

Life stories of families with a terminally ill child

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Abstract

Family units with a terminally ill child have a tendency to withdraw and this isolation may lead to problems in their mental health. A tendency with psychologists, clergy and helpers from other professions is to act as ideal experts on the lives of saddened people. From painful personal experience, this does not seem to enable acquiescence. Therefore, the aim of research on families with terminally ill children, was to explore and describe their lives and to develop an approach to facilitate their families to obtain acquiescence. In this article however, attention will be given to the life-world of families with terminally ill children. The research consists of two phases. In phase one the experiences of four families with terminally ill children are explored and described by means of phenomenological, unstructured, in-depth interviews. In phase two an acquiescence approach, which was designed for educational psychologists to facilitate families with terminally ill children to achieve acquiescence, is described. This approach is based on results from phase one. This article focuses on phase one. In this phase four families were interviewed individually, in the privacy of their homes. The interviews were audiotaped, and were transcribed for the purpose of data gathering. The data was analysed according to Tesch's method and a literature con-

trol was performed to verify the results. Guba's model for the validity of qualitative research was used.

Five recurrent themes were identified:

1. Families are able to choose their reactions to the crises of having a terminally ill child.
2. When there is a terminally ill child in the family, the family's values change.
3. Acceptance of the circumstances with a terminally ill child, makes life easier.
4. As families with a terminally ill child learn to live every moment to the full, their quality of life improves.
5. As people learn to accept support, their quality of life with a terminally ill child improves.

The research indicated that families with terminally ill children move through a lonely and painful process, which is characterised by growth at the end. This growth implies that the life skills mentioned above, were obtained after years of unimaginable suffering. In order to reduce this period of suffering, an acquiescence approach was designed for educational psychologists to facilitate discovery and acceptance regarding the above life skills with family units and thus allow them to achieve acquiescence.

Opsomming

Gesinne met 'n terminaal siek kind is geneig om hulle uit die samelewing te onttrek en hierdie isolasie lei tot geestesongesteldhede. 'n Tendens by sielkundiges, predikante en hulpverleners uit ander professies is om as kenners van hierdie tipe geestesongesteldhede op te tree.

Uit pynlike persoonlike ervaring blyk dit dat hierdie benadering nie berusting by die persoon in smart kan teweegbring nie. Die doel van hierdie navorsing was dus gerig op die verkenning en beskrywing van die leewêreld van gesinne met 'n terminaal siek kind. Hiervolgens is 'n berustingsbenadering ontwikkel om gesinne met 'n terminaal siek kind te fasiliteer om geestesgesondheid en berusting te verkry. Die navorsing bestaan uit twee fases. In fase een vind 'n verkenning en beskrywing van vier gesinne met terminaal siek kinders, deur middel van fenomenologiese, ongestruktureerde, in diepte onderhoude, plaas. In fase twee word die berustingsbenadering, wat vir opvoedkundige sielkundiges ontwerp is om gesinne met terminaal siek kinders te fasiliteer om berusting te verkry, beskryf. Hierdie benadering is gebaseer op resultate uit fase een. Hierdie artikel fokus op fase een en

word slegs gewy aan die beskrywing van die leewêreld van gesinne met terminaal siek kinders. Die navorsing het daaruit bestaan dat data-insameling gedoen is deur onderhoude met vier afsonderlike gesinne in die veiligheid van hul eie tuistes te voer. Die onderhoude is op oudioband opgeneem sodat dit getranskribeer kon word. Data-analise het deur middel van Tesch se metode van data-analise en literatuurkontrole plaasgevind om die resultate te verifieer. Guba se model vir die betroubaarheid van kwalitatiewe navorsing is gebruik.

