



City Research Online

City St George's, University of London

Citation: Willig, C. & Wirth, L. (2018). A metasynthesis of studies of patients' experience of living with terminal cancer. *Health Psychology*, 37(3), pp. 228-237. doi: 10.1037/hea0000581

This is the accepted version of the paper.

This version of the publication may differ from the final published version. To cite this item please consult the publisher's version.

Permanent repository link: <https://city-ref-test.eprints-hosting.org/id/eprint/18650/>

Link to published version: <https://doi.org/10.1037/hea0000581>

Copyright and Reuse: Copyright and Moral Rights remain with the author(s) and/or copyright holders. Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge, unless otherwise indicated, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way. For full details of reuse please refer to [City Research Online policy](#).

A Metasynthesis of Studies of Patients' Experience of Living with Terminal Cancer

Carla Willig, PhD & Luisa Wirth, BSc

City, University of London

Northampton Square

London, EC1V OHB

Tel: 0044 (0)207 040 85 22

Fax: 0044 (0) 207 040 36 37

C.Willig@city.ac.uk

'The authors would like to thank the Erasmus Mobility Programme for their support'

Abstract

Objective: The aim of this research was to produce a synthesis of phenomenological studies of the experience of living with the awareness of having terminal cancer in order to gain a more complete understanding of the parameters of this experience.

Methods: This research used metasynthesis as a method for integrating the results of 23 phenomenological studies of the experience of living with the awareness of having terminal cancer published between 2011 and 2016.

Results: The metasynthesis generated 19 theme clusters which informed the construction of four master themes: *trauma*, *liminality*, *holding on to life* and *life as a cancer patient*. Each master theme captures a distinct experiential dimension of living with the awareness of having terminal cancer. Each dimension brings with it significant and distinctive psychological challenges.

Conclusion: The results from the present metasynthesis suggest that the experience of living with the awareness of having terminal cancer is a multi-dimensional experience which patients actively negotiate as they search for ways in which they can rise to the psychological challenges associated with it. A better understanding of the parameters of this experience can help health care professionals provide appropriate support for this client group.

Key words: living with advanced cancer; metasynthesis; phenomenology of cancer; qualitative analysis; illness experienc

Introduction

Increasing numbers of people are being diagnosed with cancer and, as a result of improvements in diagnosis and treatment, people live longer with cancer even during advanced stages of the disease. This means that a large number of people with advanced cancer are now living with the awareness that the end of their life is approaching. Qualitative research has been conducted to help us understand how the dying person engages with the challenges posed by the living-dying interval (eg. Coyle, 2006; McSherry, 2011; Willig, 2015). Such research suggests that the experience of dying from cancer constitutes a threat to the individual's sense of self and the phenomenal world they are accustomed to. It requires the individual to accommodate many significant changes (to their bodies, their social relationships, their social roles, their relationship with the future, and so on). Living with the awareness of having terminal cancer confront patients with the existential paradox of struggling to live whilst preparing for death (Coyle, 2004a and b; 2006).

Although many original qualitative studies have been published on the subject, their impact has been limited because each one of them is based on a relatively small number of participants. Whilst it is not the aim of a metasynthesis to produce generalisable results, this method of analysis provides an opportunity to integrate findings from across a range of qualitative studies to produce a conceptually more robust account of the meaning and significance of a phenomenon than would have been possible on the basis of a single qualitative study.. If our aim is to acquire a comprehensive, contextualised, multi-dimensional understanding of the meaning and significance of the experience of living with terminal cancer, then metasynthesis provides us with a methodology to move towards this

goal.

Metasynthesis

Metasynthesis offers a methodology for systematically aggregating, integrating and interpreting findings from a sample of qualitative research reports (Ludvigsen et al., 2015).

As such, metasynthesis has the potential to increase the credibility and relevance of qualitative research and to help ensure that such research plays a bigger role in policy-making and evidence-based practice (Bondas & Hall, 2007: 115).

There are a number of different approaches to conducting metasyntheses and researchers have different views regarding the ideal number of studies that should be included in a metasynthesis, as well as regarding the inclusion/exclusion criteria for studies. For example, Kearney (2001) argues that greater numbers of primary studies facilitate a more saturated and transferable analysis whilst others caution that the inclusion of more than ten (Sandelowski, Docherty and Emden, 1997) or twelve (Paterson et al. 2001) primary studies is likely to compromise the depth of the analysis (see Bondas & Hall, 2007). More significantly when considering the role of interpretation, there are differences in approach regarding the extent to which primary findings should to be re-interpreted, for example by re-labelling and/or re-grouping themes with some authors disregarding the primary researchers' interpretations altogether (see Ludvigsen et al, 2015: 6).. However, as Thorne (2015: 1348) argues, any metasynthesis should constitute "a distinct piece of scholarly research and not merely an option for organising and displaying available literature in the field". As such, metasynthesis must be distinguished from meta-aggregation and other forms of qualitative research synthesis (QRS) (Major & Savin-Baden, 2010; see also Ludvigsen et al. 2015 for a summary) which focus on the identification of common themes across studies rather than also being concerned with the interpretation of difference and diversity in the data set (see Weed, 2008).

In metasynthesis, the aim is to move beyond summaries and to offer novel interpretations of findings from primary studies (Bondas & Hall, 2007).

