him a lot. You are ok my boy, just do this. As they said he must try to walk. He was so….what can I say…I encourage him and he was willingly, to do what I say and his physiotherapist told him.*" P3 stated that she had to teach her children not to be materialistic and to share things with others "*But generally my children, I've always taught them not to attach importance to any thing (material things)"*. Overall, P4 was the one that emphasized this point saying, "*I have also told her*

on that, that you have been given things here by other kids who don't need them then when you are through with playing with it you must also give your things away so it does to other needy children. So in that sense she has this broad view, that when she gets she must give." "I try to teach her and guide her as much as I can, things that I feel is good for her, for her to understand that life is not all about keeping things for herself". She also encouraged C4 to be more grateful, *"I said to her I said 'this is where you have to see you're better and you must be grateful'. So her views have changed a little bit more on that. Realising that she is, she looks after her body but the control is not hers, the control is His from the above. So appreciate and be grateful for that. For everyday, thank God that you've got today. Ya, it's it's, the level is actually very very spiritual. I'm trying to get that into her system."* P6 felt not only did she assist C6 in becoming more prosocial but also made an effort to make her feel better, *"she is more helpful now because I always accommodate her you see. And try to be closer to her, you see? Ya. Even if I can see today he is very very upset, I try to collect her and show her and do some things so that you can forget everything."*

P3 illustrated the concept of modelling when she stated, *"He (C3) tries to make them feel better about them (being dripped) now and that initially, I had to do that for him but now he does it."* P4 likewise stated, "at the same time you have to also you have to give the care to other children like the care you got" and "because we've spent a lot of time now as opposed to being in school and she spent the time with me, I think she got some of my characteristics. …….. because she tends to a lot of wise comments". P1 also talked about modelling an attitude and a sense of positivity and how it impacts on the child, "Because it's very difficult, if the parents aren't positive as well. I actually noticed in that hospital situation, things don't go that well. You have to have that mindset". An interesting attribution made by P7 about her daughter's increased level of helpfulness is somewhat linked to modelling behaviour of others but also is framed as a debt transaction, "I think maybe that can be maybe because when she was ill everyone was helping her. She had a lot of support from friends, family, everybody. Maybe its like she is kind of paying that".

For P8 and P5, they verbalised their sense of inadequacy in being able to instil prosocial behaviour and how their children did not heed to their instructions or counsels. P8 said about C8, **"**sometimes when I can ask her to wash dishes or clean the house she says "I'll do it, I'll do it" and then she doesn't". In a similar vein, P5 talked about trying to teach C5 to share when he would be possessive and to be more sociable, "*sometimes I tell him those things are just immaterial things. It's given to you, you must share. And then he would say 'but they gave me' But I said how can you play, you cannot play alone, you've gotta play with,….. with the kids*." P5 also tried to instill a sense of acquiescence "*you've got to accept what the Almighty has given you*." She described how after she would say these things to him, he would just walk away.

4.2.2 Category 2: Process of Illness

'The long beginning'

Some of the parents talked at length about how arduous and prolonged the process of diagnosis was. They felt confused and lost in the mess of information and initial misdiagnoses. Some had to consult several health care practitioners before they finally managed to come to the last point of hospitalisation. The initial shock was somewhat mentioned by a few but none spoke of denial or disbelief. Two of the participants, P1, P2 and P3 delved into this topic, speaking spontaneously and with much detail about their children's diagnosis and treatment.

Even though her C1 was diagnosed 5 years prior to the interview, P1 recollections of the initial phases were made with much detail and intact memory, "She was diagnosed in October 2003. With Euwing Sarcoma in her leg. What they did was they gave her chemo to shrink the tumour and then in December they cut the tumour out, then they gave her more chemo and she had radiation and then the rest of the treatment for the rest of the year was chemo." She also talked about the 'unknown'," I was also a bit clueless about this whole thing. So I got a whole lot of information from the books and the internet and that kind of thing, and talking to people". P2 spoke at length and also with considerable

detail about the diagnostic procedures, her initial feelings of the diagnosis and how lengthy it was, “I just noticed that he doesn’t walk like he used to in January last year 2008. I just took him to the doctors. They told me that he was born like that. So we weren’t able to see it at first…….. They said everything is ok and there is nothing wrong with him. I said ‘no how can you say that because when he walks, he walks like there is something that is put in his knees’. ……After there is a doctor who was at Union, he come from Johannesburg, when he see him he said no man, take him to Johannesburg Hospital, they have the specialists for this sickness …….they said that it is not clear what it is. Also they said there’s supposed to do a biopsy for the second time. I didn’t want to sign the paper for second time. I was so confused, I didn’t even call my mother because I knew she’d be shocked so I called my brother……Then he went for the operation. They said they still didn’t know. I was stressed, what’s wrong with my boy? ……After two weeks after the operation, they said they couldn’t find anything, so they need to do another scan. I was so shocked.” P3 likewise spoke without being prompted, “He was 10 when we came in and that was about a year ago. Actually more than a year ago, it was 2007 end of November. He finally got diagnosed with cancer and that’s when we finally came into hospital. He got diagnosed privately and then when we found out, the best doctor to see was Dr ….., the oncologist so that’s how come we came here. I suppose that’s the best thing we ever did for C3…….. we were just going from doctor to doctor and he just wasn’t getting well and they just couldn’t find out what was wrong with him and it was like sometimes every day we were at some doctor and nobody knew what was going on and nobody would tell us what’s wrong with him and they were just trying a whole lot of tests and blood tests and more tests and he wasn’t getting well, he was getting worse.” She went on to talk of her feelings of initial mis-prognosis, “The doctor that I was seeing at that time, when I asked him what are you trying to say to me, what’s going to happen to my son, are you trying to say I’m gonna lose him and he said to me maybe 5 months, that’s exactly what he said to me so obviously at that time we thought of the worst, we never thought we were going to see this day that he would be in remission.”

P5 spoke about how the initial diagnosis affected her son, “He was diagnosed in September month 2008. Is it 11th or 7th? And thereafter we were at a hospital..... He (C5) used to be normal as the other kids are (starts crying)……..and when we received this news that he’s got brain cancer, everything just went down.” She went on to discuss his initial symptoms and how difficult it was for her to know what was wrong with C5, “Apparently he started getting headaches, always got a headache, headache, headache…I would say you so young you always got a headache, I would say to him stop being in the sun, wear a cap and all that but eventually he started getting very like tired, ……..and I didn’t really take notice of it until he started vomiting and getting weak, loosing weight and always tired, tired…Until he fell at school and then the principle called me and said this child is very weak, go and take him to a doctor, that’s how we took him to hospital and we…that’s when they found out he’s got cancer.”