Die volgende vyf temas is geïdentifiseer:

1. Gesinne kan kies hoe hulle op die krisis van 'n terminaal siek kind gaan reageer.
2. Mense se waardes verander wanneer daar 'n terminaal siek kind in hul gesin teenwoordig is.
3. Die aanvaarding van omstandighede vergemaklik die lewe van gesinne met 'n terminaal siek kind. Die kwaliteit van lewe saam met 'n terminaal siek kind word verhoog soos wat gesinne leer om die "hier en nou" te waardeer.

5. Die lewenskwaliteit van 'n gesin waar 'n kind terminaal siek is, word verbeter wanneer gesinslede van so 'n kind leer om ondersteuning te aanvaar.

Hierdie navorsing het getoon dat gesinne met 'n terminaal siek kind deur 'n lang en pynlike proses gaan wat teen die einde deur groei gekenmerk word. Die groei impliseer insig in die bogenoemde vyf temas. Hierdie insig vind dikwels eers na jare se ondenkbare swaarkry plaas. Riglyne vir opvoedkundige sielkundiges ten opsigte van 'n berustingsbenadering vir gesinne met 'n terminaal siek kind word aan die hand gedoen. Die doel hiervan is om 'n konteks te fasiliteer waarin die gesin met die terminaal siek kind hierdie lewensvaardighede sal ontdek en aanvaar en sodoende tot berusting sal kom.

Background and Rationale

This article focuses on the "life-world" of families where a child is terminally ill. When a child becomes terminally ill, the family is confronted with one of the most traumatic realities possible. Members of such families would agree that this is one of the most painful and difficult challenges life can offer.

During the past few years, I accidentally came across families with terminally ill children. I was shocked to see their suffering and felt urged to help them, but I realised that my training as educational psychologist did not specifically make provision for this. I was accustomed to rate myself as an expert helper in matters of the heart, yet I felt helpless in the face of such pain.

As my domineering efforts to console them were rejected, I realised and experienced what Einstein must have experienced on his deathbed as he said: "I know that I know nothing." This moment is a great turning-point in one's life as self-importance makes way for a deep humility - a quiet sense of desiring to really know what these families experience - what their life-world looks like, in order to be able to help them achieve acquiescence.

Problem Statement

It appears that family units with terminally ill children have a tendency to withdraw and this isolation leads to problems in mental health. Anger, frustration, restlessness and depression amongst others, characterise their mental health. A tendency with psychologists, clergy and helpers from other professions is to act as "ideal experts" on the lives of saddened people. From painful personal experience, this does not seem to enable acquiescence.

In their efforts to provide consolation to the grief stricken families these helpers often overlook their real needs and forge their own views upon them. For example, a well-meaning clergyman, saying that there is a purpose to everything that happens, or, that our loved one is going to heaven. Another example, is a psychologist with rather "new age" ideas trying to console a family with theories of energy that cannot be destroyed, and the circle of life.

In my own personal experience, this way only serves to cause further damage to the mental condition of grieving families.

From the above circumstances, the following research questions were formulated:

- What does the world of the family with a terminally ill child comprise of?
- Which approach could be described in order to lead the family with a terminally ill child to acquiescence?

Objective

In this article the researcher aimed to explore and describe the life-world of families with terminally ill children.

Research design and method

The research design consisted of a qualitative, explorative, descriptive and contextual design. Qualitative research originated from the social- and behavioural sciences. This is a method that is being used in order to understand a person's unique, dynamic and holistic character (Mouton & Marais, 1990:45). Guba's trustworthiness model (Lincoln & Guba, 1985:301) was used to establish the validity and reliability of the qualitative research. The four criteria for trustworthiness are truth-value, applicability, consistency and neutrality. Using strategies of credibility and applicability by applying strategies of transferability ensured the truth-value. Consistency was ensured by strategies of dependability and neutrality by strategies of conformability.

Population

Four family units with a terminally ill child were used for the data-gathering phase of the research.

Sampling method

A purposive sampling method was used in this research, which, according to Burns and Grove (1987:751), is carried out as follows: "Judgmental sampling that involves the conscious selection by the researcher of certain subjects or elements to include in the study." Sampling was done according to the following criteria:

- willing participation;
- ability to speak Afrikaans or English; and
- the presence of a terminally ill child in the family.

