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“My bus is here”: A phenomenological exploration of ‘living-with-dying’

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Living-with-dying; advanced cancer; hermeneutic phenomenological analysis; object elicitation method; idiographic approach

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Abstract

Objectives

This paper has two aims. The first is to demonstrate how the application of an innovative qualitative methodology generated novel insights into the experience of living with advanced cancer. The paper's second aim is to challenge the idea that the identification of shared themes provides the researcher with access to the meaning and significance of the experience of 'living with dying'.

Methods

The research presented in this paper employed object elicitation together with existentially-informed hermeneutic phenomenological analysis. The analysis is based on ten semi-structured interviews with people who are living with advanced cancer.

Findings

The paper presents three brief case studies demonstrating the variability in accounts that characterizes the data set as a whole. This is followed by reflections on the way in which despite striking individual differences all participants seemed to experience 'living with dying' as an existential challenge which demands that the individual concerned finds a way of coming to terms with the very parameters of human existence.

Conclusion

The paper advocates a thoroughly idiographic approach which stays with the diversity that characterizes the experience of living with advanced cancer. The paper argues that in order to make sense of the remarkable differences between the research participants' accounts of their experiences of living with a diagnosis of advanced cancer, a focus on process (ie. what happens when people encounter their mortality ?) and meaning (ie. what does it mean to them ?) helps us to understand these as different responses to the challenge of death awareness.

Introduction

The research presented in this paper is concerned with the experiences of people who are living with the awareness that the end of their lives is not far away. These are people who have been diagnosed with advanced (metastatic) cancer and they have been told by their doctors that their life expectancy is much reduced, no more than months or a very few years at most. The research presented here is concerned with the phenomenon of ‘living with dying’, with how people experience themselves and their relationship with the world when they can see their own death on the horizon. The research question driving the research, therefore, was ‘how do people live with the prospect of their own death occurring in the not-too-distant future and how do they experience this situation?’

There is, of course, a large body of literature reporting the results of studies that have investigated the social and psychological correlates of living with life-threatening illness in general and cancer, including terminal cancer, in particular. Such studies have demonstrated that, unsurprisingly, the emotional well-being of those living with life-threatening illness tends to be compromised. Research consistently finds clinically significant levels of anxiety, depression and stress in a large proportion (around 30%) of those diagnosed with cancer (eg. Roy-Byrne et al., 2008; Sellick and Crooks, 1999). Coming to terms with a terminal diagnosis constitutes a psychological challenge in that it requires the individual to adjust to a dramatic change in what they assumed would have been their future prospects (eg. Janoff-Bulman, 1992). Researchers have identified the cognitive and narrative tasks associated with processing such a diagnosis, drawing attention to the importance of meaning-making around the new situation (Jim et al., 2006; Frank, 1995; Roussi and Avdi, 2008; Bingley et al., 2006). It seems that finding meaning in

the experience reduces symptoms of emotional distress associated with the cancer experience (Jim and Andersen, 2007; Tomich and Helgeson, 2002; Voogt et al., 2005). There is evidence suggesting that being diagnosed with cancer (even where not terminal) constitutes a form of traumatisation (Propper, 2007, pp. 34-42) whereby the individual experiences a threat to their very existence, a sense of extreme vulnerability and a concomitant loss of a sense of safety and security in the world. Within this context, the notions of post-traumatic growth (Calhoun and Tedeschi, 2001; Tedeschi and Calhoun, 2004) and post-self (Wojtkowiak and Rutjens, 2011) are also relevant as they point to the possibility of psychological growth and a concomitant increase in psychological well-being as a result of a meaningful engagement with the cancer experience (eg. Cordova et al., 2001).

Whilst existing research has generated important insights into the social and psychological correlates of living with cancer as well as into the narrative and cognitive strategies deployed by those who are diagnosed with cancer, there is scope for further work that seeks to better understand what it means to find oneself encountering one's own mortality as a result of being diagnosed with advanced cancer. The research discussed in this paper attempted to do this by focusing on the lived experience of 'living with dying', rather than examining the cognitive and emotional sequelae of a terminal diagnosis. It adopted a phenomenological perspective, thus placing particular emphasis on pre-reflective experience, attunement and mood. As such, it builds upon existing phenomenological research which has attempted to shed light on the lived experience of serious illness (eg. Toombs, 1995; Finlay, 2003) as well as death and dying (eg. Frank, 1978; Leman- Stefanovic, 1987). Most of the existing phenomenological research into the experience of living with advanced cancer has been carried out within the discipline of nursing studies. Those phenomenological studies which concern themselves specifically with the

experience of facing death from cancer (eg. Coyle, 2006; Friberg and Ohlen, 2007; McSherry, 2011) come to the conclusion that living in the face of death requires active engagement from the dying person as they negotiate the various changes and challenges that their situation throws up. Living with advanced cancer constitutes hard work because it presents the person with a series of physical, psychological, social and spiritual tasks (Corr, 1992; see also Doka, 1993, and Pattison, 1977) which demand their attention. McSherry (2011) notes that whilst research has generated a good understanding of the social and psychological requirements of the dying process, there is a lack of research into the ways in which the dying person engages with the challenges posed by the living-dying interval. Coyle's (2004a and b; 2006) work provides some important insights into the experience of living with advanced cancer, identifying the hard work of living in the face of death and the existential paradox of struggling to live whilst preparing for death as central features of the experience. In her phenomenological study of seven palliative care service users Coyle (2006) describes the "difficult dance of both living and dying" (p. 267) as the person with advanced cancer tries "to live at the same time as preparing for death" (p. 268). The research reported in the present paper seeks to add to this literature and further expand our understanding of the phenomenon of 'living with dying'.