P8 talked about the initial pain and the sequence of events leading up to C8’s diagnosis, “See before she was diagnosed she had an accident. She fell from the tree and then she had a knee operation. The leg, on the side of her. It was a big operation. So after that then she was diagnosed with cancer. I don’t know whether it started there. So she (C8) moans a lot about that.”

‘My child’s harrowing illness’

Many of the parents talked about the process of the child’s illness and treatment and their own feelings and experiences regarding it. This was once again expressed without prompting. This theme has similar aspects to the previous one, however, as was mentioned in the previous category, some subjects were further split to preserve the subtle nuances of the themes. Besides feelings of anxiety, worry and distress, some parents also spoke about their own resilient responses, self-sacrifice and around aspects of adherence and compliance to treatment and the implications thereof.

P1 spent much time describing the diagnosis, illness and treatment process that C1 underwent and how she tried to ameliorate the effects of this on her child. She also spoke of the efforts she made to obey the hospital orders “*Because of the risk of infections and that kind of thing, they said to me don’t even take her to the shops, don’t take her*

anywhere. Which obviously you religiously do. You do whatever these doctors do." She also tried to be protective over her child by talking to C1's teachers and her coach to be gentle with her and defend her. A recurring feeling was that of distress because of what her child went through "she knew that it was serious because we were in such a state, you know we were crying and we were so traumatized in the beginning. Because you don't expect your child ever to have cancer you know." She described her anxiety "as a parent you obviously know more than she does, you sit and think there are kids around you that are not making it, many kids who are passing away and you obviously worry and think how do I know my kid is going to make it." "you do get worried and you do wonder gosh, where is this going to end up."

P2 spoke mostly about the diagnosis process as outlined above and strongly reiterated how much anxiety she had, "I was so stressed". P3 talked about how she had to be strong for C3 in spite of the distress she felt, "You couldn't cry in front of him……if you cry then he would panic and he would wonder why are you crying. You wouldn't cry actually in front of him even if you wanted to, just laugh and smile because then he would think something is going terribly wrong. And maybe you're crying because you gonna feel depressed from time to time." In this vein she added, "Somehow we got strength, God gave us strength and I suppose when you're in such a situation you just need to make the best of every single day and I think you know being so focused on what was happening with him and keeping him happy and that, we didn't have time to be unhappy, to feel sorry for yourself that you, to even think what am I feeling about what's happening." P3 verbalised her worries, fears and protectiveness over C3, "I mean going home was very scary (because of risk of infections), I was so paranoid for a while that he might get sick." Around her sadness she said, "…… I used to cry and I used to worry……'I cry because I could lose you' (she said to C3)". P4 did not speak much about her own feelings except to say that she was afraid, "for us as the parents, it was more of a fear factor."

P5 was the most labile of the participants during the interview. This could very well be due to the timing as C5 was the most recent of the diagnosed and the one who was in hospital during the study. She verbalised very little about her own distress and her

response to C5's illness was more expressed in her emotions. She may also have projected much of her own feelings into others, using words like 'disappointed' and 'disheartened'. P6 likewise spoke more about how her child observed her emotions rather than speaking about them directly, C6 would say, "don't get stressed all the time" and "oh mummy is suffering." P6 also spoke of her feeling alone and unsupported through this difficulty, "I'm a single mother, but I was having his father too, but we separated so I'm alone you see?" P7 disclosed her anxiety when in the hospital context, "it's just this disease, this cancer, it worries because, every time maybe we go to hospital…… They were fine (the other children in the ward), we were with them and then the next time we go someone she knows is again gone. That kind of thing is something that stays in my child, even to us, the mothers. You are afraid because you don't know, you can't say its gone now. You don't know when they tell you when the cancer is back, it's that thing…… Now you know the whole process so it's difficult……it's worrying and also for her, when she see the other kids, now we see them, they are fine again and this is happening, someone, she pass away." P9 spoke about C9's behaviour during her treatment and how at times "it becomes quite challenging". With regards to the illness and symptoms and his difficulties with coming to terms with it he stated, "sometimes they say it affects the parents more than the child".

4.2.3 Idealisation and the Halo Effect

A cross-cutting arch-theme that weaves through all the participants' responses is a process observation rather than a recurring subject. What was found as a common pattern was that EITHER the participants perceived their child as having a more enhanced prosocial behaviour after the hospitalisation process, and/or as a retrospective part of their children's personality OR they portrayed them as having the negative behaviour or attitude owing to or attributed to the illness or the disappointment associated with the illness. Implications of this observation will be further explored in the discussions chapter. Positive prejudice is another term that can describe this process.

Some of the phrases that the parents used were: “she’s amazing”; “she’s incredible”; “she is wonderful”; “she is a very warm person”; “she is a very very very caring and loving girl” and “there isn’t a selfish bone in his body.”

CHAPTER 5: DISCUSSION AND CONCLUSION

This study aimed to explore the perceptions that the parents of children with cancer have of their possible prosocial behaviour. The research attempted to investigate several levels of enquiry: Firstly, it looked at the parents' experiences of their children and their behaviour in general from the time of the diagnosis of their illness. Secondly, it focused on the way they perceived their children's prosocial behaviour after their treatment and whether they saw changes in the levels of it. Thirdly, it aimed to explore the reasons provided by the parents as to what influenced this change.

In the proceeding sections, the results that are composed of themes gleaned from the participant's responses will be discussed against the reviewed literature. A return will also be made with regards to the researcher's redefinition of prosocial behaviour in the broad as well as narrow sense and expanded upon in the light of the findings within the backdrop of referred authors. The implications of this argument will likewise be discussed. While it was not the main aim to look at the parent's feelings and the process of the illness itself, many of the respondents spontaneously spoke of this and their narratives along this line will be discussed further under the relevant themes. An important aspect to remember is that seven out of the nine participants' children were in the maintenance phase at the time of the interview. That means that they were well on their way to remission and were out of hospital already. This clearly makes an impact on the emotional status of the parents at the time of the interview in relation to their mortality-saliency.