Research method

A multiple case study strategy was followed (Yin, 1994:44).

Data collection and analysis

Data collection consisted of family members of four families sharing their experiences with the researcher. Data analysis was conducted on the transcribed interviews that had been audiotaped according to Tesch's method (1990, in Creswell, 1994:155). Field notes were also taken into consideration. The first step was to read through each individual transcription in order to get a picture of the whole. The second step was to repeat the first step, but to underline themes, which were identified. A list of all the themes, as well as of all the similar themes that were related, were constructed. The most descriptive word for the identified theme was sought and placed into categories and sub-categories. Lastly, field notes

were used to make inferences on themes pertaining to the categories and sub-categories.

A protocol for analysis of the data was sent to an external data analyst. Consensus was reached between the researcher and the external data analyst on the results. A literature control was conducted to identify similarities and the uniqueness of the research.

Cross-validation report and literature control

A literature control was applied to confirm the results of the investigation and description of the life-worlds of the four families with terminally ill children, because a comparison of results with theory from literature promotes the confidence of the research (Woods and Catanzaro, 1988:136). A cross-validation report was integrated with the literature control in order to illuminate differences and similarities as well as unique contributions of the research.

Results

This is a realisation of the purposive sample. Four families with terminally ill children participated in the research. The writer will refer to supporting literature and will quote certain portions of the transcribed audio recordings.

The researcher concluded from the results obtained from the research that there are five recurrent themes involved. The five themes are:

- A person is able to choose his/her reaction to the crises of having a terminally ill child in the family.
- When there is a terminally ill child in the family, the family's values change.
- Acceptance of the circumstances with terminally ill children makes life easier.
- As families with a terminally ill child learn to live every moment to the full, their quality of life improves.
- As people learn to accept support, their quality of life with a terminally ill child improves.

I will now address these themes.

A person is able to choose his/her reaction to the crises of having a terminally ill child in the family

The realisation that one can choose in which way one is going to react to a crisis provides the person a degree of control over the situation; although he cannot change the situation, he can still determine how he will react. An example of this research is a father saying to his child after a long period of inner struggle: ****You get to a stage where you look at yourself in the mirror and you talk to yourself about it and then I decided: 'I have the choice to either sit down and decline and fall into total despair, or I can com-*

*mit to change my life around with force.' ****

The mother of this family also realises that she has a choice in the way that she is going to react and that she is not a victim of her circumstances; she may use anti-depressants or she may face her experiences. Her choice is the following: *"It is not going to change my situation, and I've got to learn and make the choice to make it better for myself, to make it more manageable."*

The father of family unit B experiences valuable personal growth as a father as he makes the choice of his reaction:** *"Once I decided on a course of action, it strengthened me – it was a positive experience. What I did as his father has been an experience that has been a valuable one."* He chooses to rather feel his sad feelings than to deny them and experiences this choice as healing: *"Collaring the beast of sorrow, was part of the victory against it."*

The mother of this family originally chooses to suppress her feelings of sadness and tries to maintain feelings of control by mobilising external resources. At night, however, she allows herself to cry in order to release the fear of her child dying: *"At night when I could be alone, that I could cry : just release."*

Jampolsky (1979:72) says that it may be helpful to question people's need to control the external world. They can, instead, consistently control their inner world by choosing what thoughts they would want to have in their minds. He (Jampolsky, 1979:72) concludes that peace of mind begins with their own thoughts and extends outwards; it is from their peace of mind that a peaceful perception of the world arises.

The father of family unit A attempts to maintain control by suppressing his sad feelings. Only after six to seven years of living in denial, the song "Fly" from Celine Dion triggers a crying spell that lasts for at least two months. Only after this release does he admit to feeling better for the first time.