This paper seeks to contribute to the growing field of qualitative metasynthesis in health psychology by presenting a metasynthesis of phenomenological studies of patients' experience of living with the awareness of having terminal cancer. As such, it adds to a body of qualitative research syntheses focusing on a variety of aspects of the experience of living with cancer including emotional experiences of patients living with incurable lung cancer (Refsgarrrd & Frederiksen, 2013), the impact of a brain tumour on everyday life (Sterckx et al. 2012) and the experience of living with metastatic breast cancer (Willis, et al. 2015).

Method

Design

This research used metasynthesis as a method for integrating the results of phenomenological studies of the experience of living with the awareness of having terminal cancer published between 2011 and 2016. This timeframe was chosen to ensure that the included studies were recent and thus reflect contemporary rather than historical experiences of cancer. This is important as developments in diagnosis and treatment for cancer continue to take place and these provide a context for, and therefore are likely to shape, the lived experience of cancer. In addition, the relatively narrow 2011-2016 timeframe also ensured that, given that an inclusive approach to the selection of eligible studies was taken (see below), the number of primary studies included in the metasynthesis would be manageable given the resources available to the researchers. The approach to metasynthesis taken in this research was informed by guidance provided by Bondas and Hall (2007) and Ludvigsen et al (2015). These two papers address the methodological challenges associated with conducting a qualitative

metasynthesis by drawing on Sandelowski and Barroso (2007) as well as Noblit and Hare (1988), Paterson et al. (2001) and Kearney (2001). Both papers provide clear and helpful guidelines informed by their detailed review of established procedures for selecting and retrieving, appraising, classifying, interpreting and synthesising the results of qualitative studies. As such, these papers provide a solid foundation for conducting a metasynthesis.

In line with Bondas and Hall's (2007) and Ludvigsen et al.'s (2015) guidance,

the present metasynthesis aspired to offer novel interpretations of existing findings through their integration and to facilitate theory development rather than to simply aggregate the results of existing studies. This meant that the present metasynthesis engaged in some re-interpretation of primary data where necessary (see Ludvigsen et al. 2015). Regarding the selection of studies and quality parameters applied, the present metasynthesis opted to not use standardised assessment tools and followed Sandelowski and Barroso's (2007) recommendation to not exclude studies due to poor quality. However, exclusion criteria were predetermined rather than idiographic, and studies which did not meet the inclusion criteria were excluded from the metasynthesis. Finally, following Kearney (2001) there was no cap on the number of studies to be included; this was to ensure that the results would be as saturated and transferable as possible.

Procedure

The following steps were taken to produce the metasynthesis:

i) Selection of eligible studies

Inclusion criteria were as follows: the study was published between 2011 – 2016; was based on semi-structured interviews; showed an explicit commitment to a

phenomenological or hermeneutic method of analysis; the participants were at least 18 years old and were aware of their terminal diagnosis.

Exclusion criteria were as follows: the study was using a quantitative method or a qualitative method that did not generate experiential data; was not based on interviews with cancer patients; participants' cancer was not necessarily terminal and/or they were not aware of the seriousness of their condition; the study did not focus on the patients' own experience of living with terminal cancer. Eligible studies were initially identified by the second author on the basis of their published abstracts and then reviewed by both authors after which inclusion (or exclusion) was confirmed.

ii) Determination of search terms and data bases

The following databases were used: EBSCOhost (including results from Academic Search Complete, CINAHL Plus with Full Text, Gender Studies Database, Health & Psychosocial Instruments, Medline Complete, PsycArticles, PsycInfo, SocIndex), PubMed, Scopus, Web of Science and Internurse (StarPlus). Google Scholar was used when the pdf-file was not retrievable on the database where the study was found.

The following search terms were used in the first phase of research: “phenomenological” OR “hermeneutic” AND “cancer” AND “terminal” OR “advanced” OR “palliative” NOT “survivor”. After an initial search phase, the research terms were reconsidered and a new combination of search terms was applied. The following search terms were used in the second search phase: “experiential” OR “qualitative” AND “lived experience” AND “cancer” AND “terminal” OR “advanced” OR “palliative” NOT “survivor”. A third and final search was conducted using the terms “end of life experience” AND “cancer” AND “qualitative”. The time frame was set from March 2011 to March 2016. Where possible, the criterion to

select peer reviewed papers was chosen. The searches on the different databases produced 892 hits in total (including duplicates).

iii) Selection of studies to be included

All studies identified through the above procedure were checked against the inclusion/exclusion criteria and only those that met the criteria were retained. 36 studies met the criteria (of these 21 studies had been identified during the search phase, ten in the second search phase, three in the third search phase and two had been selected from Google Scholar). The bibliographies of the selected studies were screened for further eligible studies which were then also checked against the inclusion and exclusion criteria. This process identified another six eligible studies and scrutiny of their reference lists identified one further eligible study. While searching for one study on Google Scholar, another two studies were identified. 45 studies were selected in total.

All selected studies were scrutinised and some were excluded at this stage due to not being retrievable online, being written up in a language other than English or German, taking the form of a metaanalysis or review, or due to there being a lack of clarity regarding the extent to which participants' cancer was advanced and, therefore, could be considered terminal. One further study (Esteves et al. 2015) was excluded because the presentations of its findings was merged with a review of other studies' findings which made it difficult to extract themes specific to Esteves et al's own data.