5.1 Category 1: Behavioural and Character Attributes

5.1.1 'The old child'

A salient theme that emerged in the reports of the parents was the 'adultification' of their children. They spoke of their children's rapid maturation and growth during and after the treatment process. Maeder (1989) described the term by saying that it is the transition into adult behaviour and attitude beyond the normal developmental pace. A strong pattern of the children becoming teachers and instructors of others surfaced from their narratives.

The aspect of them becoming strong enough to ease the parent's anxieties and take on more emotional responsibility than is appropriate for the age is a phenomenon that can be described as 'parentification' (Chase, 1999). As was described, this is the situation of role-reversal where the child takes care of, worries about or comforts the parent. This was supported by Vaillant, (1997) who suggested that some children who go though distressing life stressors can take on the nurturing role by caring for others as well as their parents. This was likewise suggested by Bluebond-Langner (1978), who stated that children with chronic illness can be prone to role change and they are hyper-aware, tuned into their environment and the feelings of others. Vaillant's (1997) theory was that this role of nurturer allows them to abate their own suffering by helping them focus on others' distress and therefore deflecting away from their own. This is contested by Freud (1923), who argued that this libidinal reinvestment in the other depletes the energy from the self, especially if the original roles are hierarchical as in the relationship between parent and child as opposed to that of child and peer. Miller (1995) warned that this may come at the cost of attaining their own childhood milestones and normal emotional development. She further explained that the child's anxiety is disregarded as while trying to meet the parent's needs.

It was therefore interesting that most of the parents who were interviewed expressed their pride or approval of this quality in their child and deemed it a worthy trait. They felt that this attitude of their children abated their own distress and were grateful for it.

While the aforementioned literature supported the notion of adultification of either children in adversity or more specifically, children with chronic illness, other work for example the study cited in Parker and Mauger (1979) described situations where some children with cancer emotionally regress to an infantile state and clingy behaviour. A need for attention and extra care may be sought by these children who are at the time unable to self-soothe and therefore less likely to be nurturing others. This was demonstrated by C3 and C5, who were described by their parents as being 'a baby', exhibiting irresponsible behaviour or demanding of attention. It would appear that,

according to parent's perceptions, children either became more advanced or regressed than age appropriate.

With regards to the teaching role described by the participants, the significance of this phenomenon was expressed poignantly by Kübler-Ross (1985, p.17) and quoted in Chapter 2 "Those who learned to know death (or come close to it), rather than to fear and fight it, become our teachers about life." She furthermore explained in (Kübler-Ross, 1985) that indeed, children who are hospitalised grow up quicker than others and have an intuitive wisdom beyond their years.

5.1.2 'The outgoing and confident child'

Many of the participants described their children as gregarious in general and able to be verbally expressive to a spectrum of people. They described them as affable and sociable. Some also reported an outcome of their illness as being children who wanted to speak about cancer in an effort to help others. Parents made an association between their child's verbal manner and extroversion to their desire to help others and assist with 'the cause'. Their sociable nature was harnessed for the goal of assisting others. This link is confirmed by a study cited in Eisenberg et al. (1989) which suggested that children who were outgoing and sociable were more prosocial. They were more capable of relating to others and more prone to exhibiting helping and sharing behaviour that was spontaneously motivated. As was described in Chapter 4, there is a nuanced variation of talking to teach others and doing so in a spirit of sharing experiences.

Some of the children were described as talkative and friendly before the onset of the illness and some who emerged out of their shell, however most of the respondents spoke about an increase in their children's confidence and assertiveness after the process of the treatment. In another study quoted by Eisenberg et al. (1989), assertiveness was linked to the prosocial behaviour of children. Midlarsky and Hannah (1985) argued that the more confident a child is, the more likely they will be in situations where they are in contact with others and therefore have the opportunity to help them. They are also brave enough to approach people spontaneously and assist even when unasked. This is an important

link which highlights the respondents' accounts with regards to their children becoming confident and brave. The connection between social skill and prosocial behaviour was likewise reiterated by the same authors.

5.1.3 'The jovial and resilient child'

A staggering number of the participants portrayed their children as being happy and jovial. They verbalised that this was an enduring quality for many of them. They described this attitude that their children exuded as being inspiring and worthy of praise and admiration. Furthermore, it was deemed astounding that despite the horrors and trauma of the hospitalisation process, their children continued to be positive as well as prosocial. In addition, this strength was alluded to by one participant almost as being a prerequisite to being able to deal with the situation, in so much as that the child would not have been dealt this adversity if he did not have the capacity to do so. Many of the children also shared their hopes and dreams of their future to their parents. The presence of hope can be suggested to be an indicator of resilience.

The ability to cope and adjust on a core level was termed 'ego-resiliency' by Block and Block (1973) (cited in Eisenberg et al, 1989). This was the capacity to recover and adjust well after stressors. Likewise, this was confirmed by other studies quoted by Eisenberg et al. (1989, p.63), that stated children who were prosocial were also able to be well-adjusted. These were clear predictors of prosociality in different age ranges, including adolescents. What was unclear however, was whether their resilience produced prosocial behaviour or if their strength was somewhat begotten by their prosociality. To extend the argument further, does their joviality and resilience stem from their survival of a dreaded illness or are they able to survive their cancer because of their positive attitude and ability to cope? The literature has not found support for a causal direction, however, but a study by Phipps (2007) makes a descriptive link that clearly associates children with cancer with high levels of capacity to cope and adjust well. Further studies by Brown et al (2008) and Kishon-Barash (1999) (cited in Vollhardt, 2009) emphasise the benefits of assisting and caring for others on the self despite trauma experienced. This was also

associated with lowered levels of depression and post-traumatic stress compared to a control group.

"*That she was so well. Which was nice I think for those kids to see and to try and be positive themselves."*

5.1.4 'Transcendence'

The previous theme described the ability to cope and adjust to the difficult challenge of a life threatening illness and was termed 'resilience'. However, what was found from some of the responses of the parents was their children's as well as their own process of 'rising from the ashes' through experiences that could collectively be termed 'transcendence'. Therefore it was not only that they returned to an original sense of normalcy in an elastic sense, but they developed further. Two variations of the definition of transcendence can be found in the Wordweb dictionary (2008). Firstly, "A state of being or existence above and beyond the limits of material experience" and secondly "The state of excelling or surpassing or going beyond usual limits". Both of these statements describe the process that some of the children went through after hospitalisation.