The 'Living with Dying' Study

The methodological reflections presented in this paper are based on data that was generated as part of the 'Living with Dying' study which is a collaboration between researchers at City University London (Jacqui Farrants and Carla Willig) and the London branch of Maggie's Cancer Centre (Catherine Nelson). The study employed object elicitation methodology together with existentially-informed hermeneutic phenomenological analysis in order to investigate the

meanings that people living with a diagnosis of advanced cancer attached to their experience. Data was generated by conducting individual semi-structured interviews with ten participants who had been recruited via Maggie's Cancer Centre. All participants had been diagnosed with advanced (metastatic) cancer and all were aware that their life expectancy would be significantly reduced as a result of their diagnosis. Their ages ranged from the mid-thirties to early eighties and all but one were female. Participants were asked to select and bring along to the interview a collection of objects that held special meaning for them during the current phase of their lives. The objects participants brought were varied and included photographs, books, jewelry, diaries, small household objects, items of clothing and recordings of music. During the interviews participants were invited to talk about each of the objects they had brought, one by one, explaining their meaning and significance and the role that they played in the participant's life at the present time. Interviews were conducted in a quiet room either at Maggie's Cancer Centre or in the participant's home. They lasted between one and two hours and were audio-recorded and later transcribed verbatim. Ethical clearance for the research was obtained from City University London. The 'Living with Dying' project is ongoing, and the reflections presented in this paper are based upon one of the researchers' engagement with the data from the first ten interviews.

Rationale for the choice of methodology

The research question driving the research was 'how do people live with the prospect of their own death occurring in the not-too-distant future and how do they experience this situation?'. The study of lived experience presents a challenge because it requires that the researcher finds a way of tapping into intangible dimensions of experience such as mood, pre-reflective perception

and attunement. Data collection strategies for such research need to provide an opportunity for participants to communicate subtle meanings, whilst procedures for data analysis need to allow the researcher to capture the emotional tone and the experiential quality of the phenomenon under investigation (see van Manen, 1997a and b, Ohlen, 2003). Object elicitation was used to assist data collection in this study because it was felt that by reflecting on their relationship with their chosen objects participants would be able to share more of the quality and texture of their life-world than if they had been asked to talk about their cancer experience in more general and therefore more abstract terms. The methodological risks attached to the latter strategy would have been that participants might have either shared their views and opinions about living with cancer or alternatively that they might have provided a detailed description of the processes of diagnosis and treatment of their cancer. Both of these types of data would have been important and interesting in their own right; however, it was felt that object elicitation was more likely to prompt unrehearsed, in-the-moment reflections about what it means to be ‘living with dying’ than a more conventional interview schedule would have done. The focus on the objects did not, however, preclude explicit talk about what it was like for participants to be living with a terminal diagnosis as the interviewer questioned the participants about their chosen objects’ role and meaning in their everyday life with terminal cancer (see also Silver, 2013a and b; Reavey and Johnsons, 2008; Radley and Taylor, 2003 for more on the use of visual methodologies). In preparation for the research, the researchers themselves selected objects that carried special meaning for them in relation to their own experiences with cancer (either personally or through family members and/or loved ones) and described their relationships with their chosen objects to one another. This provided them with a personal experience of the process of selecting and reflecting on significant objects and it allowed them to identify their own pre-conceptions, pre-

occupations and emotional resonances in relation to the topic. The author has previously written about her own experience of being diagnosed with cancer (Willig, 2009) and has engaged in ongoing explorations of the role of meaning-making in coming to terms with cancer (Willig, 2011a; 2011b). It is important to acknowledge that these experiences and reflections constituted as ‘way-in’ to the current data as they generated both an attitude of curiosity and a process of questioning in relation to the meaning and significance of the experience of confronting one’s own mortality; however, care was taken throughout the research to question and interrogate any assumptions made about the meaning of the participants’ experiences.

Data analysis took the form of an existentially- informed hermeneutic phenomenological analysis (eg. Willig and Billin, 2012; van Manen, 1997a). Such an analysis seeks to enter the experiential world of research participants in order to gain a better understanding of the significance, meaning and quality of the experiential phenomenon under investigation. Ultimately, the aim of such an analysis is to obtain insight into the “structure of the human lifeworld” (van Manen, 1990: 101) itself. In other words, although the research starts with a detailed analysis of individual research participants’ accounts of their experience, the purpose of existentially-informed hermeneutic phenomenological analysis is to try to make sense of what it means to be human, that is to say “what it means to live as an embodied being in a (particular) physical and social world” (Willig and Billin, 2012: 118). This means understanding how we as humans engage with fundamental existential concerns such as time, our embodied nature, and our being-in-the-world-with-others (see also Ashworth, 2003).

Analytic procedure

Each interview transcript was read and analysed individually before any attempt at integration of analytic observations was made. Each transcript was read and reflected upon in terms of what it could tell the researcher about the ‘structures of experience’ (van Manen, 1997a:79) that underpinned and shaped the account produced by each participant. Van Manen (1997a) suggests that in order to do this the researcher engages in three different types of reading to distill meaning from a text. These include a *holistic* reading (whereby the text and its message/meaning as a whole are attended to), a *selective* reading (whereby segments of the text that appear particularly revealing or significant are interrogated) and a *detailed* reading (whereby each line of text is examined for what it reveals about the phenomenon under investigation). The holistic reading generated insights into what each participant was doing as they were sharing their reflections with the interviewer. For example, whilst some participants were using this opportunity to offer in-the-moment reflections which touched on some very painful (and often unresolved) thoughts and feelings, others chose to reassure themselves and the interviewer that they had arrived at a narrative which served them well and which they did not wish to unsettle through further questioning. The selective reading allowed the researcher to focus on specific features of an account such as repetitions of certain phrases and formulations (eg. “I can’t understand”; “I don’t understand”; I just don’t understand”) or moments in the participant’s account that they identified as a significant turning point in their experience (eg. “And then all hell broke loose” followed by a description of how the participant’s life began to unravel). Finally, the detailed reading identified the underlying concerns which informed the various aspects of experience that were being described. For instance, a participant’s relationship with the future constitutes an example of an underlying concern. Finally, the results from the analysis of all participants’ interview transcript were compared and contrasted with one another and

tentative conclusions were then drawn about what may be involved in negotiating one's relationship with mortality when living with advanced cancer.