As a result of this process, 22 studies were excluded, leaving 23 studies to be included in the metasynthesis. Studies whose results were based on the same sample were included because the analyses presented in them had different foci which meant that each one of them contributed distinct insights into the experience of living with terminal cancer.

All included studies and their key features (including country of origin, sample size, gender and age of participants, type of cancer and method of analysis) are presented in Table 1.

Insert Table 1 about here

iv) Production of a summary table of results

The findings of the selected studies were compiled in a summary table in the form of themes. The themes were derived by reviewing each papers' results section and extracting themes which captured the experiential meanings that had been identified by the authors. Care was taken to ensure that the theme labels captured participants' experiences as described by the original authors rather than introducing explanatory or theory-driven constructs at this stage. However, where it was felt that the original authors' themes lacked phenomenological depth (in that they identified the topics participants talked about, for example, rather than capturing the experiential quality and meaning of participants' lifeworld), new theme labels were constructed on the basis of participants' quotes. Within this process, primary researchers' interpretations were overridden in favour of revisiting participants' own accounts, as recommended by Duggleby et al. (2012) and Lindahl and Lindblad (2011) (see Ludvigsen et al, 2015). Once completed, the summary table contained a total of 151 themes (this table is available on the journal's website).

v) Integration and Interpretation

All themes contained in the summary table were then allocated to a theme cluster. Labels of theme clusters identified by the original authors themselves provided a starting point for clustering themes from all studies. In cases where different authors had used different cluster labels to capture what appeared to be the same, or very similar, meanings, these were collapsed into one cluster and given a label that captured the shared meaning. This process generated 19 theme clusters in total (left hand column of Table 2). Again, this was an

interpretative process which required a comparative analysis of the primary studies' findings. As before, care was taken to stay as close as possible to the original authors' interpretations during this process whilst ensuring that the theme clusters allowed for a phenomenological focus

The final step in the analysis involved reviewing the 19 theme clusters in relation to one another with the aim of constructing categories of meaning of a higher order which would pull together and crystallize the meanings contained within the original theme clusters. This was done by looking for connections and relationships between the clusters and their thematic content. This process led to the construction of four master themes (*Trauma, Liminality, Holding on to Life, Life as a Cancer Patient*) which identify the parameters of the experience of living with the awareness of having terminal cancer; together they map out its experiential possibilities. It was decided to use the label 'master themes' to designate these higher order categories of meaning as this resonates with terminology used in Interpretative Phenomenological Analysis (Smith et. al, 2009). This seemed most compatible with the phenomenological focus of the present metasynthesis.

The relationships between the 19 theme clusters and the four master themes are represented in Table 2 and will be discussed in more detail in the next section.

Insert Table 2 about here

Results

The present metasynthesis was based on 23 qualitative studies of the experience of living with the awareness of having terminal cancer conducted in a variety of countries comprising Australia, Israel, Norway, Taiwan, USA, Sweden, Denmark, Ireland, Thailand, Canada and the United Kingdom. The total number of participants across the 23 studies lies between 318

and 332 patients. Due to the overlap of participants who generated data for some of the studies, as discussed above, it was not possible to determine the exact total sample size. Participants were between 26 and 92 years old. They were suffering from a variety of cancer types (see Table 1).. Most of the patients were suffering from metastatic cancer; however, the studies only named the primary cancer site so not all cancer types the patients were suffering from were listed. In some studies the type of cancer remained unspecified.

The present metasynthesis generated 19 theme clusters which informed the construction of four master themes: *trauma*, *liminality*, *holding on to life* and *life as a cancer patient* (see Table 2). Each master theme captures a distinct experiential dimension of living with terminal cancer and together the master themes illuminate an experience which is characterised by a wide range of experiential possibilities that bring with them significant and distinctive psychological challenges. Five theme clusters contributed to more than one master theme because the concerns contained within these clusters manifested within different experiential contexts. For example, the theme cluster ‘impact on the psyche’ features in all four master themes because each of the four experiential dimensions of living with terminal cancer involves a psychological response of some kind. When choosing labels for the four master themes an effort was made to ensure that they spoke to and reflected the experiential concerns contained within their constituent theme clusters whilst at the same time help to crystalise meaning by conceptualising and thinking about aspects of participants’ accounts in terms of theory-inflected notions (such as ‘trauma’ and ‘liminality’). As such, the selection of labels for the master themes was an interpretative act. Each master theme is introduced below, before their relationships with one another are discussed. This is followed by reflections on the implications for the types of support that psychologists and other health care professionals might be able to offer to patients in this situation.

Master Theme 1: *Trauma*

This master theme was informed by the content of seven theme clusters ('Interruption', 'Impact on the Psyche', 'Loss and Decay', 'Death', 'Threat', 'Control' and 'Suffering'). It captures the catastrophic interruption that a terminal cancer diagnosis constitutes as it impacts upon all aspects of the patient's life, including their anticipated life trajectory, their relationship with the future, their personal relationships and social commitments as well as their sense of self and their social identity. This experience of traumatic interruption is described in terms that invoke a degree of violence and destruction akin to a physical blow. The impact on the patient's state of mind is profoundly negative as s/he experiences an intense sense of vulnerability and lack of physical and emotional safety in the face of the magnitude of the threat. In addition, a series of actual and anticipated losses, such as a loss of health and customary functioning and a loss of one's former sense of self, contribute to the patient's distress. The sudden emergence of one's own mortality as a lived reality brings with it a strong sense of existential anxiety. Finally, the loss of control over one's body and one's physical functioning instils a fear of the future and the threat of impending suffering.