Some of the participants talked about spiritual faith and the support this had provided them and their children during their hours of ordeal. They likewise talked about gratitude for this experience and the lessons borne of the suffering they endured. Then arising to go over and beyond the ability to 'just' cope and extend their sense of being beyond material comfort and exude a wisdom and radiance that spreads to others, either through prosocial acts or exemplary attitudes. While this ability was critiqued in some of the mentioned literature, it was deemed a special and unexpected by product not only by the parents but also by other authors such as Vollhardt (2009) who said that people in these situations become altruistic not only despite the trauma they go though but also because of it and described this as a positive outcome. Some of the parents' attributions therefore of the prosocial behaviour of their children, was the suffering they went through and the sense of otherness they developed as a function of having come close to death. One parent described it by saying in paraphrase, that one learns not to be possessive of things when

you have come so close to losing your life. This would then be especially the case with children who have a life-threatening illness like cancer.

This concept of 'detachment' altruism was further explained by Cozzolino et al, (2004) in relation to the term 'mortality saliency'. They stated that very ill patients who come in contact with the realisation that they might die may at the onset go through an existential crisis. Therefore the possibility of 'death' becomes an important part of their consciousness. They may become more self-centred and possessive, however, as they work through and process this experience, they may gain a feeling of transcendence from the ephemeral aspects of life and grow from it. These are the patients that then engage in prosocial activities. So for those of the children such as C5 who became withdrawn, demanding and self-involved, this may among other reasons be partly be due to Cozzolino et al's (2004) description of the early days of mortality salience.

This was similarly confirmed by Bernie Siegal's (2005) case study of "exceptional cancer patients" who end up expressing their suffering in acts of prosociality. This was in response to the feeling of the ephemeral and transitional nature of the contingent existence. Transcendence or indeed spirituality is a rather under-researched topic in academia. This aspect of human experience is many times not considered worthy or frequently avoided from formal research pursuits perhaps due to its abstract quality.

Similar to Cozzolino et al's (2004) breakdown of the different stages of mortality saliency, the different stages of working through the acceptance of death conceptualised by Kübler-Ross (cited in Cook, 1974) provides a useful framework. Bearing in mind that this model can be applied to the processing of serious illness as well, the stages mean that reactions to illness are not homogenous but vary according to how recently the diagnosis was made and other similar factors. If the child is therefore in the anger or depression stage, he/she will not show joviality, resilience or prosocial behaviour as was the case in C3 and C5. Conversely, in the bargaining stage, the child may manifest increased prosociality in the instance of 'reparative altruism' which is prosocial acts done to repair either relational damage, abate guilt or make amends.

Furthermore, Kübler-Ross (1985) spoke about the spiritual transcendence children reach when they come in contact with the possibility of death. This consciousness may be below the surface rather than full awareness but still is there. She explained the different dimensions of the child as quadrants of physical, spiritual, emotional and intellectual parts. The weaker one gets in one of the quadrants, the stronger another becomes to compensate. This is how she argued that those children who become physically weaker or compromised, have a heightened sense of spirituality as well.

5.1.5 'The cancer made them bad'

Several of the participants reported spurts of behaviour that was difficult or challenging for the parents. They described their children as at times being moody, withdrawn, irritable and short tempered. Some of those who verbalised this concern did so with hesitation and thereafter rapidly moved on to their children's commendable qualities. Others emphasised this topic and stayed with the difficult feelings this may have evoked for longer.

The central reason that many of them provided for this behaviour was their treatment, mostly in the direct effects of chemotherapy on their mood. The review of literature and consultations with medical doctors for this study did not provide a straightforward link to the chemical components of cancer treatment causing mood swings per se. The exceptions to these were corticosteroids which are one type of chemotherapy that causes irritability and mood fluctuations (Hukovic & Brown, 2003). The secondary effect of general chemotherapy is that it suppresses the immune system which makes the child more vulnerable to stress. Effects of the treatment on their children's emotional state due to the arduous process was not as emphasised except for 2 participants who felt that it was because of the disappointments, fear and loss that cancer comes with. One parent specified that the child's loss of control over the process made her take control over that which she feels she can, which is over people and things. Another related it to the pain the child was going through. Some of the parents were clear as to the distinction of what

they felt was causing the concerning behaviour, clearly associating the irritability with the pharmacological component of the treatment, others were more vague. Once again as stated above, the type of behaviour the child exhibits may correlate with the Kübler-Ross's stage of death acceptance (cited in cook, 1974). Their anger or depression stage may be expressed in withdrawal and irritability.

A few of the parents also cited fatigue as causing the decrease in prosocial behaviour stating that they are "just not up to it". This is confirmed by Gaillot (2006) who suggested that prosocial behaviour can be reduced with lowered metabolic energy. Interestingly, what the parents did not comment on is the impact of developmental stages such as adolescence on certain behaviour.

5.1.6 'Concern'

Even though some of the questions posed during the interviews were related to specific expressions of prosocial behaviour, many of the parents chose to dwell specifically on care and concern for others. They described heightened levels of empathy and ability to tune in to other's suffering and pain whether it was in relation to asking about the well-being of their fellow cancer patients, comforting their own parents as stated in theme one, caring for younger children or even a generalised worry about the plight of the homeless and other strangers. Cook's (1974) comments on this topic affirm this phenomenon of attunement to one's environment in children with life-threatening illnesses. Their sensitivity to their peers in the ward and their self-perception of having the mission to take care of others was especially emphasised in this study.

For many of the parents, this was a shift in outlook and orientation towards the well-being of others since hospitalisation and provided this as an attribution for the increased prosociality. Others gave the reasons of increased exposure by their children to the suffering in the hospital context and more opportunities to demonstrate such concern as was supported by a study by Hannah & Midlarsky (2005) cited in Vollhardt (2009). Most of the participants remarked on how inspirational this quality was.

Studies that were mentioned in previous themes reiterate the positive effects of prosocial behaviour and concern on the carer (Vollhardt, 2009). Other studies cited in Vollhardt (2009) substantiate this notion and add interesting variations by stating that children who are chronically ill have self-reported levels of prosocial behaviour that are higher than control groups (Reiter-Purtill et al). Longitudinal research on chronically ill children also demonstrated a prosociality that was enduring and pervasive.

