



Give Sorrow Words: The Meaning of Parental Bereavement

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Abstract

A fundamental tenet of hermeneutic phenomenology is that people seek to create meaning of their experience from the response sited within human consciousness. The focus of this study is on the world of the lived experience as it is interpreted by participants through memory and language as accessed by interviews in order to produce an understanding of the participants' experience. Three participants were interviewed whose adult children had died as a result of an AIDS-related illness. The interviews were recorded and transcribed, and interwoven analyses sought to illustrate the participants' lived experience of the phenomenon. An attempt was made to understand how the various phenomena relating to parental bereavement were reflected by participants in the interviews. Common themes included reactions to the knowledge of the illness, the experience of being with their dying child, coping with the pain of the loss, and spiritual and existential concerns. There are references to how others judge their grieving behaviour. Issues of retribution and punishment are prominent and these appear to place a particular burden of sorrow on the grieving parent. The study provided insight into the lived experience of bereavement and the forging of new meaning structures that can accommodate the loss.

Introduction

While life is lived and experienced in the present moment, the study of the lived experience can only occur retrospectively through the use of memory and language. A fundamental tenet of hermeneutic phenomenology is that people seek to create meaning of their experience from the response sited within human consciousness. To know the meaning of an action or of a linguistic expression requires a different perception from that which is derived from sensory modalities and which may be called understanding (Polkinghorne, 1983). Understanding, in this sense, refers to the comprehension of meaning which derives neither from purely deductive nor inductive reasoning, but is rather an ongoing process operating at several levels simultaneously. In taking on a hermeneutic stance, the pretence of an acosmic, ahistorical and asocial consciousness must be abandoned as the philosopher confronts his or her own existence and the ontological meaning of it to

reveal the meaning of human expression (Kockelmans, 1967). Hence, when a text is approached by someone seeking to interpret it, the interpreter's own experiential life-world inevitably intrudes through expectations, beliefs, values and concepts, so that what emerges is an amalgam of the life-world of both author and interpreter, an idea which Gadamer (1979) termed a fusion of horizons. The concept of the hermeneutic circle illustrates this point, as the interpreter begins an interpretation with certain expectations which change as a result of these expectations not being fully met. The revised expectation is then subject to the repetition of this process so that the dialectical nature of the process is central to researching the apprehension of meaning (Polkinghorne, 1983).

Research Methods

According to Van Manen (1990) the following aspects are crucial to hermeneutic phenomenological

enquiry:

Investigation of the lived experience

“Lived experience is the starting point and end point of phenomenological research” (Van Manen, 1990, p. 35). At all stages of phenomenological research, the nature of the experience guides the investigation, as posed questions seek to answer the fundamental question of what the experience itself is really like and what it is about the experience that renders it significant. The function of data gathering is the collection of the raw and unadulterated descriptions of the experience which is being investigated (Polkinghorne, 1989). It is assumed that there is a coherent string of interlinked connections between the person’s world and experiences, their feelings and the way in which these are spoken or written about. The experience is described subjectively in a naïf and natural way, avoiding generalisations, statements of causality or interpretation.

Reflection of essential themes

While people tend to reflect easily and spontaneously on the meaning of events, the determination and clarification of such meaning is more difficult because meaning has multiple interrelated dimensions. As themes are indicative of the desire and ability to create meaning from experience they can reveal the nature of the phenomenon. Irrespective of how themes are identified, it is necessary to distinguish between those themes that are essential, and those that are supplementary to the essence of the phenomenon.

Writing up the research

Writing facilitates the reflection which evokes a form of consciousness that makes phenomenological enquiry possible. Writing also converts the experience to an abstraction making it an intellectual exercise. Van Manen (1990) stresses the importance for writing and re-writing to occur concurrently, because it is through this circular and reflective process that the coherent image of the whole can emerge. Through the process of reduction, an interpretative process is begun. The hermeneutic circle refers to the process where the global meaning of the text both shapes and determines the meaning of discrete parts of the text. This process is a continuous one, repeated until a valid and unitary meaning is forged which has internal validity. Cohen, Kahn and Steeves (2000, p. 73) posit that

the goal of the analysis is a thick description that accurately captures and communicates the meaning of the lived experience ... A thick description is one that captures the experience from the perspective of the

informant in its fullest and richest complexity.