The quality of experience captured within this master theme invokes some of the features of the impact of a traumatic event, the shock of which can shatter a person's trust in the world, its (relative) predictability and safety. The title *Trauma* was chosen for this master theme since the impact of a terminal cancer diagnosis as described by participants spoke to four out of eight dimensions that define traumatic stressors (see van der Kolk et al., 2000) including i) threat to life or to one's physical integrity, ii) serious damage or injury to one's body, iii) confrontation with unimaginable events, and iv) the realisation that one's own health is seriously threatened.

Master Theme 2: *Liminality*

This theme was informed by the content of six theme clusters ('Impact on Social Life', 'Separation', 'Impact on the Psyche', 'Relationship to Time', 'Death', (Un)certainty'). It captures the experience of inhabiting an experiential space that is inbetween what was and what will be, a kind of twilight zone on the threshold of death. This transitional space cannot be shared with those who are healthy and it separates the patient from the everyday world where being alive is taken for granted. There is a bell jar quality to this experiential space. Inhabiting the liminal space can give rise to changes in cognitive functioning (eg. difficulties concentrating and focusing on tasks at hand), and it can have emotional consequences (eg. feelings of disconnection, disorientation and isolation). It is also characterised by an altered relationship with time. Whilst in the liminal space it is difficult to make connections with either past or future as both of these lie outside of the bell jar that is the liminal space. In their (pre-cancer) past, the patient was somebody else in that they were pursuing everyday concerns in the 'land of the living' and in the future they will be somebody else again as they will join the vast army of the dead. Finding oneself in the liminal space on the threshold of death can feel like occupying a waiting room where time itself becomes both all-important and meaningless at the same time.

Being in the liminal space is not always experienced as negative as it can also make new and precious experiences possible. The detachment from everyday worries about the future, for example, and a new appreciation of the significance of the present moment can give rise to intense emotional and spiritual experiences. These can be generated on the basis of basic sensory experiences (such as drinking a cup of coffee or smelling fresh flowers) or through religious practices (such as meditation or prayer)

The title *Liminality* (Latin for 'threshold') was chosen for this master theme as its use in anthropology captures the quality of ambiguity and disorientation that arises as people transition from one sociocultural status to another (see Andrews & Roberts, 2015). The

liminal stage is the middle stage of a ritual during which participants finds themselves inbetween their previous position (eg. as a child) and their new position (eg. as an adult). This resonates powerfully with the sense of inhabiting a space inbetween (the world of the living and death itself) that the participants in this metasynthesis expressed. Our use of the concept of liminality within the context of cancer diagnosis echoes Little et al. (1998) who used it to capture the experiential quality of detachment from the healthy world and its assumptions post-diagnosis which, they argue, stays with a person, regardless of whether or not their cancer is cured.

Master Theme 3: *Holding on to Life*

This theme was informed by the content of ten theme clusters ('Impact on the Psyche', 'Coping and Reaching Acceptance', 'Needs', 'Death', 'Resistance', 'Living Life in the Present', 'Hope', 'Sense of Belonging/Attachment', 'Control', '(In)dependence'). It captures the patient's efforts to stay connected to life and to the living, and to resist being torn away from all that made life meaningful and worthwhile in the past. 'Holding on to Life' is an effortful activity which describes the hard work required of patients to find a way of living meaningfully with terminal cancer. The studies included in the metasynthesis identified numerous coping strategies including acceptance, distraction, making arrangements for future scenarios, engaging with spirituality, positive thinking/staying positive, stoicism, identifying goals, escape, mobilising various social and material resources, being realistic, furthering understanding of their situation, and making decisions about treatments. The important thing to understand is that 'Holding on to Life' is experienced as a purposeful activity, something that patients (have to) do and that takes up energy, not something that just happens to them or, indeed, that someone else can do for the patient. It is a way of meeting one's own needs (for

normality, for continuity, for a sense of belonging, for knowledge and understanding, for meaning, for hope and so on) in a situation that threatens to remove one's ability to do so. 'Resistance' (eg. by fighting the cancer and not giving up on treatments), 'Living Life in the Present' (eg. by focusing on little pleasures in daily life) and 'Hope' (by identifying and investing in a sense of the future even if that future can only be the immediate future) are important ways in which patients hold on to life in the face of the existential threat that their cancer poses. 'Holding on to Life', therefore, involves trying to hold on to some sense of control over one's life and preserving a level of independence.

Master Theme 4: *Life as a Cancer Patient*

This theme was informed by the content of five theme clusters ('Impact on the Psyche', 'Loss and Decay', 'Being a Patient', 'Suffering', '(In)dependence'). It captures the impact of terminal cancer on the patient's day-to-day life and encompasses the mundane but unavoidable and often intensely unpleasant routines and their side effects which are associated with being a cancer patient. It also captures what it means to be (treated and perceived as) a cancer patient in the social world. 'Life as a Cancer Patient' can produce strong emotions including anxiety (eg. when waiting for test results or in anticipation of new treatments) and guilt (eg. for being a burden to loved ones, for causing loved ones to feel distress). It can also generate feelings of vulnerability and a sense of helplessness within the context of receiving treatments for cancer. Being positioned as 'cancer patient' means being at the receiving end of medical services, often with limited information and little opportunity for shaping the care that one receives. This brings with it a sense of loss of control over one's body and what happens to it. Indeed, 'Life as a Cancer Patient' confronts the patient with a range of losses including a loss of dignity, a loss of energy, a loss of independence and a loss

of control. At the same time, however, *Life as a Cancer Patient* opens up an opportunity for sharing experiences with other cancer patients and this generates a welcome sense of companionship and connection. This is particularly important as it provides a counterbalance to the sense of disconnection from the 'land of the living' experienced within the liminal space between life and death (see Master Theme 2: *Liminality*).