Findings

Perhaps the most striking feature of the data corpus as a whole was the extent of the variability in both form and content that characterized the transcripts. Participants talked about their experience of living with dying in very different ways and they gave a wide range of meanings to the experience. Some accounts took the form of stories that had been told before and that represented the participant's 'serviceable narrative' (Willig, 2009) representing a way of making sense of what was happening to them that helped them cope with the situation. Other accounts took the form of in-the-moment processing of thoughts and feelings similar to what happens in a (good) counseling session (see McLeod, 1998). In terms of content, the accounts ranged from expressions of acute anxiety and utter despair to descriptions of an almost euphoric appreciation of life. Some participants described a loss of meaning and a sense of isolation whilst others had found meaning in their engagement with mortality and/or had intensified their emotional bonds with others. A first encounter with the data, therefore, left the impression that 'living with dying' is not so much a shared experience but rather a very individual challenge that is met in different ways by different people.

In what follows three brief phenomenological case studies are presented; these illustrate different ways in which participants engaged with the challenge of 'living with dying'. The aim of presenting these case studies is to provide a flavor of the diversity and range that characterized participants' accounts and to set the stage for further reflections on the methodological and

conceptual difficulties in trying to delineate one single experiential phenomenon. It is important to emphasize that the case studies do not represent a typology of three different approaches to ‘living with dying’, for example in the manner of Frank’s (1995) three illness narratives ('chaos', 'restitution' and 'quest'). Instead their purpose is merely to demonstrate that people approach dying as they approach living, namely in highly individual ways. The three cases were chosen from the data set randomly and they represent only themselves. Following the presentation of the three case studies, the paper argues that in the face of the remarkable differences between the ten participants’ accounts it is essential that any general insights about ‘living with dying’ would need to emerge from the idiographic analysis itself rather than being the product of a homogenizing methodological move (such as the identification of a set of shared themes across interview transcripts). The paper demonstrates one way of doing the former by focusing on meaning (by asking ‘what does it mean to be confronting one’s own mortality?’) and process (by asking ‘what happens when people encounter their mortality?’).

Phenomenological case study 1: Fiona¹

“My bus is here”

Fiona is a woman in her late thirties who has been diagnosed with metastatic breast cancer. She brought a range of objects to the interview including photographs, electronic devices, music and items of clothing.

Fiona’s reflections on her experience of living with terminal cancer take the form of an in-the-moment meditation on her predicament. In the process, she touches on some very painful thoughts and feelings, and she acknowledges an ongoing struggle for meaning as well as much

¹ All names have been changed in order to protect confidentiality. Any identifying details have also been removed or changed for the same purpose.

emotional suffering. Fiona's account and her presentation have a raw quality as she communicates her distress and suffering very directly and openly. She describes how her diagnosis with advanced cancer has thrown her into a mode of questioning which was both sudden and relentless ("there was no reprieve"). The sudden awareness of her mortality, which she experienced as having been forced upon her, meant that she experiences a sense of "lost innocence" and an inability to live life as she had done before (ie. without thinking about death). Although Fiona positions herself as moving towards acceptance of her situation she emphasizes that "it's really difficult to move forward".

Fiona reflects on how her experience of the past and the future have changed as a result of her illness. Her relationship with the past is now characterised by a profound sense of loss both in terms of what her illness has taken away from her (ie. the ability to work, to be "productive", to play music and to read) as well in terms of the unfulfilled potential that the past now represents (whereby things that in the past she had hoped to do, experience and achieve would not now come to pass). Fiona's comment "I look at the past with horror" captures her uncomfortable relationship with a past that has become a source of regret and pain.

Fiona's relationship with the future is also fraught; any reminder of the fact there is a future, in fact "anything that has a date", sparks thoughts and feelings about her own passing. Fiona feels as though she has lost her future because her sense of the future as consisting of possibilities has disappeared. She says, "(...) all my possibilities have collapsed (...) there's not really future (...) they have collapsed into one thing and the only certainty is that I am ill".

Fiona experiences 'living with dying' as an ongoing challenge and death awareness as a heavy burden which sometimes threaten to overwhelm her. The following quote captures this well:

“You have these strong feelings. And I have to live with that I suppose. I mean as I said I’ve been very depressed and now I feel like I’m getting out of it but the situation is such that some days I feel very alone and sad and unable to do anything because the only thing I can think of is that I’m going to die. And that’s the only certainty that I have. I know we do all have that and I know people say (...) you could cross the street and be run over by a bus. But you live your life not thinking about it. I have to deal with it. My bus is here. All the time.”

Phenomenological case study 2: Carol

“And then all hell broke loose”

Carol is a woman in her mid-thirties who has been diagnosed with metastatic breast cancer. She brought a number of photographs with her.

Carol’s account of her experience takes the form of a story about how she came to find herself within the “nightmare” that is her current reality. Carol’s reflections communicate a sense of disorientation and unreality, and they constitute an attempt to make sense of what has happened to her. Carol repeats many times that what has happened to her (ie. being diagnosed with advanced cancer) “should not have happened” and that she “can’t understand” how it could have happened. Carol’s account revolves around key moments which represent Carol’s sense of her life unraveling and which she keeps re-visiting throughout the interview. It is as though Carol tries to stake out and pin down her deeply disturbing experience by identifying the moment when events spiraled out of control. Carol’s story begins with another family member’s illness which was not treated adequately and which led to Carol neglecting her own health. Opportunities for

detecting Carol's own cancer were then missed by medical staff and as a result Carol was finally diagnosed with advanced cancer.