5.1.7 'I taught her'

A more subtle theme in this category is the influence of parents in shaping the child's prosocial choices. They felt they played a role in the instilling of not only prosocial behaviour as well as other traits that have the effect of prosocial behaviour in the broad sense, such as resilience. This was a less emphasised subject in most of the respondents except for P3, P4 and P5 who stressed their contribution in the formation of desirable behaviour. They spoke of situations when they had to teach their children to be more sharing and considerate as well as to be grateful for their own well-being by making comparisons to how much worse other children in the ward were.

It appeared that it was the more self-inclined parents who stressed this point. As was mentioned in the literature review, modelling (Berk, 2003, Seagle et al, 2002) and the socialisation process (Eisenberg et al, 1989, 1998) where children are taught socially desirable behaviour is a necessary factor in the development of prosociality. Teaching children and showing them helping, sharing and caring behaviour by example has been shown in the studies cited above to provide the guidance required for children.

In addition, the environment the children are in during the treatment process exposes them to adults like other parents, doctors, nurses and relatives who demonstrate consistent caring behaviour. This affords them greater chances for absorbing such modelling behaviour as was described by some of the participants. This was confirmed by studies that focused on the hospital environment such as Seagle et al's, (2002) study on 'the altruism choices of healthy and chronically ill children'. The increased levels of attention, care and concern for the children by their parents when they become diagnosed

is indeed mirrored by the children and spurs them towards exhibiting such behaviour themselves.

5.2 Category 2: Process of Illness

5.2.1 'The long beginning'

Another theme that emerged by some of the participants was the toilsome and protracted way that they came to understand what was happening to their children. They spoke much about the lengthy process and the confusion associated with the diagnosis and the tentative explanations that was given to them by health care professionals in the initial stages. Some felt overwhelmed and others felt like they were in the dark. They did not feel that they had sufficient information and some had to conduct research about the illness and investigate several opinions before eventually arriving at the decision on treatment. This is one of the themes that issued forth without promptings to do so.

One of the parents reported the sense of inadequacy she felt at not being able to detect the signs and manage the illness earlier. While it was only one participant who directly mentioned this feeling of guilt and others alluded to it. Furthermore there were still others from the participant pool who did not verbalise it, but one can extract further interpretations from this process around themes of guilt beyond the manifest and spoken content. Some parents spoiled their sick children by their own admittance. While this may just be due to them being sick and indeed, needing of that extra care, it may also be a reparation for the guilt felt as well – although this link was not mentioned by any of the participants. These feelings of confusion and guilt were described and supported by Pinkerton et al's, (1994) study of the parental experiences of children's cancer. They stated that at the beginning stages of diagnosis, parents may become critical of themselves where they go through self-blame for not detecting the symptoms earlier or inadequately protecting the child against illness. Defectiveness in a child is seen by caregivers as reflective of their own shortcomings. This may evoke anxiety and can diminish their self-esteem.

5.2.2 'My child's harrowing illness'

Besides the diagnostic process, the parents disclosed some of the feelings they felt and how they responded to their children's illness and treatment. As can be imagined, most were distraught and explained how traumatic it was for them. A few spoke of their shock and one of the participants simply stated "we were in such a state, you know we were crying and we were so traumatized in the beginning. Because you don't expect your child ever to have cancer you know." They described the overwhelming emotions they experienced and the terror felt at the sheer unpredictability of the prognosis. Some spoke about the sacrifices they had to make and what they had to give up in order to care for their children.

There were also financial responsibilities and other logistical matters that complicated the grieving process. Some of the parents commented on the difficulties of affording care and the limitations in their financial resources and how they had to resign from their jobs to care for their ill children. This specific concern over financial aspects was mentioned by Friedlander (2004) where it was stated that parents who are socio-economically disadvantaged may go through a heightened level of distress and less able to cope with the illness. Besides financial burdens, parents spoke about having to make sacrifices regarding time. The treatment required for cancer requires lengthy hospitalisation and/or chemotherapy and radiation treatments as well as maintenance checks which consume much of the parent's time and energy (Parker et al, 1979). Several of the parents talked about these efforts. Some also mentioned (especially P3) the toll this takes on the siblings and how they can be neglected because of the time and attention given to the sick child. This was further confirmed by Parker et al (1979). Furthermore, they discussed the measures they took to protect the child further from infections and other harm as well as the importance of following doctors' instructions. Three of the respondents emphasised this point and stated the importance of this to save the child's life. In general the feelings that emerged in response can be grouped around anxiety, self-sacrifice and distress. Many of these reactions were found in Lazarus' (1999) study, including a constant worry that their child may get worse or not survive the illness.

Once again many of the participants provided information around this theme even though it was not asked as part of the interview questions. They were comfortable to talk about their feelings and to some it felt like it was a cathartic process as one of the participants confirmed. A few spoke at length about the entire experience and were unable to focus on the topic at hand much of the time. This was a behaviour observed by Woodgate and Degner (2003) where parents of children with cancer who were asked about their children's symptoms had a tendency to expansively talk in an over inclusive way about the whole experience. Others did not talk about their feelings or experiences nor did they speak at length about the child's illness. It is wondered whether these parents are communicating an aversion to discussing anxiety-provoking feelings and whether defence mechanisms were being utilised to protect themselves against the full extent of the emotional pain involved in caring for a child with cancer. There was only one participant who became tearful and emotional during an interview.

Some of the parents spoke about what they did to cope and provided different examples such as the importance of the support of extended family, using faith and spirituality, belief in a higher being, positivity that their children can emulate as well as the care and service provided by the hospital staff and CHOC volunteers. The influence of support to parents in their ability to cope was emphasised by Woodgate and Degner (2003). In a similar vein, Lazarus (1999) found that parents who talk about their experiences in relation to family members who are sick explain how important role of positive attitude and religion played in their bid to adjust to the trauma.

It also appeared that the way the respondents interpreted their child's illness and the meanings they attached to it was varied. Some reported the sense they had that it was God's will and that they will get through it, others talked about how there was a reason behind it and how their child has grown from the experience. According to McCubbin et al, (2002) (cited in Meyler et al, 2006), those who conceptualise and construct cancer as having meaning and as being manageable, provides better ability to adjust to it and manage it. In addition, an inversion of theme, 'the Old Child' from category one would

be that it is because of the parent's ability stalwart attitude and ability to deal with the stress that the child is better able to adjust and cope with it too (Friedlander, 2004). This was seen in a few of the participant's accounts such as keeping positive as was mentioned previously. This study would also like to argue that the parent's ability to cope has bearings on and colours their perceptions of their environment in general and how they see their children's behaviour as can be interpreted from the participant's accounts. This will be further discussed in the final and overarching theme of 'Idealisation' that cuts across both categories.