Discussion of Findings

The four master themes identify distinct yet related dimensions of the experience of living with terminal cancer. They represent distinct experiential spaces which make available quite different ways of relating to the challenge of living with terminal cancer

The relationships between the master themes are complex and include a dialectic of loss and gain. There is the loss of connection with the 'world of the living' through *Liminality* on the one hand, and on the other there is the gain of a sense of connection through companionship and solidarity with fellow patients that becomes available through *Life as a Cancer Patient* as well the heightened sense of belonging and attachment found in *Holding on to Life*. There are also tensions between the catastrophic interruption that a terminal cancer diagnosis constitutes (as captured in the master theme *Trauma*) and the patients' efforts to protect parts of their life and sense of self from this intrusion through finding some normality and continuity, for example by holding on to pre-cancer roles and identities (as captured in *Holding on to Life*). Finally, within *Liminality* there are possibilities for both loss and gain as connections with the meaning and value of the everyday world weaken whilst opportunities for a heightened sense of (worldly or religious forms of) spirituality open up.

It is important to acknowledge that there were also some notable differences in the findings of the studies. Both Bondas & Hall (2007) and Weed (2008) warn against reductive tendencies in

metasynthesis research whereby an exclusive focus on common themes has a homogenising effect and screens out differences. For example, there was evidence of cultural differences in the ways in which participants coped with their situation (see Theme Cluster 6: Coping). Nilmanat et al.'s (2015) study of the experiences of Thai patients with advanced cancer demonstrated that for this group of participants the use of religious doctrine was central in helping them transcend suffering and move towards the end of their lives with serenity. Nilmanat et al.'s (2015) findings also suggest those Thai patients who had access to Buddhist teaching reframed what was initially experienced as a traumatic interruption as a manifestation of a natural process of life transition and were able to make peace with it in this way. Religion did not play such a significant role in the other studies. Participants who did not have access to religious doctrine and practices found other ways towards acceptance (eg. through normalising death, see Aoun et al., 2015, or through experiences with nature, see Karlsson et al., 2014); however, not all participants experienced acceptance. Similarly, other contextual factors (eg. whether or not the patient was living alone, their age, the stage of their cancer) mediated the ways in which participants inhabited the four experiential dimensions of living with terminal cancer. This reminds us that whilst 'Trauma', 'Holding on to Life', 'Liminality' and 'Life as a Cancer Patient' can be said to represent the experiential dimensions of living with the awareness of having terminal cancer as identified across the 23 studies, the particular ways in which patients engage with and thus experience these dimensions will be shaped by the specific contexts within which they find themselves. Further research could fruitfully be conducted in order to identify and map out contextual variations within the experience.

The present metasynthesis supports existing findings, for example in relation to the role that religion can play in helping people cope with the challenge of confronting their mortality (eg. Tarakeshwar et al., 2006), the importance of finding meaning in life post-diagnosis (eg.

Bingley et al., 2006), and the traumatic effect of a cancer diagnosis (eg. Propper, 2007). It also points to some ways in which health psychologists and other health care professionals might support people during this challenging phase of their lives. To support patients whose lives are traumatically interrupted and who are thrust into a new and terrifying reality (see Master Theme 1) psychologists can help patients re-gain a sense of continuity and agency through providing opportunities for patients to tell their stories and to author new narratives which give meaning and coherence to their experiences (see Frank, 1995, and Willig, 2009 on the role of narrative in coping with a cancer diagnosis). To assist patients in accessing the rewarding aspects of liminality (see master Theme 2) psychologists can work with patients to help them increase their sensory awareness in the here-and-now as well as provide opportunities for patients to participate in activities such as meditation, listening to music and spending time in/with nature (Brooks, 1991; Siegel, 2007). Patients' efforts to 'hold on to life' (see Master Theme 3) can be supported by providing opportunities for patients to focus on their experience of the present moment (see Theme Cluster 1: Living life (in the present)), for example, through animal-assisted therapy (Fine, 2010) or mindfulness practice (Kabat-Zinn, 2013). Finally, facilitating patients' sense of connection with other patients (see Master Theme 4) through providing opportunities for them to meet either socially or within the context of support groups could help strengthen a sense of group membership and social identity and thus counteract the negative effects of feeling disconnected from 'the land of the living' (see Haslam et al. 2009 for more on the role of social identity in health and well-being).