Carol's account contains features of a 'chaos narrative' (see Frank, 1995) in that it is concerned with describing something that does not make sense, and that she finds incomprehensible and overwhelming. The account is highly specific in its detailed and graphic descriptions of the moments that marked the turning point in her life (eg. the afternoon when Carol's relative first fell ill) but at the same time emphasizes Carol's confusion, lack of comprehension and sense of unreality in relation to her current situation of living with terminal cancer. She evokes a sense of being caught up in something terrible ("a nightmare"; "a horrendous situation") without the means of dealing with it; she concludes "Yes, you're in it and, yes, you can't get out of it". Whilst Carol is keen to identify the precise moment when things started to unravel, when "all hell broke loose" and her life departed from its anticipated course, she avoids thinking about her current situation as this feels like it would simply be too much. She explains:

"And occasionally I think, oh my God, I've got cancer and I'm dying. And I think oh my goodness. And it's just like wow it's such a big thing. But I only let myself think about that only for very short periods of time."

Phenomenological case study 3: Monica

"I'm ready"

Monica is a woman in her late fifties who has been diagnosed with metastatic breast cancer. She brought a number of photographs with her.

Monica presents her reflections in a very calm and collected fashion. Monica's account does not involve much in-the-moment processing of current thoughts and feelings. Rather, Monica takes the opportunity to explain to the interviewer how she has found a way of living with advanced cancer that feels manageable. She has come to accept her situation and she had done this by 'getting ready'. Monica describes how she had initially been angry about her diagnosis because she had had cancer twice before and had experienced recurrences despite having gone through intensive treatments each time. She explains, "I was angry because I felt like it was controlling me and there was nothing I could do about it". However, once she was informed that this time her cancer was going to be terminal, Monica decided to prepare for death rather than fight for life. This allowed her to "come to terms with it" and "sort everything out" (eg. her will, her funeral arrangements, the grave etc).

Monica's approach to preparing for death means that she is able to create certainties for herself. In contrast with her earlier experience of feeling controlled by her cancer, she re-claims control by assuming that she will not live for more than about ten months and making arrangements accordingly. There are frequent references to the near future in Monica's account as she is looking forward to events which she "will be there for". These include relatives' birthdays and other special events within the 10-month timeframe. By creating certainties such as her attendance at special events as well as her the timing of her own death ("in ten month time"), Monica fashions a future that has meaning and that is predictable, thereby removing some of the fear that can be associated with an uncertain future.

It seems that for Monica the challenge that 'living with dying' represented was to find a way of dealing with the uncertainty and loss of control that comes with serious illness. Her way of rising to this challenge involved re-creating certainties in her life, both in relation to her death (by

setting a date and making arrangements for it) and in relation to the life that remains (by identifying significant dates and events within the 10-month time span). As Monica's account represents a solution to a problem, it is understandable that she did not wish to engage in further questioning of her position and to stay with the 'serviceable narrative' (Willig, 2009) she had arrived at. The following quote sums up Monica's stance towards 'living with dying':

"(...) I came to terms with it and I sorted things out (...) I sorted out money for my will, my funeral, and for the grave, so I've done all that. But I wasn't morbid about it. And once it was done I feel relaxed and if anything happens to me now, everything is ready."

As these three brief phenomenological case studies indicate, accounts of the experience of 'living with dying' can take different forms, emphasizing different dimensions of the experience and invoking different meanings. Reading these case studies, and indeed the entire data set, creates the distinct impression that 'living with dying' does not constitute the same or even a similar experience for those who find themselves in this situation. This presents a challenge to the phenomenological researcher as the aim of most phenomenological research is to arrive at conclusions about the quality, texture and meaning of experiential phenomena. There are, of course, important differences between the various approaches to phenomenological research, particularly in relation to descriptive (eg. Giorgi, 2008) and interpretative (eg. Smith et al. 2009) varieties (see Langridge, 2007, for a helpful overview of such differences). In addition, both Finlay (2011) and van Manen (2014) offer comprehensive overviews and guidance as to the ways in which hermeneutic phenomenological research may be conducted. However, despite significant differences the foci of phenomenological research questions across approaches

indicate that phenomenological researchers tend to seek to illuminate and elucidate particular experiential phenomena (eg. how people make decisions about a particular issue or what it is like to experience a particular emotion or what it means to be living with a chronic illness, see Shinebourne, 2011) and that this means that although the phenomenological researcher engages with individual accounts of experience, ultimately these individual accounts are only of interest to the researcher in so far as they provide them with insights into the phenomenon under investigation. In other words, it is the phenomenon (here, ‘living with dying’) rather than the individual (here, Fiona, Carol or Monica, for example) that is the primary focus of the research. And so it should be as phenomenological research is ultimately concerned with gaining a better understanding of the nature of human existence and the experiences that the human condition facilitates, and this is of course what differentiates it from intrinsic case study research (Stake, 1995).

So the challenge was how to stay true to the diversity of the experience of ‘living with dying’ that had emerged from the data (and that is represented in the phenomenological case studies presented above), whilst at the same time drawing conclusions about ‘living with dying’ which have some general validity and which may be of use to health professionals and others who are supporting those who are ‘living with dying’.

Perhaps the most obvious strategy for distilling ‘shared experience’ from the data might have involved the identification of aspects of the accounts that resonated with one another and grouping them into ‘shared themes’ (such as perhaps ‘feelings of loss of control’, ‘anger’ and/or ‘a sense of unreality’ and so on) which could then be seen to capture the ‘shared experience’ of ‘living with dying’. However, given the nature of the data it seemed inappropriate to transform it in such a way as to foreground commonalities as this would have amounted to the construction

of ‘shared experience’ rather than its discovery. An alternative approach might have been to develop a typology of contrasting approaches to ‘living with dying’ taken by the participants, perhaps grouping them into types of narratives (cf. Frank, 1995) or modes of being (cf. Willig and Billin, 2012). Whilst this might have captured more of the variety and variability in participants’ accounts, it would still have required a homogenizing move to categorise the data into a limited number of types (of narrative, of mode, of approach) defined by what they have in common. Thus, whilst seeking to capture diversity the analysis would still have been driven by the need to identify and foreground commonalities.