The mother of family unit C decides to perceive her service to her sick child as her service to God and to let go of her plans to become a woman missionary in Korea, which in her view, would have been easier. : *"It would have been easier to go to Korea and do missionary work, than to handle an ill child, but this is what the Lord wants me to do."*

She believes that she alleviates her distress when she talks to her friends about it. Her husband on the other hand, becomes quiet and irritated by paltry things: *"There are bigger issues, which are of concern, but he will take it out on the small things"*. The way that he chooses to react to the crises of his terminally ill child is to wish that it would pass: *"There are times that you wish things will pass, but it has been two years now."*

There are times when he doubts his choice to believe that things will change for the better: *"You go through situations where you believe fervently - then at times you have to face*

* The direct quoted words of Afrikaans speaking respondents are translated into English and typed in *italic print*.

** The direct quoted words of English speaking respondents are quoted verbatim and typed in the same font as the normal text.

the facts."

The sister in family unit C finds that she has more responsibilities and less time for herself, but she chooses not to perceive this as negative, but rather as personal growth: *"...but while I am doing it, I realise that I'm busy teaching myself to be more responsible, just more independent."*

The reaction of the mother of family unit D is fear and loneliness and she believes the only hope for her child is to pray: *"...it is like fear. You feel lonely in a situation like this. You pray, that's all you can do. I would say, you try and fight, you stand by your child and you tell him: hold on, the Lord is alive my child, keep it up, just stay there! It's the only thing in your heart, to carry that child through."*

The fact though, that there is no way for her to alleviate her child's pain, leaves her feeling hopeless: *"Sometimes, you just feel like crying over it."* Her husband reacts negatively and he experiences his only son's illness as though he is losing his mind: *"It was terrible, from the first day we heard, I was losing my mind..."*, *"...it feels as if you are going mad, there is nothing you can do..."* and *"...your mind is at the hospital all the time, you can't think, you can't do your job, it is total chaos!"* He suppresses his feelings to the point where it becomes unbearable.

Victor Frankl (1963) writes a lot on this subject after his experiences in the Nazi concentration camps during the Second World War. Under the most desperate of circumstances, Frankl notices that some of his friends in the concentration camp survive, while others disintegrate spiritually. Although it seems human to react negatively to these unchangeable circumstances, a person still has the choice to find meaning within it: *"... even a man who finds himself in the greatest distress, in which neither activity nor creativity can bring values to life, nor experience give meaning to it – even such a person can still give his life meaning by the way he faces his fate; his distress. By taking him unavoidable suffering upon himself he may yet realise values. Thus, life has a meaning to the last breath. For the possibility of realising values by the very attitude with which we face an unchangeable suffering – this possibility exists to the very last moment."* (Frankl, 1986:xix)

Frankl (1986:xix) stresses the human quality of having choice in every situation: *"we saw how, faced with the identical situation, one man degenerated while another attained virtual saintliness. Thus, man is by no means merely a product of heredity and environment. There is a third element: decision. Man ultimately decides for himself."*

Dyer (1988:18-19) reasons that it is the essence of intelligence to be able to choose happiness rather than depression in problem situations, whether the problem gets solved or not. Bamsforth (1995:16) explains this idea from another angle, when he believes that we are all part of a "God-force", a free flowing energy within which there is always space for choice and change. According to Bamsforth (1995:16) we are all part of this power, inseparable from it but each with his or her own free will to decide their course of action.

Frankl (1963:25) explains that human freedom does not necessarily mean freedom from circumstances, but rather that it implies a freedom to adopt an attitude: *"Choosing a stand*

towards suffering means exerting freedom, in doing so, man in a sense transcends the world and his predicament therein."