For the purposes of this research, participants were chosen with the intention that they act as informants who are able to give rich and abundant descriptions of their experience of the loss of an adult offspring as a result of a long-term AIDS-related illness. During the course of participating in individually-conducted interviews, participants were asked to describe their personal grief experience with regard to their subjective experience of the meaning-making process. The interviews were semi-structured with some open-ended questions posed to all participants in order to elicit an evaluation of their experience of meaning-making. The following questions were considered:

- What meaning the participant made of the prospective death in the period prior to the death of his or her offspring.
- How the participant experienced the type of death that led to the loss of his or her offspring.
- How the participant’s sense and understanding of how the world, and his or her life in the world, has changed since the event.

The interviews were recorded and transcribed, with each transcript being faithful to the recorded content. Analysis of the transcripts enabled the identification of themes and facilitated the composition of a synthesis of themes interwoven across all three interviews.

In addition to the interviews, field notes, as recommended by Kahn (2000), captured the details of the interviewing process before the researcher’s own internal process of sense construction could begin so as to obviate a change in focus or a loss of detail. The field notes formed the basis for the personal reflection of the researcher and provided a valuable opportunity for self-reflection, which assisted in the development of the interpretive process by giving form to the nascent and tentative understanding of the researcher. This self-reflection was ultimately the most surprising of the outcomes of the research because it was unanticipated.

Research Participants

Initial contact was through a chapter of The Compassionate Friends (TCF) and a Catholic Church, with prospective participants identified through self-disclosure of the cause of their child’s death as an AIDS-related illness. In this regard, it is interesting to note that, even within the supportive context of TCF, only a handful of members were willing to disclose the cause of death as being AIDS-related,

which points to the difficulties inherent in attempting to conduct research in such a stigmatised area.

In that the literature suggests that the initial period (lasting for perhaps some months) following the loss of a child is characterised by shock and denial, a criterion for selection as a participant was that the loss should have occurred a minimum of six months prior to participation in the study. That the participants' ages ranged between 45 and 65 years was related to the age-criterion in respect of the deceased children, who were required to have been adults at the time of their death. Given the need for participants to act as informants who are able to give rich and abundant descriptions of their experience, the participant's ability to express him- or herself competently in English was of importance.

The three participants selected, whose names have been altered, were contacted telephonically and their informed consent to participate in the study obtained. The first contact between researcher and participant served to clarify the purpose of the research and how it would be operationalised. This included informing the prospective participants of the nature of the interview, and that it would be recorded and transcribed. It was made clear to them that there was no obligation to participate, and that they were free to terminate their participation at any stage of the process if they so desired. Prospective participants were also assured of anonymity and that any information which was potentially revelatory of identity would be removed or disguised. Furthermore, participants were offered support through the possibility of a debriefing session, or referral to a counsellor, if so desired.

The venue for each interview was selected by the participant concerned, with two of the interviews taking place in the respective participants' homes and one in a Parish office.

Introduction to Selinah

Selinah is the single mother of an adult daughter who died as the result of an AIDS-related illness. Selinah has been working as the domestic worker of the same family in the city for many years. Prior to her illness, Selinah's only child lived in a rural area. She came to the city in order to seek treatment for pernicious and worrying illnesses, and it was here that she and her mother learnt of her condition. At the time of diagnosis, the illness was already in an advanced stage and Selinah nursed her daughter until the day before her death, when she was taken to a Hospice. A mainstay of Selinah's life is her religion, as was also the case for her daughter while she was still alive.

Researcher's impression of Selinah

Selinah appeared calm and composed when I arrived, but talking about some of the events relating to her daughter's death were highly distressing for her, and consequently for me, as I felt responsible for having elicited this reaction and helpless in the face of her suffering. The pace was greatly slowed at this point and elements of the interview were inaudible as she had placed her head on her arms, which were resting on the table in front of her. However, as the interview progressed she regained her composure and this continued until the end of the interview.

Introduction to Rosemary

Rosemary is the widowed single mother of six children. She is a seamstress and lives in modest circumstances. Her eldest son died in violent circumstances some years before her daughter contracted HIV. Since her daughter's death she has been taking care of her daughter's child. Her hope for him is that he might become a doctor or another professional and she has been putting money aside in order to enable him to attend university once he leaves school.

Researcher's impression of Rosemary

Rosemary was eager to see me, and began to talk about her losses immediately on meeting me. Her style was very forceful and she presented as very determined and in control of her emotions at all times during the interview. It was difficult to pose questions as she would interrupt almost as soon as I had begun talking. About half-way through the interview her pace slowed somewhat, even though she continued to return to the proselytising stance which appeared the most comfortable for her. At all times during the interview she maintained a forceful and unemotional presence.

Introduction to Lorraine

Lorraine is the retired mother of two adult children. She discovered that her son had contracted HIV approximately eight years ago. He subsequently died as a result of an AIDS-related illness. For some months now she has been unwell, suffering numerous lung infections and depression.

Researcher's impression of Lorraine

At the time of our meeting, Lorraine was not well, having just overcome a bout of illness. She appeared quite frail, with a nervous edginess. For most of the time she spoke almost without interruption so that it was often difficult to break into the narrative. Although she spoke of her distress she did not show evidence of this during the course of the interview.

Common Emergent Themes

The following themes represent a summary of those themes that appeared most frequently during the interviews.

Reaction to the news

Themes of disbelief, lack of understanding or denial, were touched on by all participants. Denial can also be seen as a wish to not give up hope for oneself, or for one's child. This is illustrated in the following excerpt. At the outset, the constant illnesses of her daughter were a source of concern for Selinah who could not account for them:

"I couldn't understand, until I knew what was wrong with her."

Selinah also describes very clearly the sense of disembodiment she experienced on receiving the news of the diagnosis:

"I don't know how to say this. At that moment I feel like I'm living in another ... I am in somebody else's body or mind or something. I couldn't ... ja ... I, I, I couldn't feel myself, I don't know how to say it ..."

This excerpt is prefaced and closed by the same phrase indicating her inability to express herself in this matter. This is possibly an indication of just how alien such feelings are to her and that, if they are so out-of-the-ordinary, this means that others too would not understand this sense of dislocation and disembodiment. Lorraine echoes these sentiments in describing the sense of the unreality of life and of disembodiment since her son's death:

"Everything just seems so unreal ... that I'm just going from the one day to the other, but everything ... it's like I'm not in my body."

Selinah attempts to explain that it was not solely that she no longer felt herself, but also that "*it was like it's the end of everything*". In order to elucidate the meaning of this, she explained how her very being was threatened with extinction as a result of this event:

"Maybe ... I'm going to die with her, because she was everything to me, all my hopes: she was my life" ... so to find out that she's got that disease everything just cut off my life."

Relating to their dying child

Although being HIV-positive is not characterised by symptoms, as the disease runs its course and the immune system is negatively impacted, AIDS-related symptoms begin to manifest and the person so affected requires progressively more care.

Hoping against hope

Although Selinah could understand the inevitability of death once her daughter became very ill, this understanding is still subject to a hopeful questioning that Selinah knows is unrealistic. For instance, she explained how she hoped,

"That maybe she's gonna live maybe for me, for a long time. I don't know how, but since she was my only child ..."

It is almost as though Selinah wants to believe that, by her daughter desiring it, it could be possible to stave off death even though it is an inevitable outcome in every other case. In a different vein, Lorraine expresses a not dissimilar idea:

"No matter how he felt, if I wanted him to do anything, he'd do it. He said, 'I'll do anything just as long as my mother's happy'."

Yet, whatever hopes survive, they are undermined by the self-evident progressive nature of the illness, which erodes this hope, rendering it forlorn:

"I see the changes in her body, I can see the changes, she was getting thinner, and thinner, and thinner and thinner."
(Selinah)

This then is the demise of the last remaining shreds of hope and, for Selinah, existence becomes a succession of terror-filled events as she lives in momentary expectation of her child's death. Even going shopping is fraught with the anxiety of what might await on her return:

"Living that life every day. When I have to go to the shops every day, and when I come back, and open that gate, I get so frightened, if I have to go into my room."

Powerlessness and helplessness

The sense of helplessness, and of being unable to help or ameliorate the multifarious symptoms of the disease makes it very difficult for those who are taking care of AIDS patients, and especially for parents who watch the suffering and physical

deterioration:

“If someone can’t get better, then it’s very sad.” (Selinah)

“It hurts to see your child withering away. Looking at her every day until she becomes so small. It hurts.” (Rosemary)

“It was dreadful to watch him suffer the way he was suffering.” (Lorraine)

The malevolent intention of the person who infected Lorraine’s son is one instance that provokes a sense of powerlessness for her:

“He was actually murdered because he met somebody and they had sex and afterwards the person told him that he was HIV-positive.”

For all participants their inability to ease the obvious suffering is particularly awful:

“There isn’t a thing that is not sore. Whatever you touch it’s eina, eina. [ouch, ouch]” (Rosemary)

“He got candida ... It was just too dreadful and at first the stuff that he took for it, it did help [but] then he got immune to it.” (Lorraine)

“There is nothing you can do to help that person, ... Day and night you’re just sitting there and staring ... There is nothing you can do.” (Selinah)

A prevalent theme in Rosemary’s narrative is the sense of life as unpredictable. Life is uncertain and prone to ending unexpectedly. Death is thus an ever-presenting reality existing as a possibility that waits to impose its grim reality on the lives of those who are at risk of death simply by virtue of human mortality:

“There’s nothing I can do. I can cry, I can run away, I can hang myself, it’s there.” (Rosemary)

However, an unwitting cruelty arises when one has such limited access to resources as a result of straitened economic circumstances that simple survival consumes much of one’s reserves:

“Try to do whatever they tell you to do: eat healthy and all that. We don’t all have those

monies to eat what they want us to eat.” (Rosemary)

Even where medical assistance is forthcoming it appears to take away something else so that longer life is only bought at the cost of greater suffering and indignity:

“They can keep you to live longer. But ... if these things can keep you living longer, why at the end must you suffer like that? Shrunken, full of pain ... ?” (Rosemary)

As death approaches, being with their children becomes intolerable and neither Selinah nor Rosemary were present when their daughters died. The situation for Lorraine was unclear because she skimmed over the actual death, moving from her son’s being in a coma to a brief and singular mention of the funeral. However, in common with the Selinah and Rosemary, visiting her son was hard for Lorraine:

“I keep thinking of going to the hospital, ... I couldn’t watch. I used to stay there maybe 10 or 15 minutes, and then I’d come home, and say, I can’t bear to see this.” (Lorraine)

The stigma of the disease

As far as Selinah is concerned, she believes that AIDS differs from other fatal illnesses only insofar as “it’s a new thing”. However, she refers to thinking of AIDS at the time of diagnosis as “that disease” without identifying it. When referring to AIDS for the first time, Rosemary also struggles with it: “It was now ehm what’s the name? ehm ... AIDS”. Later she refers to AIDS, calling it “this thing that’s so incurable”. It seems, therefore, that naming the illness may be difficult.

For two of the participants there was some reticence in disclosing the cause of death at the beginning of the interview. Rosemary believes that the reason for this reticence with regard to disclosure in general is that the system of beliefs that attach to HIV/AIDS confer a tainted moral identity on the bearer:

“They emphasised entirely on sleeping around.”

She believes this to have changed more recently, with better information on alternative possibilities for contracting the virus, which do not imply immoral behaviour:

“But now you get it through needles, you get it from many things.”

“So really, it is easy to pick it up.”

Being able to publicise those alternative means of transmission, Rosemary was able to disclose the cause of death of her daughter, so that “*now it’s in the open*”. A difficulty which Rosemary well understood that afflicts the person who is HIV-positive is the subjective sense that one’s status is visible to the casual observer: “*You see somebody looking at you maybe for a time. It’s as if that somebody sees through you what is your status*”. It seems as though this is something she has argued with herself:

“The thing is they don’t. It’s in your head.
They don’t see what it is ... as long as you
take care of yourself.”

The Role of God

The participants each refer to their relationship with God in their interviews, though for each the nature of this relationship is very different.

AIDS as punishment

In spite of their avowals to the contrary, there appears to be a persistent view of HIV/AIDS as a punishment for immorality among the participants. Rosemary sees it as a latter-day plague:

“I think it’s a [plague] really.”

In this respect, then, it may be thought that HIV/AIDS takes on a sense of Divine retribution. Hence the questioning that occurs in those affected by HIV/AIDS makes sense, as they try to understand the cause of their punishment. As Rosemary comments, “*you keep on questioning yourself why, why me, how did it happen?*”. Selinah is angry that God has chosen to punish her daughter who was not promiscuous:

“That was [her] first boyfriend and her last
boyfriend ... She was very open and I
couldn’t understand. I still don’t.”

And yet she ponders, “*maybe she did wrong, I don’t know*”.

Reconciling Divine retribution and forgiveness

Each participant refers to their relationship with God, though for each of them the nature of this relationship is very different. It is also different for each of them at different times. During the time when her daughter was ill, Selinah seems to have wondered whether AIDS could be a form of retribution from God. Uppermost in her mind was the quandary as to God’s motivation for causing her daughter to suffer from the illness as her daughter loved God, and was not promiscuous (and therefore was innocent of wrongdoing). Not finding an explanation leads

Selinah to assume a measure of guilt in the first year after the death, believing that it is she whom God wishes to punish because what she is experiencing watching her daughter suffering and dying feels like the most extreme form of punishment:

“That’s why I thought at that time that
maybe God is punishing me ... Maybe I
did something wrong before God, so
maybe He’s punishing me.”

However, resolution of these conceptual difficulties eventually leads her to view her daughter’s death as a demonstration by God to the world that anyone can be infected with AIDS, even moral, good people who love God and the church, as was the case here:

“Maybe it’s just that horrible disease will
have to come to her so you can’t say this
one can’t get this, it’s too good to get
that.”

Reconciling Divine goodness and evil death

If “*God doesn’t hurt*” (Rosemary) people, it appears difficult to understand how death and suffering can be permitted by a benevolent God. Rosemary resolves this dilemma through a split whereby she suggests that “*death really is devil’s work*” and that it is “*evil ... a lot of evil*” that causes suffering. How then to reconcile the fact that an omnipotent God has the power to bring about healing, and yet does not necessarily choose to do so? For Rosemary it appears that she achieves this reconciliation by understanding healing differently. Even when one is not cured from HIV/AIDS it is possible to attain healing in other spheres of one’s life:

“Even if you are so sick, once you give
yourself unto the Lord, you become
healed.”

“People can see you are sick, but inside I
can say you are free. You are free, you
feel happy.”

It seems that for Lorraine there is no clarity about whether God even exists, perhaps because it seems to her inconceivable that the God she had believed in could not have responded to pleas for healing. Consequently she wonders about the nature of an after-life:

“Where’s he gone ... How can anybody
know? Nobody can know. Maybe there is
such a thing as heaven, with God sitting
there. But I don’t know that.”

Finally, she concludes that she “*can’t ask why, can’t*

ask questions", perhaps because there either are no answers to be received, or perhaps because the only answers that present themselves are unacceptable to her.

AIDS as a test

Each of the three participants, regardless of personal background, refers to the experience of losing a child to AIDS as a test, perhaps imposed on them by God:

"So I stood up to that test up to now."
(Rosemary)

"Maybe God, He knows maybe something prepared for me - maybe He's testing me with all this stuff." (Selinah)

"I probably said why has God done this to me, and then I think, maybe he's testing me for something." (Lorraine)

Following this line of thought, Lorraine eventually concludes that, if being tested is a Divine plan to produce greater resilience and strength, then it is spurious and contemptible in light of the experiences that she has undergone and those that she still suffers:

"They say you get stronger when something like this happens. You know that's just a lot of bullshit. You don't get stronger."

The Grief Landscape

The grief of bereavement is so intense and all-pervasive that it changes the way life itself is experienced. The following themes were common to all participants and highlighted how in these respects the world seems so different.

Feelings of emptiness

Many of the images used by the participants to convey their experience refer to emptiness, desolation and devastation. Selinah describes how her body is emptied of that which or who she is, and seems "*empty, [and] feeling ... emptiness*", perhaps "*because everything I ... loved, it's gone*". The nature of this emptiness is almost that of an infinite void and it seems to her that "*there is nothing that can fill that space*". Being in such a state means that "*day and night you're just sitting there and staring*". Normal bodily functions too seem to be suspended and "*you can't sleep, you can't eat*", so that she still does not understand how it was possible to survive. There is also a great sense of an empty void when Lorraine makes the following comment:

"I was like standing there, with nothing, with absolutely nothing."

For the participants the loss of their child is a cataclysmic event which makes much that was normal unfamiliar. The old world is all around, and the person lives within it, but it can never again be accessed, rather as though one has stepped through a one-way mirror. Janoff-Bulman (1992, p. 51) refers to this as a shattering of the assumptive world where old meaning structures no longer hold. Hence, memories seem to threaten survival, eliciting anxiety and dread, or, as Attig (2001, p. 37) terms it, soul pain:

"Everything ... I loved, it's gone ... and then I'm living for what?" (Selinah)

"What have I got to try for, ... for who, what am I trying for?" (Selinah)

On being alone

Although Lorraine recounts that "*in the beginning everybody comes*", the sense of being alone made it feel for her as though it would be impossible to continue living. The frantic and busy schedule which is governed by caring for the ill transmutes with suddenness and finality into an empty loneliness without function or purpose:

"I wonder how I survived afterwards, because I felt so alone, because you are alone. At the end of the day you're on your own." (Lorraine)

It is not the absence of people, but rather the lack of understanding that causes participants to feel the presence of others not only fails to diminish the loneliness, but exacerbates it:

"There's nobody for me except God. You can have families and everything; what they do is say 'shame, shame'. It doesn't help us." (Rosemary)

For the bereaved person, it is possible to understand how others view them better than its converse, they felt like that before the loss of their children and understand that to know or see what has occurred, is not the same as living through the experience.

The pain of the loss

Each participant describes the depth of the pain that the loss has caused, the enormity of which feels life-threatening. Rosemary warns that:

"It can kill you! It can cause a stroke or it can cause a heart attack because there's

not a single day that your heart is free.
You are mourning day in and day out.”

When asked to explain about the nature of the hurt, Rosemary reflects that “*it’s a wound that’s so sore, ... it’s ... unexplainable ... it takes years to heal*”.

“I’ve never ever ever known such pain
... I was devastated.” (Lorraine)

The repetition of the words “never, ever, ever” emphasises its unchangeable quality, so that the facile and specious clichés used by people to comfort her merely emphasises their inability to understand:

“They say you get over it, but you don’t.
And sometimes it gets worse than
others.” (Lorraine)

Surviving the pain of the loss

In the face of such intense suffering, each participant struggles to find a way to survive the crushing pain that results from remembering. The words “*for ever*” appear only three times in Selinah’s transcript: the first two instances are in conjunction with the expressed apprehension for the duration of the pain of the loss. The third refers to her assertion that her daughter’s presence will be henceforth always at hand by thinking of her. Thus it provides a way to get out of the difficulty posed by the possibility of an ever-present pain. In this sense, her ability to change the ‘innerscape’ enables her to cope with the ‘outerscape’, and this is important insofar as she has a sense of being obliged to remain within these confines. It also provides for her an answer, albeit obliquely, to the rhetorical question posed earlier in the interview:

“Why do I have to go through all this
horrible stuff and then stay to live?”

Rosemary’s strategy for coping with many of life’s difficulties, with bereavement being the greatest of these, is to avoid brooding on the events. Although this is difficult, she believes that perseverance will eventually succeed:

“If you keep [on], continue with it, you
forget. That’s how I pulled through.”

A second strategy that Rosemary uses, is to avoid being alone, particularly in the early stages of loss, and to be involved in activities especially with others:

“Don’t be alone when it’s still fresh, try to
mix, keep yourself busy, meet people.”

Importantly, in a world where one has no agency or influence over the course of events, especially regarding life and death, accepting that which occurs is vital and a cornerstone for survival:

“I just accepted it. There’s nothing I can
do.” (Rosemary)

“I had to accept it, what could I do?”
(Lorraine)

Since the death of her son, Lorraine attempts to cope by keeping busy or distracted, but, even with the best of intentions, at times her strategy is invalidated by her inability to adhere to it almost as though compelled to do so:

“On Friday, I was devastated, because ...
it was his birthday, and I’ve [kept] all the
insertions in the paper, all the cards
people sent, and I said to myself, ‘Don’t
look at it,’ and I looked, and I said,
‘Leave it.’ No but I had to take it out, so
that set me off.”

Change and transformation: the world since the loss

That the world is a very different place since the death of their children is expressed by all the participants. Such change requires an accommodation that permeates to the very core of their being, and perhaps is never fully wrought.

Desiring a restoration of hope for living

Selinah reflects that she continues to hope for a cessation of pain. This is perhaps the only thing that enables her to continue:

“Sometimes I have that hope that maybe
some day maybe I will just think of [her]
without crying.”

This hope which appears is almost forlorn and has a now-you-see-it-now-you-don’t character:

“Maybe I do have hope for tomorrow,
sometimes I don’t.” (Selinah)

Thus even hope seems to flicker, and perhaps it would be more accurate to say that she hopes that there may be a more consistent hope in the future. When she is able to connect with the sense of hope she is able to think differently about the future:

“I think it will go easier and easier, but
how, and when, and how long it’s going

to take, that's the thing I don't know but I believe it will go away."

Lorraine also expresses a hope for the future, and this is expressed as a hope for another life despite her earlier doubt:

"Maybe there is such a thing as heaven, with God sitting there ..."

And so, just in case perhaps, she supplicates:

"I just pray just to be well and healthy, just ... for a little bit of inner peace just to be happy."

Being able to believe that even her suffering can be a part of God's plan, even though it remains beyond her understanding, has been helpful and has enabled Selinah to return to regular worship at church. Although it was painful at first, she comments:

"I enjoy the service."

Forging a new relationship with the deceased

The factor which appears to be at the basis of nascent hope for participants, is the belief that their deceased children will always be accessible in thought and in mind. Since the death of her daughter, it seems to Selinah that her daughter is still a part of her and accessible to her in her thoughts. This is in contrast to the experience of dissociation at the time of diagnosis and also to the emptiness experienced when her daughter died:

"No matter she's gone she will be a part of my life for ever because she won't ... nothing will just wipe her out of my mind. So she will be still there ... thinking about her that's how she become a part of my life every time ... the time I'm thinking about her then she's there."

Although for the present this is something of a mixed blessing, the hope that she expressed regarding her desire to be able to think of her daughter without sadness appears a strong motivating factor:

"Sometimes ... I think about her ... and then I laugh about it sometimes. It makes me feel happy. Sometimes I will just laugh at myself and laugh harder, sometimes you know, like she's here, ja. Talking to her, remembering what she's saying that time to me or doing something funny and then we laugh about it."

Lorraine also refers to such imaginary encounters, almost a type of magical thinking, where her son is still alive and where together they relive some beautiful moments that they have shared in the past:

"I still just imagine ... that I'm going to fetch him to take him out."

"[My son] always was always interested in how I looked. You know if I buy something, I say to myself, I wonder if [he] would like this."

Two elements help Rosemary achieve a sense of control over life and the ever-present fear of death and dying: The first is Faith in God and the second is altruism:

"That little time you've got, make something of it. Help somebody if you can."

In this lies the possibility for her to "*make [her]self happy*".

The value of these idiosyncratic resolutions is not so much that they represent a final solution or even an adequate one, but rather that they enable the bereaved to form one new area of control. Exerting such control may help to establish a sense of agency which combats the helplessness and powerlessness of their experience, and which is an illustration of thrownness (*Geworfenheit*) as described by Heidegger (1962). At the heart of being-in-the-world is prior existence, so that the human being is constantly coming-to-existence where there is not limitless choice about existence. It is through such thrownness that the person learns to understand how he or she is differentiated from the world and others who equally exist in it.

Personal Reflection of the Researcher

A journal was kept to assist in bracketing and to develop a self-reflexive stance in order to develop an awareness of the role of researcher as participant in the research. The contents for the section that follows were derived from such a journal.

Having had extensive experience in the area of parental bereavement the idea of this research was not daunting to me. On my first interview, however, I discovered that interviewing parents in the role of researcher is very different from being with them in the role as counsellor and also-bereaved parent. During counselling bereaved parents, feelings of helplessness, panic, fear and intense sorrow are

frequently experienced, but the process is conducive to their expression and subsequent containment. As an interviewer, however, this process is not available to one, so that it seemed that asking for this experience to be laid out to view was both intrusive and hurtful, providing little opportunity for relieving the painful feelings it elicited. The sense of helplessness that this engendered in me was so unbearable that it often fuelled a strong desire to leave physically or by changing the subject, both of which were at odds with the goals of the process.

There was also a difference between listening to stories of bereavement and transcribing them. When listening to someone, the time of exposure to any comment is brief, as the narrative moves on. In transcribing the interviews, however, it was often necessary to replay a particular phrase to transmute it into written speech, thus boosting its significance and affecting power, so that time and time again I had to take a break in order to regain composure because at that moment the pain seemed almost unbearable.

Listening to the interviews an image would flash into my mind: This was a scene from the film *Beetlejuice* (Burton, 1988) where the protagonist has died unbeknownst to her. She finds herself in her own house, which, while familiar in every respect, is at the same time strangely odd. She steps out of the door, whereupon the house disappears and she is cast into a boundless, featureless infinity of yellow sand with a large sandworm threatening to swallow her.

This image made the intense sense of dislocation and threat very tangible and put me in touch with the difficulties inherent in being with a person suffering intense pain. If the capacity for empathy arises from the observation of the other's response that gives the person an awareness of their experience, then the listener has access to another's experience as a perception of a raw event in much the way that a memory is related to a natural event. As Moran (2000, p. 177) notes,

the other is a phenomenological modification of myself, ... grasped only 'within my ownness'.... When I experience another person, I *perceive* them as having the kind of experiences I would have if I was over there.

Thus the difficulty for the listener is less a problem of lack of understanding, but of too much understanding of the situation through vicarious experience. The human vulnerability revealed in the suffering of others, and the seeming inability to contain it within oneself, provokes a desire to soothe the pain of it for

the sufferer (and consequently for the self) by reducing or escaping it (as evidenced by my reaction of wishing to leave or change the subject). Another common strategy is to misattribute responsibility for the event, which allows others to maintain the illusory belief that random suffering will not be visited upon them. This indeed appears at the heart of many of the social and interpersonal difficulties that the bereaved parent experiences. While others are sympathetic to the plight of the bereaved parent, their felt inability to soothe it, coupled with the extreme discomfort that it engenders, is manifested in many of the reactions that bereaved parents find distressing and often refer to in counselling. These include avoiding the bereaved, hurtful judgements, spurious curiosity or offering well-meaning, but often spectacularly insensitive, comments or specious clichés. In the light of this, it is interesting that, of the thousands of articles which have been written on the subject of bereavement, it appears that this aspect has not been researched.

As the reaction of others becomes clear to bereaved parents, they learn to present two different façades. One is the coping self, which is presented to the world in general, and which enables the person to manage the day-to-day requirements of living. They become adept at sensing how they need to present to others, and this is more a function of the ability of the person receiving it than a reflection of the reality of the bereaved. The other façade surfaces only when they believe that it will be accepted, or if they no longer care about how their behaviour is viewed by others.

Seeing bereaved parents coping provides a comfort to others because it fosters the hope that it is possible to survive a loss of such magnitude. For the bereaved parent, however, it appears that there is also a strong need to express the grieving aspect as well. Events stand out for the participants in this study in a way that needs due recognition, and yet the significance of these events is not accessible to understanding in the normal way. This may explain why there is a sense of understanding the world differently from those who have not experienced such a loss. To understand it, there has to be a stepping out of the accepted and acceptable stream of social thinking and this occurs in periods of active grieving. As noted by the participants, grieving may have benefits in regard to making new meaning. However, much of the meaning that is created may appear less than comprehensive and idiosyncratic, and may attach to seemingly unimportant events.

Conclusion

Van Manen's (1990) work has emphasised how phenomenological research is totally situated in the

lived experience of the phenomenon. The present phenomenological enquiry into the lived experience of parental bereavement, especially after the death of an adult child as a result of HIV/AIDS, has yielded some pertinent insights into the phenomenon. In particular, the felt experience of the retributive aspects of the illness were a common theme which linked to the stigma which attaches to the illness. As regards the dynamics of reconstruction of meaning structures for the bereaved parent, it would appear that bereaved parents tend to regulate shifts between coping and active grieving. While active grieving may be emotionally challenging, its value may lie in its capacity to enhance the process of meaning-making. The layers of meaning revealed in the process have made possible a rich and complex understanding of the phenomenon through the linked connections that expose how meaning is configured within consciousness.

The phenomenological framework of the study generated a description which transcends the listing of

attributes, and adds a complex and textured quality to the understanding of the phenomenon in question. The commonalities which emerged, despite the diversity of participants, serve to demonstrate the ubiquity of the experience as observed in the research. It appears that there are commonalities among participants as regards a changed understanding of the world, both in relation to others and to themselves, which necessitates the forging of new meaning structures that can accommodate the loss. The process of forging such new meaning structures, however, tends to be idiosyncratic for each participant and is often orientated around negotiating daily challenges such as keeping traumatising memories from becoming overwhelming. The value of these can only be fully comprehended through understanding how they facilitate the construction of such new understandings of the world.

About the Authors

Anne-Marie Lydall was born in Johannesburg, where she grew up. After her marriage, she continued her studies through the University of South Africa (UNISA), obtaining an Honours degree in Psychology in 1988. During the years which followed, Anne-Marie's energies were focussed on raising five children and working in the field of Market Research on a freelance basis. After a lengthy association with The Compassionate Friends, she resumed her studies in 2002 at the Rand Afrikaans University (RAU), where she spent a challenging and highly fulfilling three years obtaining first a Master's degree and subsequently a D.Litt. et Phil. in Psychology. She is currently working as a psychologist in the community and continues her association with The Compassionate Friends as a trainer, time permitting.



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Anita Stuart completed her postgraduate studies at the Rand Afrikaans University (RAU), where she gained both her BA Honours and MA (Psychology) *cum laude* before proceeding to a D.Litt et Phil. A full professor in the Department of Psychology at the University of Johannesburg, she has been Departmental Head since 2002 after a number of years as Acting Head and Deputy Head. Her fields of specialization are Neuropsychology and Personality Psychology, in which terrains she has published extensively, utilizing both quantitative and qualitative research paradigms. The results of her research are regularly disseminated at both local and international congresses.

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