5.3 Idealisation and Halo Effect

It was decided after the analysis of the data that this should be a stand-alone theme. It is a thread that runs through and looms among the other themes. It is a process feature that comments on both manifest and latent communication, attitudes and tone of what is being said. It was interesting to note that most parents felt that their children were special and had astounding characters in prosocial aspects as well as general personality. They described these traits as either being present prior to the hospitalisation process and thereafter increased after hospitalisation or that they had new levels of virtues after the illness process. The two parents that stated their child became less prosocial and more irritable and demanding explained that it was due to the illness and treatment that they became this way and not as an expression of their own character or even developmental level. What was noted was the above mentioned correlation between parents' ability to cope and perception of their child. Interestingly, it was P5, the only one who broke down in tears during the interview that perceived her child in the most negative manner. She was also the most recent of the parents who were interviewed which was a month after diagnosis. This means that she had not had the chance to process and work through the news and may have been on Kübler-Ross's (1969) earlier stages of trauma acceptance. This was however the exception to the data set.

Most of the parents therefore tended to paint their child in virtuous terms and even when stating their weaknesses, they framed them in more endearing ways or glossed over them. Some (and mostly P1) used adjectives such as 'amazing', 'incredible', 'special' and

'wonderful' to describe them. These parents were in awe of their children's traits and found them inspirational. The argument to be explored here is whether this was firstly, a perception and secondly, if it is related to their child's suffering and if the cancer is being used as a backdrop to their portrayal. In other words, does their virtue stand out in contrast to their trauma? Research was not found that makes this direct link, however constructs around 'the halo effect' coined by Kelly (1955) (cited in Kalick, 1988) which is a marketing theory about consumer bias (this concept and its generalisation to other situations such as interpersonal relations was made in chapter 2) is an intriguing spin on the research. Therefore, as much as there is the phenomenon of negative prejudice, there is also its counterpart, positive prejudice.

As was argued in chapter 2, it may be so that one's perception of a vulnerable population may be skewed and out of proportion with their true qualities be seen as good in a holistic sense. It is commonly accepted that parents have tendencies to perceive their children in more glowing terms than is the case in actuality (Hannig, 2002), however, what is being argued by this research is that there is a particular idealisation of children with cancer above and beyond this familial bias. However, what should be noted is that the reviewed literature argues that chronically ill children do tend to be more prosocial than control groups (Vollhardt 2009, Seagle, 2002). It may then be more prudent to state that even though this may have been found in empirically researched cases and the exceptional quality of these children in relation to prosociality may have been observed, it may still be that there is a inflation of these traits from the position of their parents.

This research would like to posit and further extend the argument utilising psychoanalytic theories. What has been observed and tentatively interpreted is the following: the realisation that one's child has a life-threatening illness is a traumatising experience for parents as was described by the parents and confirmed by studies (Parker et al, 1979). In the face of anxiety and personal crisis, these parents may make use of defence mechanisms to cope. While they may adopt coping strategies that are healthy, there may be defences at play as well (Fonagy & Target, 2003). Other more primitive defences such as denial which is the refusal to see aspects of reality because it causes anxiety (Fonagy

& Target, 2003) may be used. A more relevant defense to this paper and which is also lower level is idealisation. The question posed is why would they choose, albeit unconsciously, a defence like idealisation? Several tentative explanations pegged to the notion of why we use defense mechanisms in the first place can be used: defenses not only protect against anxiety but also aggressive instincts and anger. There may be several reasons that arouse such emotions in the parent even if irrational. These may be that they are angry with the child because they are sick, they may be disappointed with the heath system for prolonging the diagnostic or treatment process or making it painful, they may be upset with God for allowing their child to get sick or with themselves for not protecting their child enough. Defenses detract from feeling these raw and unwanted feelings and allow avoidance by channeling it into more positive emotions and behaviour such as dotting on their child. Another emotion they may try and guard against is fear that their child may die and it is a universal phenomenon that one 'does not speak ill of the dead'. One could reason that if the 'mortality saliency' of their child is high, they may already perceive them as near-death and the same adage can apply but in this case 'one does not speak ill of the ill'. Therefore speaking about them in glowing terms and investing energy into perceiving their saintliness may be a manifestation of this phenomenon. Sublimation is another defense described as "transformation of negative emotions or instincts into positive actions, behavior, or emotion." as was heard in the interviews by reporting such actions as rising from the grief to care for the child. While altruism is said to be a defence mechanism by some theorists (Fonagy et al, 2003), this researcher would argue that this reframing of the concept minimises this particular quality and renders it valueless. The stance of this study is one of seeing these children as being indeed more prosocial and having the qualities that transcendence brings about as they strive to gain mastery over their illness but that at the same time, their parents idealise them further. This process of idealisation may have far-reaching benefits for the child as the parent's doting of them can further encourage their prosocial behaviour, which as seen above can enhance their resilience and thereby foster the healing process. This cyclical feedback system can very well be the very mechanism of mutual healing.

In an empirical study, parental bias would be an obstacle to measuring true levels of prosociality in these children with cancer. However, the very ontological paradigm on which this study rests not only exempts it from such requirements of validity but rather enriches it by adding further exploratory enquiries.

5.4 Definition of Prosociality Revisited

In the light of the findings that were presented in the previous chapter and discussions that followed in the present chapter, it becomes increasingly clear that the argument that started in the literature review of this research project should once again be reiterated. One of the main inconsistencies in the reviews of the literature was the definitions of prosocial behaviour and altruism and their interchangeablity and indiscriminate application. It was decided that this research will attempt to use the meaning of prosocial behaviour in the loose and general sense which is any behaviour or attitude that results in a beneficial effect. A definition which most closely reflects this but albeit not entirely adequately, was taken from Eisenberg and Mussen (1989, p. 3) which stated, “prosocial behaviour refers to voluntary actions that are intended to help or benefit another individual or group of individuals” and “although they are intended to have positive consequences for others, they may be performed for a variety of reasons (including selfish ones)”.