When there is a terminally ill child in the family, their values change

The values of the father of family unit A changes in different ways: He is giving up perfectionism: *"I'm not going to fight with you when all the things in the house are not a hundred percent the way they used to be."* His relationship with his wife changes in that he is more tolerant of her: *"If she...in a moment gives me such a pinch with her mouth, I would tell her 'it is OK, you know, I understand, be aware, you are stressed.'"*

When he observes how his little girl fights for her life and how she positively changes situations, he learns many things and believes he became a wiser person because of that. He also obtained a sensitivity, which he is becoming more aware of in his relationships with his colleagues at work: *"I became a wise man once on the other side", "...that sensitivity that you have when you are with people to say 'What is bothering you?'"*

His wife's values concerning this also changes as she states that she now sees other people's pain and actively reaches out to help them. The values of the mother in family unit C changes and she judges what others find important, as futile: *"I can't go to a stupid thing such as a cocktail party anymore. The other day somebody held a stupid conversation about a holiday house...that it remotely crosses your mind to talk about such nonsense."*

She becomes candid with herself: *"There is no aspect of myself, which I need to lie to myself about."* With reference to this, Bamforth (1993:17) states that it is especially during times of the worst physical illness or emotional trauma when people question the purpose of life, that people are forced to come face to face with their own true selves.

The mother of family unit B becomes more honest in relationships and would confront people more easily than before: *"When I discover that another person is not totally truthful, I will confront that person about it."*

The values of the father of family unit B also changes and it seems as if he realises the meaning of love: *"You dealt with a life-threatening illness, a life of a child, very few things, or people, can scare you after that, so you know that there is nothing you can't cope with."* He states that relationships, friendships, time, time with his children, family values, to keep his family together, to be able to support other families in the same circumstances became important matters to him. According to Jampolsky (1979:17) people's lives are more meaningful when they focus on things that really matter; things they could call love, there is no space for fear, and in the process where fear makes way for love, they undergo a personal transformation.

The father of family unit B, originally believes that all sickness is from the devil and that God never makes anybody ill, and that Calvary means complete healing of illness if you have faith. When healing does not take place, it is an indica-

tion that his faith was not strong enough. The attitude of his church is that it is unfair that his child became ill. The reason for their attitude is that they feel that his family serves the Lord in exemplary fashion. The mother also experiences her daughter's illness as punishment from God. Then the father takes a definite stand when he says: *"I don't think it is a matter of having done anything wrong. I think you are going to punish yourself unnecessarily if you are going to do that to yourself. We are not going to do that."*

Elizabeth Kübler-Ross (1974:349) states that many people perceive suffering and loss negatively as God's punishment, where they could actually experience inner peace if they realised that it is an opportunity for growth.

The father of family unit C struggles with the loss of control and the uncertainty this involves: *"Why her?"* Then one day, he realises with a shock that from his four children, his ill girl is the only one who could handle the circumstances. This realisation brings him peace as he sees God's hand in the circumstances. *"...giving trust that God does not stand outside the situation."* From the aforementioned, Bamforth (1995:18-19) states that growth and change that follow from suffering is a process of letting go of the inclination to control up to the tiniest aspect of your life, and to learn to trust your intuition which is the channel to universal energy, or God.

The mother decides to spend more time with her child when she realises the effect of her easily uttered words such as *"Mommy can't just now."* She decides that she will never again be the way she was before, even if her child recovers: *"...then I will spend my time differently, to assist these children."* It seems that this mother learned that when you help someone else to alleviate their pain by supporting them, your own pain has the opportunity to rise to the surface and gets released automatically.

The mother from family unit D seems to have gained wisdom: *"One is so apt to think: 'Oh I wish I could be like that one, you know, or if only my child could be like that one', but you never turn back to see how good the Lord is to you; that your child is still with you. You are so apt to always want to know, oh, that guy, how much money does he have, or how... but you never think about how privileged you yourself are....you often think: there are so many children in the world, not so? Why must I be overtaken by misfortune? But what makes me so much better than them? That guy, maybe in his future there might be something that he could handle, which I would not have been able to handle."*

She realises the value of life and that a child should be respected: *"...when the Lord takes these children from you, then you have nothing", "...a child is never in the way"..., "...a child is just as important as you are."* She also states that she got much closer to the Lord since her child became ill. It seems that she makes a conscious effort to change her values when she says: *"... you have to get your act together. I can't live the way I used to before, and you can't live in the world and ask the Lord to help you every two minutes: 'Lord, please, I have an emergency now! You have to do what the Lord wants you to do as well...I try to live my life in such a way that my situation will be right, should the Lord be fetching me before my husband or child.'"*

It seems that this woman looks deep into herself and grows and changes in consequence of her child's illness. Frankl (1980:18) states that it is indeed suffering that gives people the opportunity to grow and change themselves and that suffering has meaning only if you change in consequence of that, only if you become another person.

Bamforth (1995:29) concludes that nothing happens by chance; that there is purpose in everything that happens and that people could open themselves up in faith to see what they could learn from a certain crisis.

Accept your circumstances

The father of family unit A decides to accept reality when he says: *"Father, we choose to believe that you decided this."* His wife immediately experiences peace when she accepts the circumstances: *"I believe that the Lord can heal her, but if he takes her, it will be right as well - and after this I experienced a sudden complete change."*

Proceeding from the previous, Scott Peck (1990:13) says that life is difficult and as soon as we accept and understand this truth, we transcend it and it doesn't bother us so much anymore.

The mother of family unit B attempts to accept the circumstances by making practical arrangements: *"...I have completed a list in writing, for the day he has to die, to phone this and this, that and that and that, this is the minister and this is what he has to say, and this is the way the funeral will be: it's there."* Her acceptance of the circumstances is also obvious in the following: *"everyone gets the parcel the Lord thinks he can carry, and you carry it."*

The father of family unit B accepts tension in his marriage as a consequence of the circumstances: *"part of the process. Part of the inevitable consequences of a series of very intense relationships undergoing the most severe strain and crisis, quite to be expected though."* He handles this by giving his wife more space and expecting less emotional support from her for himself. He realises that this difficult situation can be, as Shantideva (in Dhammananda. 1989:14) puts it, be handled in one of two ways: We could do something about it to change it, or we could accept it. He handles it by making fewer demands on his wife.

His instinctive reaction is to accept the circumstances: *"to face it and to help him (the son) face it"*. He admits though, that it is hard to accept sad feelings: *"but it is very sad to see – very hard to see when a child suffers – it's continual pain."* He learns that sadness is not necessarily negative, and states that by handling the most severe sadness, it becomes a cleansing and strengthening experience. He continues that by accepting sadness, happy moments become intense experiences in which reality shines bright and authentic. This, according to him, gives profound depth and quality to life.

Cooper and Sawaf (1997) say, proceeding from the previous, that our ability to experience happiness depends upon our capacity to feel sadness and mourning. To the degree to which we avoid feeling pain, we blunt our ability to experience joy. Kahlil Gibran (1955:32) comments so beautifully on this with the following: *"The deeper sorrow cuts into your being, the*

more joy it contains.” Bradshaw (1992:126) also focuses on this feature of polarity of reality.

The mother of family unit C accepts the circumstances when she sees the illness of her child as her service to God. The mother of family unit D says the following regarding acceptance: *“We are lent to this earth, but the Lord is still, how could one say, good to us. He gives another chance; some don’t get another chance. I don’t know, you have to start accepting it in a way.”*

Longacker (1997:48) says pain is unavoidable, but suffering is optional. Suffering, according to Longacker, (1997:48) stems from our aversion and resistance to our painful circumstances and not from pain in itself: Suffering is “our agony at losing our hopes and expectations, being forced to relinquish control, and feeling vulnerable and powerless against the underived change or loss.”

The above is worded as follows in the Serenity Prayer (Beatie,1992:41):

“God, grant me the serenity
to accept the things I cannot change,
Courage to change the things I can,
And the wisdom to know the difference.”

A course in miracles (1992:126) says that as long as we deny reality, we are prone to fear, depression and panic.

Appreciation of the current reality

The father of family unit A is being confronted with the mortality of his family since his son got ill, and he realises the limited nature of time now. He realises the importance of valuing his loved ones in such a way as if he could lose them at any moment: *“Your time is limited...and I was shocked, and I said to Him, maybe I should do what I want to do, quickly, and I should finish it quickly.”*

Concerning this, Kübler Ross (in Campbell, 1995:12) says: “Death can show us the way, for when we know and understand completely that our time on this earth is limited and that we have no way of knowing when it will be over, then we must live each day as if it were the only one we had.”

It seems that the husband and wife of family unit B grab the here and now as they seek marital counseling intending not to stay discontented like many couples who hope that things will sort themselves out, do: *“...we try and sort things out, because life is too short for this.”*

Dyer (1976:34) says that the present moment should be observed as the only one we have and thus we should make the most use of it. He continues to see actions of hoping, wishing and blaming as dangerous tactics to avoid the here and now. As a father he also realises the value of time spent with his child: “ .. you live two days at a time, your relationship with your child is very intense.”, “...when a child is very ill, one does live from day to day, each day you know, I used to say to myself, I used to say ‘God has given me a child for one day, enjoy that day, and that’s the way we go’. Those were wonderful days, to be able to sit and read a chapter of a book, you

are, it becomes very intense, I’m still emotional about it.”

Stephen Levine (in Campbell, 1995:13) says that as soon as we start to use death as a means to focus on life, everything becomes exactly the way it is; only this moment becomes important; an outstanding opportunity to really live. According to Bradshaw (1994:127) it is soulful to be present in the here and now, because only then do we really see and hear, this special space enables authentic contact with each other and thus authentic contact with reality as well.

The father of family unit C says: *“With time, one begins concentrating on immediate things.”* It is as if he realises the futility of regret about the past health of his daughter or worrying about the future possibility that she may become sterile as an adult as a result of the chemotherapy. He sees the uselessness of planning ahead and even his daughter is not pleased with long term things, and you can see the things she concentrates on are the things important to her at that moment.

The father says: *“Later, you begin thinking to yourself more - what is important to the child now, and one becomes attuned in such a way that you want to do everything she enjoys you possibly can. You are apt to try to enjoy that which is available now.”*

Jampolsky (1979:106) focuses on the fact that the past is over and that the future still has to arrive and that peace can only be experienced in the present. The mother learns to appreciate the here and now as well and earlier she would have said: *“Mommy can’t now”* when her child would have asked, for example, if they could play “battleships”. She now agrees: *“...and we play ‘battleships’ because it is important to her to play ‘battleships’ now and it is enjoyable to the little family to sit together and play ‘battleships’ .”*

The mother of family unit D realises that the present is all she really has: *“... and that is why I turned back and just thanked the Lord for every day I can spend with him, every day I can see him laugh, and I don’t look at other people’s things anymore, to see why he can’t be like that, or, why I can’t be like that.”*

Accept support

It seems that the father of family unit A appreciates a simple act of kindness rather than words: *“People think they can fix something with words, and they cannot. We have been removed from other people so that they couldn’t reach us with words. Somebody, once, managed to do the right thing... they brought us Kentucky Fried Chicken and left it for us with a little note.”*

It seems that the father of family unit A suppresses his emotions for six to seven years after the beginning of the illness. He experiences the support of specific ministers as insufficient, due to their lack of experience in dealing with similar situations. He experiences the song from Celine Dion, “Fly” as supportive in a sense, because he could identify with her pain. (The song is dedicated to the artist’s sister’s child who died of leukaemia.) The song enables him to express his own feelings and by doing so, bringing about healing.

The mother of family unit A values practical support: *“When*

my children were little the Lord sent me time and again, when she was on a drip, someone that helped me in a practical way." She finds the help from other mothers with ill children to be very helpful: "the mother just hugs me and cries with me and says: *"If the sun rises tomorrow, then it will be better."*

The father of family unit B accepts support from his friends, and by doing so he feels that he is getting the strength to go on: "...by being able to talk about it to friends and having friends who are good enough friends to be able to listen to it, talking about it, and using it as sort of energiser to fight the cancer." He states that for support to be of value it should be sincere, consistent and the person should be willing to give of him- or herself. According to McIlwraith (1998:38,39) the most productive support is when space is created for people to acknowledge and express their feelings, by people who had similar experiences.

The mother of family unit C experiences it negatively when people phone continuously to enquire after her child's health: "How the hell must I tell them how he is when he was about to die?" The father of family unit C values practical support in the sense of people who are willing to sacrifice their time: "...people sat with her through the night, working parents helped us until two 'o clock at night. People prepared food for us, it was very difficult to cook meals and run a house."

The mother of family unit C experiences support when she knows that there are people who are praying for them: "...the congregation really supported us spiritually and physically and we received a lot of support and had numerous days of prayer and days of fasting on her behalf." She values practical support: "People who brought us food, not because we are poor, but because it is practically difficult to prepare a decent meal every day, when your child is in hospital for a week". "Friends took turns to stay with her through the night, so that we could sleep". "Somebody who is willing to drop off and pick up your kids to care for them."

The father of family unit D values financial support coming from the hospital: "... the hospital helped me with the medical stuff and I felt better after a while." He appreciates it that his colleagues at the mine where he is employed, are willing to do his job for him in periods of crises, in order for him to still receive his salary. He also appreciates friends and family who are ready to sacrifice time: "... my sister in law, next door, when you called on them, then they were there - and people like that, they assist you through."

Bradshaw (1994:301) says in connection with the previous that people need more help and support in their lives when they are in grief than at any other time, as they struggle to think clearly and they regress to the earliest phases of childhood. They are like "an infant crying in the night with no language but a cry." (Bradshaw, 1992:301) Longacker (1997:55) states that these families need a comforter which, when it is translated directly from the Greek word paraclete - means "one who comes to walk alongside." Longacker (1997:54) states that everybody who is suffering needs their pain to be validated, they need to feel safe in order to give expression to their pain and to experience that their feelings are understood. Longaker continues that they need to feel re-

spected and accepted, no matter what their circumstances are.

Bradshaw (1988:138) says, proceeding from the previous, that people suffer from delayed grief because of the lack of someone to support and validate their feelings. Jane Middleton-Moz (in Bradshaw, 1988:138) says the following in this regard: "One of the things we know about grief resolution is that grief is one of the only problems in the world that will heal itself with support."

Conclusion

The above concludes the findings of the research. The researcher believes that a family unit with a terminally ill child does not stay the same - the crises change them in time. The cross validation analysis enabled the researcher to illuminate similarities as well as differences between the four family units. These findings were affirmed with a thorough literature control. The research proved that family units with a terminally ill child, undergo the following changes: The family unit comes to the realisation that they may choose how they will react to the crisis of having a terminally ill child in their midst. The research also found that having a terminally ill child, changes the values of the family unit. The research proved that although it sometimes may take years, the family accepts their circumstances. Another change that takes place in these families and which the research validated is that they learned to value the here and now - they learn to live every moment to the full. Lastly, the research found that family units with a terminally ill child, come to realise the importance of accepting support in their painful situation.

Limitations

A possible limitation to this study is that the four family units who agreed to take part in the study are an exception to the large number of family units I approached, but who turned down my request for participation, some even with anger. This proves again how difficult it is to get access to those families who are obviously suffering unbearable pain.

Recommendations

Recommendations were made to psychology practitioners as well as practitioners from other disciplines, to psychology research and education.

Psychology practice

Knowledge of the changes the family units with a terminally ill child need to undertake, will enable psychologists to provide appropriate facilitation in order for the family units to achieve acquiescence.

Health professionals

The conclusions and recommendations of this research are shared with all health professionals.

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