Reflections on the Use of Metasynthesis Methodology

Reading, reviewing, coding, interpreting and synthesising 23 sets of results was time-consuming and demanding work. At the same time, paying close attention to the voices of so many research participants (over 300 across the 23 studies) describing their experience of their final life challenge was a rich and rewarding experience. The process of synthesising the results enabled the production of a complex and yet coherent picture of the parameters of the experience of living with terminal cancer. From an ethical point of view, metasynthesis research in this field is to be welcomed as it allows researchers to gain a better understanding of patients' experiences without overresearching already vulnerable people whose resources (eg. in terms of time and energy) are limited (see Sandelowski, Docherty and Emden, 1997). However, it is important to bear in mind that being interviewed about their experience can be a rewarding and meaningful experience for people who are facing their own death (see Kleiderman et al, 2012, and Sivell et al. 2015, for a discussion of the ethics of interviewing terminally ill patients).

Integrating the findings from the 23 studies involved a process of interpretation on the part of the researchers. Grouping the 19 theme clusters under the four master theme headings required the researchers to contribute to the meaning-making process. In addition, conceptualising and thinking about aspects of participants' accounts in terms of theory-inflected notions such as 'trauma' and 'liminality' made it possible to extract and communicate more of the meaning and significance of the impact of living with terminal cancer than might have been possible on the basis of staying at a more descriptive level. It is not easy to find a balance between integrating findings across studies and preserving the unique features of each study's finding, particularly where the primary studies subscribe to a methodology such as phenomenology which is concerned with individual experience and which takes an idiographic approach to the analysis. This is, of course, a challenge posed by

all qualitative research when it seeks to capture a range of individuals' experiences in the form of shared themes (see Willig, 2015).

There were some limitations to the search strategy which may limit the validity of the findings. Only systematic electronic searches together with a follow-up of references were used. There were no manual searches or follow up 'cited by' columns of data bases. This means that articles which did not use standardised key words or which might have used idiosyncratic language to describe their research would have been missed. Also, unpublished dissertations were excluded as were other metasyntheses.

It is important to bear in mind that all participants knew about and did not question their terminal diagnosis (although some expressed hope of new treatments becoming available in time for them). The findings, therefore, do not represent a phenomenology of living with denial or ambivalence regarding a terminal cancer diagnosis.

Finally, this report does not include quotations from the participants in the studies that were synthesized. This is mainly due to space restrictions but also reflects the metasynthesis' primary function which is to map out the experiential spaces available to people living with terminal cancer and to identify their defining features. Separate papers on each of the four master themes will be published which will give voice to participants and explore the tensions and contextual dimensions of the themes in more detail (eg. Willig & Wirth, under review).

Conclusion

The results from the present metasynthesis suggest that the experience of living with terminal cancer is a multi-dimensional experience which includes experiential themes of connection as well as disconnection, living as well as dying. Patients find themselves in the challenging

position of having to negotiate tensions as they move between these dimensions. This is not a linear process of moving through consecutive stages of an experience but rather a moving back and forth between available experiential spaces which offer different ‘takes’ on living with terminal cancer. The present metasynthesis demonstrates that in this process patients are active and agentic as they search for ways in which they can rise to the psychological challenge of living in the face of death. It seems that doing nothing is not an option as the intensity of their experiences calls for a response of some kind. This observation reminds us that suffering is not a passive state. It seems that, as Coyle (2006) suggested, living with terminal cancer does indeed require a sustained effort on the part of the person as they attempt to find a way to live meaningfully whilst preparing for death. Health psychologists are well placed to support patients in this effort.

References

- Andrews, H. & Roberts, L. (2015) Liminality, *International Encyclopedia of the Social & Behavioral Sciences*, 2nd edition, volume 14. <http://dx.doi.org/10.1016/B978-0-08-097086-8.12102-6>
- Aoun, S.M., Deas, K., & Skett, K. (2015) Older people living alone at home with terminal cancer, *European Journal of Cancer Care*, May 2016, vol.25, Issue 3, pp. 356-364
DOI: 10.1111/ecc.12314
- Bentur, N., Stark, D.Y., Resnizky, S. & Symon, Z. (2014) Coping strategies for existential and spiritual suffering in Israeli patients with advanced cancer, *Israel Journal of Health Policy Research*, 3:21. DOI: 10.1186/2045-4015-3-21
- Bingley, A.F., McDermott, E., Thomas, C., Payne, S., Seymour, J.E. & 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: 183-195,

<http://dx.doi.org/10.1191/0269216306pm1136oa>

Bondas, T. and Hall, E.O.C. (2007) Challenges in approaching metasynthesis research,

Qualitative Health Research, 17: 113-21.

Brooks, C. (1991) *Erleben durch die Sinne*. Munich: DTV 1991, [ISBN 3-423-15085-8](#).

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 and Symptom Management*, 27: 300-309, <http://dx.doi.org/10.1016/j.jpainsymman.2003.08.008>

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

Coyle, N. (2006) The hard work of living in the face of death, *Journal of Pain and Symptom Management*, 32: 266-274. <http://dx.doi.org/10.1016/j.jpainsymman.2006.04.003>

Dale, M.J. & Johnston, B. (2011) An exploration of the concerns of patients with inoperable lung cancer, *International Journal of Palliative Nursing*, 17(6): 285-290.