While some of the interview questions in the present study operationalised prosociality in the forms of helping, caring, sharing behaviour, it was observed that the other interview questions were general enough to elicit variations of prosocial traits that did not only necessarily fit these expressions in the strict sense. The researcher added two important aspects to the overall definition of prosocial behaviour: firstly that the initial transaction does not necessitate a dyad. This subverts or at the least amends Dovidio et al’s (2006) prerequisite of a prosocial situation which is that there needs to be two or more people involved in the interaction. Secondly, that prosociality does not have to be a single, goal-directed behaviour or act but that it can be manifested in a collection of subtle traits or provide a prosocial result through a stance or attitude such as will be discussed earlier in the themes under ‘resilience and joviality’. This second point resolves a philosophical

contradiction by critiquing Ayn Rand's (cited in Rushton & Sorrentino, 1981) objection of altruism based on the premise that it stifles the individual's rights and well being.

This paper aimed to argue that the very act of being prosocial with or without the intention to do so can have the unintended benefit of helping the child recover as was described in Vollhardt's (2009) study which found that altruism can be bidirectional and can allow a better coping of the illness or adversity through it may not necessarily be done consciously. While studies have not been found as yet that conclusively link prosocial behaviour with children with cancer in this manner, the inference that was made using the study by Block and Block (1973, cited in Eisenberg et al 1989) on the direct relationship between ego-resiliency and prosocial behaviour and the research by Phipps (2007) on how resilience and adaptive defences helped the child with cancer survive can be used to make a deductive hypothesis. So while Eisenberg et al (1989) may state the action or attitude may not have the intended goal of benefit another, it may come as a spontaneous by product of the act or attitude.

5.5 Conclusion

This was a qualitative study which looked at the perceptions of parents regarding the prosocial behaviour of their children. These children were a special group since they were afflicted by a type of chronic illness that is notoriously feared – cancer. Although paediatric cancer survival rates have increased in recent years, this disease continues to be an anxiety provoking condition for parents. There has been ample research about the medical and general social impact of cancer but it was found that there was a scarcity of studies relating children with cancer and their prosocial behaviour.

Some of the recent literature reviewed argued that indeed, children with cancer have been shown to exhibit an array of prosocial behaviours at higher rates than control populations. This was confirmed by most of the parents that were interviewed for this research project. Some of their attributions were the existential meaning-making opportunities that being close to death or having a serious illness provides. Others gave reasons around their own role in instilling desirable behaviour. There were several arguments made around this

complex topic in this study: Firstly, prosociality was re-defined to include descriptions by the parents beyond the scope of the operationalised terms in the interview schedule. It was debated whether a transactional dyad was necessary in the definition or if an internal traits and attitudes begotten by hardship and suffering can have the added by-product of being beneficial to others, including the parents and therefore can be termed 'prosocial'. These traits were maturity, resilience, positivity, confidence and sociability.

Secondly, it was suggested that it may very well have been the case that these children did have a heightened sense of prosociality since hospitalisation as supported by the reviewed literature. Attributions to why this may be the case have been postulated to be that the level of transcendence achieved when faced with the possibility of death as was stated above. Another aspect was again the use of defences by the children themselves as well as their journey through Elizabeth Kubler-Ross's (1969) five stages. However, in addition to these expressions of virtue and resilience in actuality, the parents may also have had an enhanced view of their children's prosocial behaviour not only as a factor of their kinship bias but also due to their children's position of vulnerability as cancer patients. It was surmised that parents have an idealised perception of their children as a defence they use to cope with the horrors that such an experience produces.

Lastly, it was found that indeed it was those parents whose children had already gone through the hospitalisation and treatment process and who were well on their way to remission that spoke of their children in more glowing terms. This correlates befittingly to Elizabeth Kübler-Ross's (1969) stages of acceptance. The following sections will provide limitations of the research as well as recommendations for future research

5.5.1 Implications and Limitations

This research project was a qualitative study that explored the perceptions of parents of the prosocial behaviour in children with cancer. A significant implication of this study and of further studies that can emerge from it, is that it potentially affords health professionals and other stakeholders working with cancer children, the opportunity to view their strengths, resilience and positivity and can allow for better rapport and

increased support. It can also provide parents with insight into their own inner workings so as to better adjust to their children's needs, even if it implies that they invoke their 'rose coloured' defence mechanistic lenses to abate their anxieties and to know when to remove them so as to not overwhelm their children with undue pressures to be parentified and adult-like.

This study was confronted by several limitations: the first challenge was on a meta-theoretical level, the issue of definitions of prosocial behaviour and its theoretical underpinnings set up a difficulty in undertaking the research. The operationalisation of the concept of prosocial behaviour into helping, sharing and caring behaviour potentially reduced the level of exploration required by this type of design, which is essentially a phenomenological one. What assisted the participants to delve deeper into the subject was the general questions that were included in the interview schedule such as asking about 'general behaviour' of the child. What was found was that parents chose to discuss aspects of what they felt to be prosocial behaviour. The research thereafter re-constructed the limited definitions to be broader and inclusive of attitudes, motivations and personality patterns that may as a result have the effect or consequence of benefitting the other, such as resilience and positive disposition. These traits were then deemed prosocial above and beyond the operationalised terms by utilising definitions of prosociality in the loose sense.

A second limitation was the replacement of the original sample due to their vulnerability. The main participants were to be the children themselves, but due to the ethical considerations, it was changed to the parents. This poses difficulties on several levels: prosociality can then only be explored vicariously through the parent's perspectives instead of the child's. This further dilutes the data that can be obtained and needs to then shift focus to more perspective based, interpretive reports. Instead of thwarting the study however, using the perceptions of the parents serendipitously provided richer, more original material that provided ample arena for discussion.

A third limitation was also due to ethical issues of the type of questions to be posed which compelled the researcher to err on the side of caution. Questions that could have provided a deeper exploration into the worlds of the parents regarding their children had to be excluded so as not to arouse emotional discomfort. This concern of participant lability limited the scope of the research. This aspect will be further discussed under the next section on future research.

A fourth limitation was the limited level of conversational English of some of the participants. While some of their difficulty to express themselves was thought to be due to defences against the anxiety evoked by the topic, it was also largely a case of communication problem. There may have been more material obtained if there was a translator present. However, this third dimension of translator poses its own challenges.

A final weakness of the study that requires discussion and at the same time can allow for the interpretive flavour of this study to take on better shape is with regards to the researcher's own bias. My own vicarious idealisation of the children through contact with the anecdotal reports of 'angelic cancer children' can taint, pre-empt and sway the reports of the parents through unconscious ways of arousing suggestibility such as posing leading questions. However, the reflexive nature of qualitative research as outlined in the Methods Chapter allowed for a constant audit of this bias.