For these reasons a third approach was chosen. Instead of searching for shared themes in an attempt to capture the quality and texture of the experience of ‘living with dying’, a focus on process and meaning was adopted. So instead of asking ‘what is it like to be living with dying ?’, the questions driving the analysis became ‘what happens when participants encounter their mortality?’ (focus on process) and ‘what does it mean to them to be confronted with their mortality ?’ (focus on meaning). In this way the analysis became focused on what may be involved in negotiating one’s relationship with mortality when living with advanced cancer, and this meant being able to stay with the idiographic readings whilst at the same time looking across cases in order to better understand the nature of the challenge of ‘living with dying’.

And a challenge it seemed to be for the participants as all of them had felt the need to deal with the situation in some way. Carrying on as though nothing had happened did not seem to be an option. So although the ten participants described very different and very personal ways of engaging with their situation, they all shared a sense of being confronted with something of enormous significance that could not be ignored. Fiona’s comment,

“It’s like in my face all the time and the only way is to turn your head to the other side but it doesn’t last long you know...”

gives expression to this feeling, as does Carol’s “Yes, you’re in it and yes, you can’t get out of it”, whilst Monica’s declaration that she is “ready to go” confirms that avoiding death awareness is not an option. As such, mortality, once encountered on a personal level, presents itself as something that cannot be sidestepped, and therein, of course, lies the challenge.

So what is it about death awareness that constitutes such a challenge ? What happens when the reality of one’s own death appears on the horizon and how does this change one’s lived experience ? A examination of the data with these questions in mind led to the identification of participants’ relationship with temporality as central to their experience. It became apparent that participants’ experience of ‘living with dying’ was mediated by their changing relationship with the dimensions of time. It seems that being given a terminal diagnosis constitutes a challenge because it unsettles, in a fundamental way, one’s experience of time itself. One participant (Cara) described the challenge of a terminal diagnosis as follows:

“What is so difficult to grasp when you get a diagnosis like this is that the progression of your life isn’t going to happen in the way that you naturally expect.”

This loss of a presumed future, in turn, has repercussions for the experience of the present, as the meanings attributed to the present often derive their significance from their relationship with the future. As Julia put it:

“One difficulty I have (...) is that a lot of things are pointless because there isn’t a future (...) I’m not doing things for a future so that can take the point out of things, and an interest in a way.”

However, whilst the loss of the future can strip the present of meaning, this changed relationship with the present can also generate new and intense in-the-moment experiences. For example, several participants drew attention to the sensual pleasure of drinking coffee, the joy of being with nature or listening to music, as well as great delight in sharing experiences with friends and family, experiences which since being diagnosed with advanced cancer had become more intense and rewarding. Cara talks about her sense of time “expanding outwards (...) in moments of extreme intensity” and how this feels as though she were literally “stepping out of time”. It seems that by disconnecting the present from the future, participants are more able to value and enjoy the experiences the present offers them in the here-and-now.

The past, too, is changed by the loss of the future. A life that was being lived towards the future is transformed into a story that is coming to an end. As a result, what was work-in-progress is turned into unfinished business, and past events acquire a new significance because they will not be followed by more of the same. For example, Cara reflects on two intimate relationships she has had in the past and concludes that their meaning is changing as a result of her diagnosis:

“If I think about two men that I loved in my life, my relationship with them (...) is different because I’m not going to be able to go on and have another man. So somehow they have a weight (...) in my life, so it’s the weight that changes, you’re not actually changing events but the weight is changed because there isn’t going to be a future.”

Again, this changed relationship with time can have both positive and negative consequences.

For some participants the past became a source of regret (eg. Fiona who says “I look at the past with horror”) whilst others took the opportunity to celebrate their life story by producing a record of it (eg in the form of a photo album or a book).

Many of the objects that participants brought to the interviews invoked the poignancy of their changing relationship with the temporal dimension in their lives. For example, photographs were talked about as pointing to the significance and indeed reality of the past (eg. photos of parents and oneself as a child) as well as the future (eg. photos of children and grandchildren who would survive the self), serving as a reminder of the existence of an objective timeline independent of the participant’s own unsettled relationship with time. Some objects represented ‘unfinished business’ (eg. unfinished artworks, writing or needlework) whilst others (eg. a piece of jewelry) were brought because they signified continuity since they had remained the same and would remain the same irrespective of their owner’s passing. Diaries, family histories, and memoirs represented participants’ construction of a story of their life that they could feel comfortable with and that gave meaning and coherence to the past.

It seems, then, that what is shared in ‘living with dying’ is the challenge to reconfigure one’s relationship with time itself. In her discussion of the existential meaning of ‘the event of death’ Leman-Stefanovic (1987) reminds us that “the fundamental existential constitution of a Being-there (...) is defined in terms of its future projections” (p. 166). As a result, she argues, the world as experienced by the individual with a terminal diagnosis has undergone a fundamental transformation whereby all familiar points of orientation in time and space have disappeared. It is not surprising, then, that an encounter with one’s own mortality constitutes a “moment of

shock" (Leman-Stefanovic, 1987: 171) and this was reflected in our research participants' accounts when they described their encounter with their mortality as "a bolt", as "hitting me" or as "blowing my mind", as well as "unreal" and "surreal". It also echoes Coyle's (2004) description of the moment when her research participants realized that their own death was imminent as an "existential slap" as. Drawing on Heidegger (1927/1962), Leman-Stefanovic's (1987) argues that people living with a terminal diagnosis find themselves in a "strange and alien" situation and need to re-orient themselves within a "new and fundamentally different way of being-in-the-world" (p. 177). It could, therefore, be argued that in general ontological terms 'living with dying' constitutes a fundamental existential challenge which requires an immediate response from those who are faced with it. Fiona's proclamation "My bus is here" provides a powerful metaphoric image that captures the quality of this challenge in that death arrives uninvited and often unexpected (the bus arrived without waiting for Fiona to be ready for it), it is of enormous significance and cannot be ignored (Fiona's bus is confronting her directly; it is 'in her face') and it cannot be sidestepped (Fiona's bus is here specifically for her).

The analysis presented here suggests that 'living with dying' constitutes an existential challenge because it requires the individual to find a way of re-configuring their relationship with time and to find a way of living meaningfully without a presumed future. This observation reflects existential philosophy's concern with temporality as a fundamental structuring dimension of human being in the world (Heidegger, 1927/1962), and as such it provides us with an insight into how we as humans engage with this dimension under a particular set of circumstances. Other important dimensions of the human lifeworld such as being (in) a body and being in relation to other people could be fruitfully explored in another round of analysis of the data although it

would be important to ensure that theoretical concepts are not imposed upon the data at any stage of the analysis.

Discussion

Existentially-informed hermeneutic phenomenological analysis of interviews with participants living with advanced cancer drew attention to the way in which their situation challenges them to find a way of living with death awareness. Although the interviews revealed highly idiosyncratic ways of making sense of ‘living with dying’, all participants seemed to experience a sense of being confronted with their mortality in a way that did not allow for evasions, and that required that they found a way of living without a future, thus supporting the conclusion drawn by other phenomenological studies that living with dying constitutes hard work, often stretching the individual’s resources to cope with it to their very limits. It seems that it is this existential challenge itself which is a shared experience whilst the ways in which participants rose to this challenge varied greatly. As such, the analysis presented in this paper resonates with McSherry’s (2011: 112) observation that the lived experience of the ‘inner life at the end of life’ among the ten hospice patients who took part in her phenomenological study included “a range of shared dimensions, punctuated by specifically unique experiences as they engaged in a search for meaning and significance”. I would argue that the existentially-informed hermeneutic phenomenological methodology adopted in the research presented here allowed it to achieve a balance between a commitment to respecting diversity (idiographic focus) and an aspiration to further our understanding of what it means for human beings to be ‘living with dying’ (phenomenological focus), thus enabling the analysis to capture the quality of the ‘mineness of existence’ (Heidegger, 1927/1962) in the face of death awareness which is both profoundly

individual (as it is specific to a particular embodied being and cannot be shared) whilst also being a feature of being human (and, therefore, potentially shared by all humans).

If ‘living with dying’ constitutes an existential challenge which demands that the individual concerned finds a way of coming to terms with the very parameters of human existence and if, as the research presented here indicates, this challenge tends to be met in highly individual ways, how may psychologists best support those who are engaged in this process ? In recent years it has been argued that meaning-focused interventions are important as they can assist people during a process of cognitive re-structuring prompted by an encounter with life-threatening illness (eg. Coward, 2000; Breitbart et al., 2010; Henry et al. 2010). Such interventions aim to provide an opportunity for people to render their experiences meaningful and thus to help them move beyond a sense of being overwhelmed and threatened by events that do not make sense and that feel out of control. However, I would argue that it is important that meaning-focused interventions do not prescribe which meanings are helpful and which are not, even if these prescriptions are based on research evidence, as is, for example, Coward’s (2000:168) recommendation to use breast cancer support groups in order to “facilitate self-transcendence views and behaviours” as these tend to be associated with emotional well-being (Coward, 1990, 1996). This is because each individual’s encounter with their mortality and their sense of the “mineness of existence” (Heidegger, 1927/1962) is an acutely personal and, by definition, solitary moment which means that the individual’s way of responding to that situation will need to be their own creation. In fact, a ‘solution’ to the problem in the form of a recipe for ‘living with dying’ offered by well-meaning others may well compromise the individual’s recovery of a sense of agency that might otherwise have emerged from their personal struggle for meaning

(Willig, 2009; Kellehear, 2009). Frank's (1995) account of the nature and function of what he calls the 'chaos narrative' of illness is helpful here. Frank (1995) argues that the 'chaos narrative' is the opposite of the 'restitution narrative' which is the preferred illness narrative in our culture. Restitution talk involves foregrounding hope and confidence in an improvement in the situation; it is optimistic and does not acknowledge the possibility that things may not get better. Chaos talk, by contrast, reveals vulnerability, futility and impotence, and it is hard to listen to as it feels threatening and it provokes anxiety (after all, chaos narratives remind us "how easily any of us could be sucked under" as Frank puts it (1995:97)). However, Frank argues that it is important that the voice of chaos is heard so that a story can emerge from the experience of chaos. To have another person sit and listen to a narrative that is really an "anti-narrative" (Frank, 1995:98) in that it does not 'make sense' of events but rather describes their meaninglessness, paradoxically allows new meaning to emerge, if only initially through the meaning that resides within the act of claiming the right to tell a chaos story. To support those who are confronting the challenge involved in 'living with dying', then, would mean offering opportunities for descriptions of and reflections on their experience in a non-directive, non-judgmental setting in the presence of another person who is able to hear accounts of chaos and distress without seeking to steer the story teller away from the chaos and the pain of feeling that life does not make sense anymore.

Conclusion

The phenomenon of interest to this research- 'living with dying'- has been shown to be characterised by both universal (ie. the human experience of being challenged by death awareness) as well as highly idiosyncratic (ie. the ways in which this challenge is met) features.

This dual aspect needed to be accommodated methodologically and the paper outlined one way in which existentially-informed hermeneutic phenomenological analysis could be used in order to transcend the tension between the idiographic and the phenomenological aspirations of the research. It was possible to make sense of the remarkable differences between the ten research participants' accounts of their experience of living with advanced cancer by conceptualising them as different responses to the challenge of engaging with death awareness. Here, the universal and the particular were not seen as alternative foci or even opposing viewpoints, but rather as complementary in that they were examined in relation to one another thus shedding further light on the phenomenon of interest.

The research is ongoing, and the observations and reflections presented in this paper by no means constitute the end-point of the analysis. Phenomenological analysis is potentially interminable as new meanings continue to emerge through the researchers' hermeneutic engagement with the data. The aim of phenomenological analysis is to amplify meaning by shedding light on the various dimensions of the phenomenon of interest which means that a final conclusion about what the data 'really' mean cannot be drawn. However, as new aspects of the totality of a phenomenon are revealed, it gains "clarity, richness and meaningfulness" (Cohn, 2005:221), and this can be helpful to those who are working in the field, as indicated in the previous section.

Potentially fruitful points of departure for further analysis include a focus on change over time as well as gender. Most of the participants had been informed of their terminal diagnosis between one and two years before the interview; however, some (such as Monica) had been diagnosed with cancer before. Further analysis of the data might involve an examination of the process of moving from the initial shock of the encounter with one's mortality to an acceptance of its

inevitability. However, it will be important to avoid the imposition of a prescriptive ‘stages’ view of ‘living with dying’, perhaps akin to the stages of grief model (eg. Kubler-Ross & Kessler, 2005) as this would not be compatible with a phenomenological approach as outlined above.

All but one of the participants were female which raises questions about the extent to which the experience of ‘living with dying’ described by them represents a specifically female take on it. This seems unlikely, particularly as the female participants differed in terms of their ages, marital status and motherhood experiences; however, it remains a possibility and could be further explored.

To conclude, an existentially-informed hermeneutic phenomenological approach to the analysis of interview data has been shown to allow for a combination of idiographic commitment and phenomenological aspiration, generating insights into experiences of ill health which are both respectful of individual differences as well as revealing of a shared (perhaps even universal) dimension of experience. As such, the approach presented here has the potential to be fruitfully employed within the field of health psychology.

References

- Ashworth, P. (2003) An approach to phenomenological psychology: the contingencies of the lifeworld, *Journal of Phenomenological Psychology*, 34(2), 145-156.
- Bingley, A., McDermott, E., Thomas, C., Payne, S., Seymour, J. & Clark, D. (2006) Making sense of dying: a review of narratives written since 1950 by people facing death from cancer and other diseases, *Palliative Medicine*, 20(3), 183-195.
- Breitbart, W., Rosenfeld, B., Gibson, C., Pessin, H., Poppito, S. Nelson, C., Tomarken, A., Timm, A.K., Berg, A., Jacobson, C., Sorger, B., Abbey, J. & Olden, M. (2010) Meaning-

centered group psychotherapy for patients with advanced cancer: A pilot randomized controlled trial, *Psycho-Oncology*, 19, 21-28.

Calhoun, L.G. & Tedeschi, R.G. (2001) Posttraumatic growth: The positive lessons of loss. In R.A. Neimeyer (ed) *Meaning re-construction and the experience of loss*. Washington, DC: American Psychological Association.

Cohn, H. W. (2005) Interpretation: Explanation or understanding ? In E. van Deurzen & C. Arnold-Baker (eds) *Existential perspectives on human issues: A handbook of therapeutic practice*. Basingstoke: Palgrave Macmillan.

Cordova, M.J., Cunningham, L.L.C., Carlson, C.R. & Andrykowski, M.A. (2001) Posttraumatic growth following breast cancer. A controlled comparison study, *Health Psychology*, 20, 176-185.

Corr, D.A. (1992) A task-based approach with dying, *Omega: Journal of Death and Dying*, 25:81-94.

Coward,D.D. (2000) Making meaning within the experience of life-threatening illness. In G.T. Reker & K. Chamberlain (eds) Exploring existential meaning. Optimizing human development across the lifespan. *Thousand Oaks*: Sage.

Coward, D. (1996) Self-transcendence and correlates in a healthy population, *Nursing Research*, 45, 116-121.

Coward, D. (1990) Correlates of self-transcendence in women with advanced breast cancer. Doctoral dissertation, University of Arizona, 1990. *Dissertation Abstracts International*, 524(1), 158.

Coyle, N. (2004a) In their own words: seven advanced cancer patients describe their experience with pain and the use of opioid drugs, *Journal of Pain & Symptom Management*, 27(4): 300-3009.

Coyle, N. (2004b) The ‘existential slap’ a crisis of disclosure, *International Journal of Palliative Nursing*, 10(11): 520.

Coyle, N. (2006) The hard work of living in the face of death, *Journal of Pain and Symptom Management*, 32(3): 266-274.

Doka, K.J. (1993) *Living with life threatening illness*. Lexington, MA: Lexington Books.

Finlay, L. (2003) The intertwining of body, self and world: A phenomenological study of living with recently-diagnosed multiple sclerosis, *Journal of Phenomenological Psychology*, 34(2), 157-178.

Finlay, L. (2011) *Phenomenology for therapists: Researching the lived world*. Chichester: Wiley-Blackwell.

Frank, A.W. (1995) *The wounded storyteller. Body, illness, and ethics*. Chicago: The University of Chicago Press.

Frank, A.W. (1978) Anxiety aroused by the dying, *Journal of Phenomenological Psychology*, 9(1), 99-113.

Friberg, F. and Ohlen, J. (2007) Searching for knowledge and understanding while living with impending death- a phenomenological case study, *International Journal of Qualitative Studies on Health and Well-being*, 2: 217-226.

Giorgi, A. (2008) Phenomenological psychology. In C. Willig and W. Stainton-Rogers (eds) *The Sage handbook of qualitative research in psychology*. London: Sage.

Heidegger, M. (1927/1962) *Being and time*. Trans. J. Macquarrie & E. Robinson. Oxford: Basil Blackwell.

Henry, M., Cohen, S.R., Lee, V., Sauthier, P., Provencher, D., Drouin, P., Gauthier, P., Gotlieb, W., Drummond, N., Gilbert, L. Stanimir, G., Sturgeon, J., Chasen, M., Mitchell, J., Huang, L.N., Fertland, M-K. & Mayo, N. (2010) The Meaning-Making intervention (MMi) appears to increase meaning in life in advanced ovarian cancer: A randomized controlled pilot study, *Psycho-Oncology*, 19(12), 1340-1347.

Janoff-Bulman, R. (1992) *Shattered assumptions*. New York: Macmillan.

Jim, H.S. & Andersen, B.L. (2007) meaning in life mediates the relationship between social and physical functioning and distress in cancer survivors, *British Journal of Health Psychology*, 12(3), 363-381.

Jim, H.S., Richardson, S.A., Golden-Kreutz, D.M. & Andersen, B.L. (2006) Strategies used in coping with a cancer diagnosis predict meaning in life for survivors, *Health Psychology*, 25(6), 753-761.

Kellehear,A. (2009) On dying and human suffering, *Palliative Medicine*, 23: 388-397.

Kubler-Ross, E. & Kessler, D. (2005) *On grief and grieving: Finding the meaning of grief through the five stages of loss*. London: Simon & Schuster Ltd.

Langdridge, D. (2007) *Phenomenological psychology. Theory, research and method*. Harlow: Pearson Prentice Hall.

Leman-Stefanovic, I. (1987) *The event of death: A phenomenological enquiry*. Dordrecht: Martin Nijhoff Publishers.

McLeod, J. (1998) *An introduction to counselling*, second edition. Buckingham: Open University Press.

McSherry, C.B. (2011) The inner life at the end of life, *Journal of Hospice & Palliative Nursing*, 13(2): 112-120.

Ohlen, J. (2003) Evocation of meaning through poetic condensation of narratives in empirical phenomenological inquiry into human suffering, *Qualitative Health Research*, 13, 557-566.

Pattison, E.M. (1977) *The experience of dying*. Englewood Cliffs, NJ: Prentice Hall.

Propper, M. (2007) *Gestalttherapie mit Krebspatienten. Eine Praxishilfe zur Traumabewältigung*. Köln: Peter Hammer Verlag.

Radley, A. and Taylor, D. (2003) Images of recovery: a photo-elicitation study on the hospital ward, *Qualitative Health Research*, 13(1), 77-99.

Reavey, P. & Johnson, K. (2008) Visual approaches: using and interpreting images in qualitative research. In C. Willig and W. Stainton-Rogers (eds) *The Sage handbook of qualitative research in psychology*. London: Sage.

Roussi, P. & Avdi, E. (2008) Meaning-making and chronic illness: Cognitive and narrative approaches, *Hellenic Journal of Psychology*, 5, 147-178.

Roy-Byrne, P.P., Davidson, K.W., Kessler, R.C., Gordon, J.G., Asmundson, R.D., Renee, D., Goodwin, M.P.H., Kubzansky, L., Lydiard, B., Massie, M.J., Katon, W., Sally, K., Laden, M.S. & Stein, M.B. (2008) Anxiety disorders and comorbid medical illness, *General Hospital Psychiatry*, 30, 208-225.

Sellick, S.M. & Crooks, D.L. (1999) Depression and cancer: An appraisal of the literature for prevalence , detection, and practice guideline development for psychological interventions, *Psycho-Oncology*, 8(4), 315-333.

Shinebourne, P. (2011) Interpretative phenomenological analysis. In N. Frost (2011) *Qualitative research methods in psychology. Combining core approaches*. Berkshire: McGraw Hill

Silver, J. (2013a) The experience of body dysmorphic disorder: An interpretative phenomenological analysis and photo elicitation study. In C. Willig (2013) *Introducing qualitative research in psychology*. Third edition, appendix 2, Maidenhead: McGraw Hill/Open University Press.

Silver, J. (2013b) Visual methods. In C. Willig (2013) *Introducing qualitative research in psychology*. Third edition, chapter 13, Maidenhead: McGraw Hill/Open University Press.

Smith, J.A., Flowers, P. & Larkin, M. (2009) *Interpretative phenomenological analysis. Theory, method and research*. London: Sage.

Stake, R.E.(1995) *The art of case study research*. London: Sage.

Tedeschi, R.G. & Calhoun, L.G. (2004) Posttraumatic growth: Conceptual foundations and empirical evidence, *Psychological Inquiry*, 15(1), 1-18.

Tomich, P.L. & Helgeson, V.S. (2002) Five years later: A cross-sectional comparison of breast cancer survivors with healthy women, *Psycho-Oncology*, 11, 154-169.

Toombs, S.K.(1995) Sufficient unto the day: A life with multiple sclerosis. In S.K. Toombs, D. Barnard & R. Carson (eds) *Chronic illness: From experience to policy*. Bloomington and Indianapolis: Indiana University Press.

Van Manen, M. (1997a) *Researching lived experience*. 2nd edition. Ontario: The Athlone Press

Van Manen, M. (1997b) From meaning to method, *Qualitative Health Research*, 7, 345-369.

Van Manen, M. (1990) *Researching lived experience*. 1st edition. Ontario: The Althouse Press.

Van Manen, M. (2014) *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing*. Walnut Creek, CA: Left Coast Press.

Voogt, E., van der Heide, A., van Leeuwen, A.F., Visser, A.P., Cleiren, M.P.H.D., Passcher, J. & van der Maas, P.J. (2005) Positive and negative affect after diagnosis of advanced cancer, *Psycho-Oncology*, 14, 262-273.

Willig, C. (2009) “Unlike a rock, a tree, a horse or an angel...”: Reflections on the struggle for meaning through writing during the process of cancer diagnosis, *Journal of Health Psychology*, 14(2), 181-189.

Willig, C. (2011a) Cancer diagnosis as discursive capture: phenomenological repercussions of being positioned within dominant constructions of cancer, *Social Science and Medicine*, 73(6): 897-903.

Willig, C. (2011b) *The ethics of interpretation*. Existential Analysis, 22.2: 255-271.

Willig, C. & Billin, A. (2012) Existentialist-informed hermeneutic phenomenologu. In D. Harper & A.R. Thompson (eds) *Qualitative research methods in mental health and psychotherapy. A guide for students and practitioners*. Chichester: Wiley-Blackwell.

Wojtkowiak, J. & Rutjens, B.T. (2011) The postself and terror management theory:Reflecting on after death identity buffers existential threat, *The International Journal for the Psychology of Religion*, 21, 137-144.