Devik, S.A., Enmarker, I., Wiik, G.B. & Hellzen, (2013) Meanings of being old, living on one's own and suffering from incurable cancer in Norway, *European Journal of Oncology Nursing*, 17: 781-787

Devik, S.A., Hellzen, O. & Enmarker, I. (2015) "Picking up the pieces"- Meanings of receiving home nursing care when being old and living with advanced cancer in a rural area, *International Journal of Qualitative Studies on Health and Well-being*, 10:28382-
<http://dx.doi.org/10.3402/qhw.v10.28382>

Douglas, A.C., Mills, J.E., Niang, M., Stepchenkova, S., Byun, S., Ruffini, C., Lee, S.K., Loutfi, J., Jung-Kook, L., Atallah, M. & Blanton, M. (2008) Internet addiction: Meta-

synthesis of qualitative research for the decade 1996-2006, *Computers in Human Behaviour*, 24: 3027-3044.

Duggleby, W., Hicks, D., Nekolaichuk, C., Holtslander, L., Williams, A., Chambers, T. and Eby, J. (2012) Hope, older adults, and chronic illness: A metasynthesis of qualitative research, *Journal of Advanced Nursing*, 68: 1211-1223.

Esteves, A., Roxo, J., & da Conceicao Saraiva, M. (2015) The lived experience of people with progressive advanced cancer, *British Journal of Nursing (Oncology Supplement)*, 24 (10): 515-521.

Fan, S-Y. & Eiser, C. (2012) Illness experience in patients with hepatocellular carcinoma: an interpretative phenomenological analysis study, *European Journal of Gastroenterology & Hepatology*, 24(2): 203-208

Fine, A.H (ed) (2010), *Handbook on Animal-Assisted Therapy. Foundations and Guidelines for Animal-assisted Interventions*, 3rd edition. San Diego: Academic Press,

Frank, A. W. (1995) *The Wounded Storyteller. Body, Illness, and Ethics*. Chicago, Il.: The University of Chicago Press.

Hansen, L., Rosenkranz, S.J., Vaccaro, G.M. & Chang, M.F. (2015) Patients with hepatocellular carcinoma near the end of life. A longitudinal qualitative study of their illness experience, *Cancer Nursing*, 38(4): 19-27.

Haslam, S.A., Jetten, J., Postmes, T. & Haslam, C. (2009) Social identity, health and well-being: An emerging agenda for applied psychology, *Applied Psychology: An International Review*, 58(1): 1-23.

Haug, S.H.K., Danbolt, L.J., Kvigne, K. & Demarinis, V. (2015) How older people with incurable cancer experience daily living: A qualitative study from Norway, *Palliative and Supportive Care*, 13: 1037-1048.

Kabat-Zinn, J (2013). *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness*. New York: Bantam Dell.

Karlsson, M., Friberg, F., Wallgren, C. & Ohlen, J. (2014) meanings of existential uncertainty and certainty for people diagnosed with cancer and receiving palliative treatment: A life-world phenomenological study, *BMC Palliative Care*, 13:28.

<http://biomedcentral.com/1472-684X/13/28>

Kearney, M.H. (2001) New directions in grounded formal theory, in R. Schreiber and P. N. Stern (eds) *Using Grounded Theory in Nursing*. New York: Springer.

Kleiderman, , E., Avard, D., Black, L., Diaz, Z. Rousseau, C. and Knoppers, B.M. (2012) Recruiting terminally ill patients into non-therapeutic oncology studies: views of health professionals, *BMC Medical Ethics*, 13: 22, <https://doi.org/10.1186/1472-6939-13-33>

La Cour, K. & Hansen, H.P. (2012) Aesthetic engagements: “Being” in everyday life with advanced cancer, *American Journal of Hospice & Palliative Medicine*, 29(2): 126-133.

Levy, A. & Cartwright, T. (2015) Men’s strategies for preserving emotional well-being in advanced prostate cancer: an interpretative phenomenological analysis, *Psychology & Health*, 30(10): 1164-1182.

Lindahl, B. and Lindblad, B.M. (2011) Family members’ experiences of everyday life when a child is dependent on a ventilator: A metasynthesis study, *Journal of Family Nursing*, 17: 241-269.

Little, M., Jordens, C.F.C., Paul, K., Montgomery, K. and Philipson, B. (1998) Liminality: A major category of the experience of cancer illness, *Social Science and Medicine*, 47 (10): 1485-1494.

Ludvigsen, M.S., Hall, E.O.C., Meyer, G., Fegran, L., Aagaard, H. and Uhrenfeldt, L. (2015) Using Sandelowski and Barroso's metasynthesis method in advancing qualitative evidence, *Qualitative Health Research*, 1-10, Doi: 10.1177/1049732315576493

Major, C.H. and Savin-Baden, M. (2010) *An introduction to qualitative research synthesis. Managing the information explosion in social science research*. New York: Routledge.

McSherry, C.B. (2011) The inner life at the end of life, *Journal of Hospice & Palliative Nursing*, 13: 112-120. <http://dx.doi.org/10.1097/NJH.Ob013e318207af49>

McTiernan, K. & O'Connell, M. (2015) An interpretative phenomenological analysis exploring the lived experience of individuals dying from terminal cancer in Ireland, *Palliative and Supportive Care*, 13: 641-651.

Missel, M. & Birkelund, R. (2011) Living with incurable oesophageal cancer. A phenomenological hermeneutical interpretation of patient stories, *European Journal of Oncology Nursing*, 15: 296-301.

Nedjat-Haiem, F., Carrion, I.V., Lorenz, K.A., Ell, K. & Palinkas, L. (2013) Psychosocial concerns among Latinas with life-limiting advanced cancers, *OMEGA*, 67(1-2): 167-174.

Nilmanat, K., Promnoi, C., Phungrassami, T., Chailungka, P., Tulathamkit, K., Noo-urai, P. & Phattaranavig, S. (2015) Moving beyond suffering. The experiences of That persons with advanced cancer, *Cancer Nursing*, 38(3): 224-231.

Nissim, R., Rennie, D., Fleming, S., Hales, S., Gagliese, L. & Rodin, G. (2012) Goals set in the land of the living/dying: A longitudinal study of patients living with advanced cancer, *Death Studies*, 36: 360-390.

Noblit, G.W. and Hare, R.D. (1988) *Meta ethnography: Synthesizing qualitative studies*. Newbury Park, CA: Sage.

Ohlen, J., Gustafsson, C.W. & Friberg, F. (2013) Making sense of palliative treatment. Its significance to cancer care communication and information provision, *Cancer Nursing*, 36(4): 265-273.

Paterson, B.L., Thorne, S.E., Canam, C. and Jillings, C. (2001) *Meta-study of qualitative health research. A practical guide to meta-analysis and meta-synthesis*. Thousand Oakes, CA: Sage.

Philip, J., Collins, A., Brand, C.A., Moore, G., Lethborg, C., Sundararaj, V., Murphy, M.A. & Gold, M. (2014) "I'm just waiting...": An exploration of the experience of living and dying with primary malignant glioma, *Support Care Cancer*, 22: 389-397.

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

Refsgaard, B. and Frederiksen, K. (2013) Illness-related emotional experiences of patients living with incurable lung cancer. A qualitative metasynthesis, *Cancer Nursing*, 36(3): 221-228.

Saeteren, B., Lindstrom & Naden, D. (2010) Latching on to life: Living in the area of tension between the possibility of life and the necessity of death, *Journal of Clinical Nursing*, 20: 811-818.

Sandelowski, M. and Barroso, M. (2007) *Handbook for Synthesizing Qualitative Research*. New York: Springer.

Sandelowski, M., Docherty, S. and Emden, C. (1997) Qualitative metasynthesis: Issues and techniques, *Research in Nursing & Health*, 20: 365-71.

- Shelgrove, S. and Liossi, C. (2013) Living with chronic back pain: a metasynthesis of qualitative research, *Chronic Illness*, 9(4): 283-301.
- Siegel, D.J. (2007) *The Mindful Brain: Reflection and Attunement in the Cultivation of Well-being*. New York: W.W. Norton & Company.
- Sjovall, K., Gunnars, B., Olsson, H. & Thome, B. (2010) Experiences of living with advanced colorectal cancer from two perspectives- inside and outside, *European Journal of Oncology Nursing*, <http://dx.doi.org/10.1016/j.ejon.2010.11.004>
- Sivell, S., Prout, H., Hopewell-Kelly, N., Baillie, J., Byrne, A., Edwards, M., Harrop, E., Noble, S., Sampson, C. and Nelson, A, (2015) Considerations and recommendations for conducting qualitative research interviews with palliative and end-of-life care patients in the home setting: a consensus paper, *BMJ Supportive & Palliative Care*, doi: 10.1136/bmjspcare-2015-000892
- Smith, J.A., Flowers, P. and Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.
- Stapleton, S. & Pattison, N. (2014) The lived experience of men with advanced cancer in relation to their perceptions of masculinity: A qualitative phenomenological study, *Journal of Clinical Nursing*, 24: 1069-1078
- Sterckx, W., Colbrandt, A., Dierckx de Caterlé, Van den Heede, K., Decruyenaere, M., Borgenon, S., Mees, A. and Clement, P. (2013) The impact of high-grade glioma on everyday life: A systematic review from the patient's and care-giver's perspective, *European Journal of Oncological Nursing*, 17: 107-117.
- Tarakeshwar, N., Vanderwerker, L.C., Paulk, E., Pearce, M.J., Kasl, S.V. & Prigerson, H.G. (2006) Religious coping is associated with the quality of life of patients with advanced cancer, *Journal of Palliative Medicine*, 9(3): 646–657. doi: 10.1089/jpm.2006.9.646

Thorne, S.E. (2015) Qualitative metasynthesis: A technical exercise or a source of new knowledge ?, *Psycho-Oncology*, 24: 1347-8.

Van der Kolk, B.A. and McFarlane, A.C. (2000) Trauma- ein schwarzes Loch. In: B.A. van der Kolk, A.C. McFarlane & L. Weisaeth (Hrsg.) *Traumatic Stress: Grundlagen und Behandlungsansätze*. Paderborn: Junfermann.

Weed, M. (2008) A potential method for the interpretive synthesis of qualitative research: Issues in the development of 'meta-interpretation', *International Journal of Social Research Methodology*, 11(1): 13-28.

Wiik, G.B., Devik, S. & Hellzen, O. (2011) Don't become a burden and don't complain: A case study of older persons suffering from incurable cancer and living alone in rural areas, *Nursing Reports*, 1:e3, pp. 7-14.

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

Willig, C. (2015) "My bus is here": A phenomenological exploration of 'living with dying', *Health Psychology*, 34(4): 417-25.

Willig, C. & Wirth, L. (under review) Liminality as a dimension of the experience of living with terminal cancer

Willis, K., Lewis, S., Ng, F. and Wilson, L. (2015) The experience of living with metastatic breast cancer- a review of the literature, *Health Care for Women International*, 36: 514-542.