5.5.2 Recommendations for future research

This study can be used more as a pilot enquiry because it raised questions that can provide impetus for further quantitative research. Recommendations for further research include an empirical study that looks at the levels of prosocial behaviour in relation to prognosis of illness, stage of cancer and if it was after survival. Another study could be a qualitative one that explores the cultural variations and gender differences in the perceptions of parents of the prosocial behaviour of children with cancer using more fathers as a sample. Further research can be conducted on variations of the topic around parents of children with cancer, their prosociality and the type of discipline employed to maintain boundaries, since one of the aspects noted is that parents may be less inclined to

discipline their children who are ill as they deem them fragile and may be one of the expressions of their guilt.

5.5.3 Reflections

Lastly I myself as the researcher grew through this research experience. The material enhanced my own levels of empathy, sense of gratitude for health and heightened my consciousness around my own prosocial disposition. It also raised existential questions and philosophical debates around death, resilience and personal defences employed in the face of crises. It is hoped that it arouses similar questions for readers.

"Such is man, his nobility is in his virtues, not in that which covereth him."

Abdu'l-Baha Abbas

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7. APPENDICES

Appendix A: Interview Schedule for Parents

Appendix B: Questionnaire for Nurse

Appendix C: Information Sheet for Parents

Appendix D: Consent and Confidentiality Form for Parents (Interview)

Appendix E: Consent and Confidentiality Form for Parents (Recording)

Appendix F: Permission Letter from Head of Haematology/Oncology Ward

Appendix G: Ethics Clearance Certificate

7.1 Appendix A: Semi-Structured Interview Schedule for Parents

How has your child differed in their behaviour in general since they have been at the hospital?

Have you noticed any changes in their behaviour regarding sharing and if so, in what ways?

Have you noticed any changes in their behaviour regarding helping and if so, in what ways?

Have you noticed any changes in their behaviour regarding caring and if so, in what ways?

What are the possible reasons for the change?

How does your child talk about and make sense of his/her illness?

What has your child's experience been like since hospitalization?

What has your child been talking about since hospitalization?

What has been the general mood of your child like since hospitalization?

7.2 Appendix B: Questionnaire for Nurse

How long has the child been in the hospital?

_____

What type of cancer does s/he have?

_____

What is the general mood of the child like since s/he has been in hospital?

_____

7.3 Appendix C: Information Sheet for Parents



School of Human and Community Development
Private Bag 3, Wits 2050, Johannesburg, South Africa Tel: (011) 717-4500 Fax: (011) 717-4559

Dear Sir or Madam,

Re: participation in a research

My name is Nadia Belete and I am conducting a research for the masters programme in Clinical Psychology at the University of the Witwatersrand. The aim of this study is to explore parental perceptions of prosocial behaviour in children with cancer. Prosocial behaviour is explained as behaviour that is beneficial to others such as caring, sharing and helping.

I would like to invite you as the parent of one of the children at Johannesburg General Hospital to participate in the study. Your involvement will entail you participating in an individual interview. The interview will last approximately one hour and will be held at Johannesburg General Hospital or a venue convenient to you. All of your responses will be kept confidential. Participation is voluntary, and there will be no negative consequences for not partaking in the study. You are free to withdraw from the interview or the study in general without any consequences, if you feel it is causing you discomfort or you experience any negative effects.

If you choose to participate in the study I can be contacted at 0769841274 or you may return the consent letter at the front desk of the Haematology Oncology ward of the hospital.

Your participation in this study would be greatly appreciated.

Yours sincerely,

_____

Nadia Belete

7.4 Appendix D: Consent and Confidentiality Form for Parents (Interview)

I _____ consent to **being interviewed** by Nadia Belete for the study on parental perceptions of prosocial behaviour in children with cancer.

I understand that:

- Participation in this interview is voluntary.
- That I may refuse to answer any questions I would prefer not to.
- I may withdraw from the interview or study at any time.
- No information that may identify me will be included in the research report, and my responses will remain confidential.

Parent:

Signed _____ Date _____

Researcher:

Signed _____ Date _____

7.5 Appendix E: Consent and Confidentiality Form for Parents (Recording)

I _____ consent to my interview with Nadia Belete for her study on parental perceptions of prosocial behaviour in children with cancer being **tape-recorded.**

I understand that:

- The tapes and transcripts will only be processed by the researcher and her supervisor.
- All recordings and tapes will be destroyed after the research is complete.
- No identifying information will be used in the transcripts or the research report.
- Relevant quotes from the interviews may be included in the research report, but any identifying information will be excluded and confidentiality is assured.

Parent:

Signed _____ Date _____

Researcher:

Signed _____ Date _____

7.6 Appendix F: Permission Letter from Head of Haematology/Oncology Ward

Division of Paediatric Haematology
and Oncology, Ward 294
Johannesburg Hospital
Private Bag X39
JOHANNESBURG
2000

OUR REFERENCE :
YOUR REFERENCE :

Tel. No. : +27 11 488 3290/3967
Fax No.: +27 11 488 4152

31 July 2008

TO WHOM IT MAY CONCERN

I hereby give permission for your research study entitled "Caregivers' Perceptions of the Prosocial Behaviour of Children with Cancer" to be conducted with the understanding that written participant consent will be obtained.

Yours sincerely,

DR. JANET POOLE
PRINCIPAL PAEDIATRICIAN AND
HEAD: PAEDIATRIC HAEMATOLOGY
AND ONCOLOGY

7.7 Appendix G: Ethics Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: MCLIN/08/005 IH**
PROJECT TITLE:	Parental perceptions of the prosocial behavior in children with cancer.
INVESTIGATORS	Nadia Belete
DEPARTMENT	Psychology
DATE CONSIDERED	18/03/08
DECISION OF COMMITTEE*	Approved

This ethical clearance is valid for 2 years and may be renewed upon application

DATE: 20 May 2009

CHAIRPERSON _____
(Professor K. Cockcroft)

cc Supervisor:

Dr. Mambwe Kasese-Hara
Psychology

DECLARATION OF INVESTIGATOR (S)

To be completed in duplicate and **one copy** returned to the Secretary, Room 100015, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure, as approved, I/we undertake to submit a revised protocol to the Committee.

This ethical clearance will expire on 31 December 2009

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES