

# An interpretative phenomenological analysis exploring the lived experience of individuals dying from terminal cancer in Ireland

KARA MCTIERNAN H.DIP.PSYCH., M.PSYCH.SC., AND MICHAEL O'CONNELL, PH.D.

School of Psychology, University College Dublin, Dublin, Ireland

(RECEIVED January 24, 2014; ACCEPTED February 19, 2014)

## ABSTRACT

*Objective:* The experience of living with dying has attracted limited research. We utilized interpretive phenomenological analysis to explore the lived experience of individuals with terminal cancer receiving palliative care in Ireland.

*Method:* Participants were purposely selected from public interviews that had been conducted between 2006 and 2011. The study included the accounts of eight participants ( $N = 8$ ; six females and two males) with a diagnosis of terminal cancer. Participant ages ranged from 36 to 68 years.

*Results:* Three master themes emerged from the analysis: the personal impact of diagnosis, the struggle in adjusting to change, and dying in context. The results revealed that participants were still living while simultaneously dying. Interestingly, participants did not ascribe new meaning to their lives. The terminal illness was understood within the framework of the life that had existed before diagnosis. They strove to maintain their normal routines and continued to undertake meaningful activities. Management of unfinished business and creation of a legacy were salient tasks. Social withdrawal was not present; rather, participants engaged in emotional labor to sustain valued roles. However, we found that within the public domain there is a paucity of education and discourse supporting individuals at the end of life. The hospice was noted as an important external resource. Each participant experienced a unique dying process that reflected their context.

*Significance of Results:* Healthcare professionals need to recognize the subjectivity of the dying process. Dying individuals require support and options to maintain their personhood.

**KEYWORDS:** Living/dying, Terminal cancer, Ireland, Interpretive phenomenological analysis

## INTRODUCTION

Cancer accounts for more than 8,500 deaths annually in Ireland (Irish Cancer Society, 2013). Medical advances have lengthened the time between diagnosis and death, which has resulted in individuals presenting with multiple comorbidities (Nissim et al., 2012). A range of psychological constructs have been posited to explain the dying process (Kastenbaum, 2000). Kübler-Ross (1969) postulated that dying individuals

pass through the stages of denial, anger, bargaining, depression, and acceptance. However, it has been argued that this undermines individual coping and pathologizes individuals who do not respond in a sequential manner (Corr et al., 1999; Wright, 2003). Clinical evidence suggests that individuals oscillate between emotions (Copp, 1998). Pattison's framework (1977) holds that with a terminal diagnosis the living–dying interval emerges with acute crises, chronic, and terminal phases, while Corr's (1991) model considers the completion of tasks within physical, psychological, social, and spiritual domains. It has been suggested that psychological frameworks have minimized dimensions of well-being, with

Address correspondence and reprint requests to: Kara McTiernan, School of Psychology, Newman Building, University College Dublin, Belfield, Dublin 4, Ireland. E-mail: [karamctiernan@gmail.com](mailto:karamctiernan@gmail.com)

research prioritizing fear of death over acceptance (Wong & Tomer, 2011). With the exception of Corr (1991) and Copp (1996), physical dimensions of dying have also been neglected (Kastenbaum, 2000). Scholars wonder if a theory of dying is required or if it relates to other experiences involving separation (Corr et al., 1999). Some theories have had a broad focus rather than providing insights into the individual's dying experience (Nissim et al., 2012).

Cancer in Western society is the most feared of all illnesses, and lifestyle choices are implicated in its development (Fife & Wright, 2000; Carlson et al., 2011). Public discourses construct cancer as a solvable problem with military metaphors utilized to instruct patients to engage in treatment (Willig, 2009). Positive thinking can obstruct expressions of anger, grief, and planning (McCreddie et al., 2010; Willig, 2011). Perceptions that a person is dying may lead to changes in interactions, such as the withdrawal of others, a process that Sudnow (1967) calls "social death." According to Talwar et al. (2011), personal death is beyond comprehension. While humans can intellectually accept death, they cannot feel it. Conversely, terror management theory holds that individuals are aware of their mortality. This induces death anxiety, which is managed through cultural worldviews (Greenberg & Arndt, 2011). In the West, evading death has become the meaning of life, as death anxiety is suppressed through various routines (Willmott, 2000; Byock, 2002). Kastenbaum (1996) contends that humans are not inherently anxious about death; rather, this is learned through socialization. The surge in debates concerning issues such as euthanasia may indicate emerging changes in public perceptions (Silverman, 2004).

## Diagnosis

With a terminal diagnosis, the individual becomes conscious of impending death (Coyle, 2004). This can cause a psychological disruption resulting in shock, which alters the individual's sense of security (Bury, 1982; Bingley et al., 2006). Relief may also prevail as a complaint is validated (Willig, 2011). Individuals become immersed in uncertainty (McKechnie et al., 2007). They shift from habitual behavior as they attempt to understand and import meaning onto the diagnosis (Kuhl, 2002; Coyle, 2006). They reflect on their identity and lifestyle choices, and consider life assumptions including the future, relationships, and control (Brennan & Moynihan, 2008). A life review can restore temporal order and meaning but can also activate unresolved issues (Kearney, 1996; Carlick & Biley, 2004). Yedidia and MacGregor (2001) stipulate that individuals integrate diagnosis into their life perspective. Others contend that mean-

ing reconstruction transforms worldviews (Carlick & Biley, 2004).

## Responses to a Terminal Diagnosis

There are varying postulations as to whether individuals respond to a terminal diagnosis with similar methods of coping or if individual differences are more marked. However, there is consensus that most individuals strive to maintain control and normality (Reeve et al., 2010; Krikorian et al., 2012). They set goals and involve themselves in completing unfinished business (Nissim et al., 2012). Legacies facilitate the partial dissolution of ego boundaries and establish after-death identities (Kearney, 1996; Exley, 1999). According to McGrath (2003), connection with family, friends, and work is as vital spiritually as transcendent meaning making. The family can support individuals to continue living (Coyle, 2006). However, relatives may avoid discussing death in order to protect each other (McCarthy et al., 2010a). This contributes to fear and isolation (Kuhl, 2002).

Marrone (1999) asserts that the ability to ascribe meaning to a changed world is more significant than the content by which that need is filled. Finding meaning while dying reduces suffering (Chan et al., 2007; Wrubel et al., 2009). Certain individuals rate their quality of life as higher after diagnosis (Kuhl, 2002). However, most individuals experience some suffering and grieve losses (McKechnie et al., 2007). A predominate pain when dying is caused by separation from loved ones (Grumann & Spiegel, 2003). Individuals also report anxiety regarding the impact of their death on others, including leaving dependent children (Bell & Ristovski-Slij, 2011). Concern for others can result in underreporting pain and feeling pressurized to undergo treatment (Quinlan & O'Neill, 2009). Intense suffering ensues when dying undermines everything that is meaningful to the individual (Cassell, 2004). This can include changes in physicality and fear of burdening others, and loss of control, roles, or goals (Chochinov & Cann, 2005; Krikorian et al., 2012). The demoralization syndrome arises when individuals experience feelings of hopelessness, meaninglessness, and diminished self-esteem. It significantly correlates with a desire for a hastened death (Kissane et al., 2001). Persistent hopelessness is not a normal feature of dying (McCarthy et al., 2010a).

## External Resources

External resources support individuals and their families. These include access to treatments, psycho-oncology teams, and palliative care professionals. The Health Service Executive recognizes the differing

requirements of individuals and aims to provide such interventions on the basis of assessed individual needs (Health Service Executive, 2013). In reality, though, such resources are unevenly distributed throughout the country (Murray, 2013). Treatments such as chemotherapy and radium invariably induce such side effects as fatigue, physical pain, and distress, as well as financial concerns (Hubbard & Forbat, 2012). However, they can lengthen lifespan, and certain individuals may engage in clinical trials for altruistic reasons (Nissim et al., 2012). If treatment is discontinued, patients need their physical pain managed, which is imperative for maintaining quality of life (Kulh, 2002). They also require that their existential concerns be addressed (Breitbart, 2006). While hospitals are in the process of adapting a hospice philosophy, they are underresourced (McKeown et al., 2010).

The hospice responds to an individual's holistic needs, which is pivotal to supporting quality of life (Levine & Karger, 2004; Murray, 2013). A hospice ideal is a death that individuals choose (Farber et al., 2004). A range of interventions are utilized to relieve pain (Kuhl, 2002). Surface interventions target physical, emotional, and social distress at the conscious level (Kearney, 1996). In-depth interventions reconnect individuals with meaningful aspects of life (Kearney, 1996). Individuals may pursue writing, music, life review, psychotherapy, and therapeutic touch (Chochinov & Cann, 2005). When individuals engage with their inner process, the meaning of the illness becomes less overwhelming (McSherry, 2011).

If interpersonal and internal conflicts remain, uncontrolled pain may persist (Byock, 1996). Professionals bear witness to this, and sedation may be used, which can unintentionally hasten death (Farber et al., 2004; Balducci, 2012). Despite public fears concerning the hospice, service users report that it is empowering (Broom & Cavenagh, 2011). Social support can also maintain self-esteem and buffer against death anxiety (Mikulincer et al., 2003). Such external resources increase in importance in instances where family support is absent (Brennan & Moynihan, 2008). However, where relatives are present, excessive intervention can undermine the support of primary carers (Brennan & Moynihan, 2008).

An individual's response to dying reflects their context, including their mental maps of the self, the world, and external supports (Brennan & Moynihan, 2008). Qualitative research captures varying perceptions of dying among individuals with a terminal illness (Yedidia & MacGregor, 2001; Wright, 2003; Coyle, 2006). Nonetheless, there is a dearth of research in this area (Armstrong-Coster, 2004). The current study explored how individuals with term-

inal cancer make sense of their dying experience within an Irish context.

## METHOD

The ethics board at University College Dublin approved our study. Convenience sampling was applied. The Broadcaster RTE granted permission to utilize audio-recorded public interviews from the programs "Live-line," "Marian Finucane," "The Hospice," "The Late Late Show," and "Would You Believe" ( $n = 7$ ). Another interview was accessed through *The Irish Times*.

Six interviewers completed interviews within hospice or residential settings from 2006 to 2011. Their experience ranged from 28 to 37 years. Three participants were interviewed on more than one occasion. One participant was interviewed a second time in a broadcasting studio. All interviews were semistructured. There were eight participants—six females and two males—all of whom had terminal cancer. Participant ages ranged from 36 to 68 years. They were residents of Ireland and receiving palliative care. Participants were alert, cognizant of their diagnosis, and voluntarily participated to share their experience.

Interpretative phenomenological analysis (IPA) explored how individuals made sense of their lived experiences (Smith & Osborn, 2003). This approach privileges the perspective of the participant, yet recognizes that the researcher's conceptualizations are required to interpret an individual's personal world (Smith et al., 2009). The interviews were transcribed verbatim. As outlined by Smith and Osborn (2003): (a) each transcript was read independently numerous times, (b) preliminary themes were identified, (c) themes were interrelated and clustered, and (d) shared themes were organized across transcripts. The emerging themes captured the quality of participants' experiences rather than arising from frequency in transcripts (Willig, 2001). Two psychology postgraduates audited the transcripts and confirmed the themes. The findings were also compared with similar research.

## RESULTS

### Demographics

Table 1 presents the demographics of the sample.

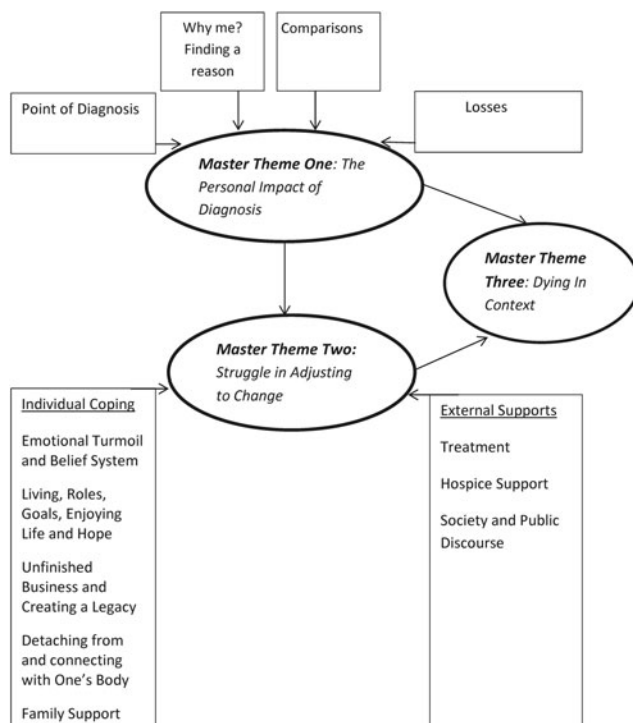
### Master Themes

Figure 1 illustrates the three master themes that emerged from the analysis: the personal impact of diagnosis, the struggle in adjusting to change, and dying in context.

**Table 1.** Summary of participants' demographics (N=8).

Variable		N%
<b>Gender</b>	Male	2 (25%)
	Female	6 (75%)
<b>Age</b>	≤25*	0 (0%)
	19–40	3 (37.5%)
	40–65	2 (25%)
	≥65	3 (37.5%)
<b>Ethnicity</b>	Irish	8 (100%)
	Home	4 (50%)
<b>Interview Setting</b>	Hospice	1 (12.5%)
	Both Home and Hospice	2 (25%)
	Other	1 (12.5%)
		1 (12.5%)
<b>Death After Final Interview</b>	≤1 week	2 (25%)
	≤1 Month	3 (37.5%)
	≤2 months	1 (12.5%)
	≤7 months	1 (12.5%)
	≤14 months	1 (12.5%)
<b>Year of Death</b>	2011	1 (12.5%)
	2008	1 (12.5%)
	2007	2 (25%)
	2006	4 (50%)

\*Age divisions align with Erikson's Psychosocial Stages (1950).



**Fig. 1.** Thematic map, illustrating three master themes. Adapted from the thematic map framework provided by Braun and Clarke (2006).

## The Personal Impact of Diagnosis

### Point of Diagnosis

Diagnosis was captured as a distinctive event resulting in shock, articulated by Levina thus: "If you had of hit me in the face it would have been easier." Each participant referred to the doctor in the third person. Mary explained how when she "heard the word *terminal*" she sought information, and "He said, well, I have the information on me now if you want to know, but I think that you should have someone with you." Mary would have preferred to have been informed independently. Levina explained how her doctor "just turned, and she says to me, well, Levina, she says, there is no easy way to say this, she says, you have a tumor."

### Why me?

The participants searched for reasons for the cancer and reflected on their identity. For instance, Emer described herself as "a nurse" and "a good mother." Mary articulated, "there has to be a reason." Some considered lifestyle choices. Nuala attributed illness to smoking, whereas Levina queried, "How can my liver be in such a bad way? I don't drink; I don't smoke." Others engaged in social comparisons. John reflected on how numerous people receive such diagnoses: "I sit here saying, Jesus, sure, why not me." Conversely, Beverley wondered, "Why can't it be somebody else?"

### Comparisons

The participants compared the diagnosis to past struggles. Bill explained, "A terminal illness is, eh, not as bad as the depths of clinical depression." He elucidated, "I don't think that I have ever been happier." John considered his current situation as more favorable than the time when he contemplated suicide. He reported improved well-being following diagnosis, which he attributed to pain management. Doon also described how prior to diagnosis she was "emotionally numb" and how following it she had connected with her feelings.

### Losses

Participants reported losses. For instance, Beverley explained how her children "want you to do things with them and you can't." John said goodbye to his home and commented, "that was a sad auld moment." Future goals were also relinquished. For instance, Doon was "unspeakably sad" with the realization that she "would never know" her grandchildren. Emer and Levina relinquished travel plans with their husbands.



## The Struggle in Adjusting to Change

The participants drew on individual coping and external resources in adjusting to change.

### Individual Coping

#### *Emotional Turmoil and Belief System*

As captured by Emer, participants experienced a “myriad of emotions,” which could conflict with how they wanted to be. Levina was “determined to fight” cancer while reporting to be in denial. Beverley also denied being ill while arranging her funeral. Bill expressed happiness and later reported “a dent in the positiveness of my existence.” John hoped for a miracle while accepting death.

Each participant extrapolated from their beliefs. Six participants drew on religious beliefs, which were fluid. For example, Beverley maintained, “If there was a God out there, he wouldn’t do this,” yet later she prayed, “Tomorrow, please God, I will be even stronger.” John believed that “Healing is finally greater than the illness.” Emer believed that “We all have inner resources that we don’t tap into everyday, but when your back is against the wall, you do.” Bill articulated, “There has to be some assistance within our psyche which allows us out of the world.”

#### *Living*

Participants were living not dying, captured by Doon thus: “I am living my life, not my death.” They coped by living day to day. Focusing on the present facilitated appreciation of what they found meaningful. For Bill, this included music. Beverley appreciated that “I have been here to see my son go to school.” Only Nuala considered herself to be “actually dying.”

Participants held multiple roles, which they worked to maintain. Doon instructed friends, “Don’t treat me any differently.” Emer continued her parenting role and highlighted, “I don’t know when this journey is going to end, but in the meantime I think it’s nice that families write letters to their kids.”

The participants set goals. Beverley had a “wish list,” and Doon established “a plan of life goals.” Five participants organized trips to spend time with others or for other meaningful reasons. Beverley commented, “Every time I go away, when I come back I seem to get sick,” implying that trips were a form of escapism. Participants continued to enjoy life. Mary enjoyed “having a laugh” with her sister. John laughed as he recalled stories. Doon viewed humor as a “valuable technique allowing all sorts of things be dealt with.”

Each participant expressed hope, which manifested in various forms. Levina hoped that “God leaves me another twenty or thirty years.” Mary hoped for an afterlife. Bill articulated how he hoped to die.

### *Unfinished Business and Creating a Legacy*

Participants managed unfinished business. Doon ended her marriage. Three participants reported the need to say goodbye. Through counseling Mary resolved “issues” concerning her daughter. Three participants had unresolved issues that contributed to suffering. Bill explained, “I have regrets in things that I did wrong, which I don’t have the opportunity to put right, and I wish to goodness I had.” Levina was grieving for her father and felt that she couldn’t die since her family needed her. Beverley too was “worried” about leaving her children.

Three participants reported having no unfinished business. John explained, “I got a great run at life. I’m sixty-eight years of age.” Doon declared, “I’ve achieved everything that I wanted to achieve.” Emer accepted death, believing that her children would “be alright” and that “you can’t ask for anymore.”

In addition to completing public interviews, five participants reported creating other legacies. Emer prepared “gifts” for her children, recorded a film, and wrote journals—activities that were “therapeutic.” Beverley created memories with her children and mindfully purchased a cemetery seat. Doon created a DVD for her children of photographs of their childhoods. Levina did not create a legacy. She couldn’t write to her son because she perceived it as “bad enough” for him to cope with her death.

### *Detaching and Connecting with One’s Body*

Participants separated their identity from the cancer and their bodies. John alluded to “cancer of the liver.” Doon considered, “once this cancer goes wild.” Emer drew on a metaphor that the disease was “galloping ahead” and how at times “you just wanted to curl up and just say, ‘I have had enough.’” Reconnection with their bodies facilitated the realization of imminent death. Beverley reconsidered fighting as, “Seriously, see me, I am going downhill, so that’s that.” Levina reported not perceiving physical changes that reinforced her belief of being “one of the lucky ones.”

### *Family Support*

Each participant highlighted the importance of or the desire for family support. Beverley explained, “The fight in me is my children and my husband.” Levina emphasized, “At a time like this, I think you need your family.” Bill requested relatives to be at his deathbed. Participants acknowledged that dying affected their family, captured by Emer thus: “It was hard on the family.” Levina explained, “I take my vengeance out at times, and God help Mick

and the kids, they are the ones who get it." In contrast to Emer, Levina did not discuss illness with her children.

## External Resources

### *Treatment*

Six participants discussed completing chemotherapy to fight cancer. John described how the doctors were "putting up a real old fight; do you know they are giving me the chemo." Levina explained, "As it is going to keep you alive, that is the added bonus and you have to go through it." Levina and John believed that a "miracle" could happen. Nuala rejected chemotherapy: "There is no chance of a cure." Participants detailed treatment side effects. Doon highlighted fatigue. Levina explained, "You are like a pin cushion" and the "chemo does get in on you." Emer concurred that "All the treatments, it just gets to you." Emer discussed losing her hair three times. Conversely, Levina retained her hair and self-image.

### *Hospice*

Pain management was salient to each participant. Bill considered pain as his "one fear," and its control through the hospice care was "a great consolation." Emer "embraced" hospice home care "as they look after your symptoms." The hospice reportedly was empowering, cared for a range of needs, and improved quality of life. Mary described it as "absolutely brilliant, and there is nothing else that gives you reason to get up early." Levina highlighted, "I wouldn't be here today if it wasn't for them." She emphasized that professionals phoned regularly inquiring, "Is there anything I can do?" Mary explained, "You come in, have a chat, a cup of coffee, and then you can have alternative therapy." The hospice also supported families. Levina highlighted how the social worker "has been excellent with the kids." Mary found hospice counselors as helpful for issues "you are not able to solve yourself." Six participants embarked on new endeavors, with three undertaking alternative therapies.

### *Society*

Participants received support from friends. Doon processed her diagnosis "by talking to my friends." John noted how he was "gathering all that Christian medicine" from his neighbors. Participants highlighted a dearth of societal discourse and education concerning terminal illness. Doon commented that acquaintances crossed the street to avoid her. Levina underlined how "It isn't until it hits in your own home, Pat, that you actually realize what the hospice does." Emer emphasized the paucity of support

within schools as her daughter would say, "Will you put on your wig when you collect me from the school." Doon explained how wigs "make other people feel more comfortable." Nuala commented that "People seem frightened or repulsed, and that is why I went and got a wig." Despite this, participants drew on the artifacts of culture. For instance, John described dying as an "endgame now in the real Beckett sense," while Mary listened to the radio during her illness.

## Dying in Context

Each participant was living with uncertainty, captured by Beverley thus: "I don't know how long I have." The length of the illness facilitated coping. Emer revealed, "I have had extra time because initially my diagnosis was two to three years." Beverley disclosed, "I have put up a fight for so many years; now this year, now, there is no more fight left." Doon stated, "Now over six years from my diagnosis, knowing that I will die from cancer." Conversely, Levina was not afforded time to adjust. Upon diagnosis, her doctor informed her, "If you had come to me a year ago, I would have given you a year to live."

Each participant's dying experience was unique. They attributed their own meaning to it. Bill viewed it as another life struggle and expected "an average result from an average life." Emer perceived dying as "Everyone has a cross in life to bear and, er, maybe this is my cross." John viewed it as a "transformation." Mary believed it would lead to an afterlife. Doon perceived dying as a quest. Nuala lost quality of life and used the time to say goodbye. Beverley fought dying and summoned characteristic inner strength. Levina was unable to attribute meaning to dying but chose "to fight" as if "God is going to take me; let him take me the way I am."

## DISCUSSION AND CONCLUSION

The accounts support findings that diagnosis is a biographical disruption resulting in shock (Bury, 1982; Coyle, 2004; Brennan & Moynihan, 2008). However, for individuals who had encountered adversity, diagnosis was less traumatic compared to previous life struggles. Hardship theory stipulates that such individuals have developed resources to manage illness (Atkinson & Rubinelli, 2012). Participants were susceptible to interactions with doctors. Third-person pronouns can function to psychologically distance individuals from events (Fujita et al., 2010).

Our findings align with research where terminal diagnosis initiates a life review (Murray, 1999; Coyle, 2006; Brennan & Moynihan, 2008; McSherry, 2011); participants searched to find a reason for the illness. As stipulated by Coyle (2006) and Willig (2009), this

involved reflecting on identities and lifestyles. However, in contrast to Willig's (2011) assertions, only one participant reported responsibility for the illness and attributed it to smoking. Levina was unable to find a reason. Murray (1999) notes this impedes individuals from processing the diagnosis and exacerbates suffering. Three participants reported improved quality of life following diagnosis, as per Kuhl's (2002) findings. Conversely, Nuala reported reduced quality of life. As shown elsewhere, participants experienced losses, some of which were abstract (Coyle, 2006; McKechnie et al., 2007).

The participants presented as complicated individuals experiencing multiple emotions and internal conflicts. This resonates with other research findings (Levine & Karger, 2004; Kreuter et al., 2007). Participants utilized numerous methods of coping. As noted by Yedidia and MacGregor (2001) and Grumann and Spiegel (2003), this included drawing on beliefs, which were fluid. Certain participants stated that they did not believe in God, yet later utilized religious discourse. Six participants drew on Catholicism, which Quinlan (2009) notes influences how Irish people negotiate death. Religious beliefs can construct meaning and reduce suffering (Breitbart, 2002). In variance to suggestions by Neimeyer et al. (2011), religion did not promote fear of death. Three participants believed in their self-efficacy, which Bandura (1989) links with improved coping. Coyle (2006) contends that emotional turmoil is lessened when individuals develop a philosophical approach to dying.

Participants focused on living, not dying, which is congruent with other findings (Benzein et al., 2001; Kuhl, 2002; Nissim et al., 2012). They strove to maintain roles, as found by McGrath (2003). They perceived themselves foremost within roles they always held, rather than as patients. This contrasts with postulations that dying individuals establish new identities (Carlick & Biley, 2004). The participants illustrated a multiplicity of self by holding numerous roles simultaneously. At variance with Charmaz's (1994) research, they were able to fulfill their roles. However, as noted by McKechnie (2007), diminished energy did change how participants conducted duties. Clarke and Black (2005) noted that sustaining valued roles even in a modified form contributes to quality of life. Aligning with previous research, participants set goals that included organizing trips (Nissim et al., 2012). Such tasks maintain self-esteem, protect against death anxiety, and facilitate attending to controllable aspects of life (Greenberg & Arndt, 2002; McSherry, 2011). Humor was also an important coping mechanism. It can enable dying individuals to discuss sensitive issues (Exley & Letherby, 2001).

Concentration on the present facilitated participants to recognize what they found meaningful. According to Arndt et al. (2002), consciousness of personal death raises awareness of what is important to an individual. Certain participants expressed gratitude. McSherry (2011) found that cognizance of mortality induces appreciation. Each participant retained hope. Even when dying, the capacity for hope remained (Clayton et al., 2008).

Completing unfinished business was indeed an important task (Wilson, 2007; McSherry, 2011). As denoted by Pinquart (2005) age influenced whether participants were satisfied that they had completed life tasks. Three participants had unresolved family issues, which contributed to emotional suffering. McSherry (2011) noted that dying with regrets and unsuccessful goal attainment induces pain. Kearney (1996) emphasized that to process pain dying individuals must shift from a cognitive understanding to connecting with their dying experience. Certain participants reported suffering from knowing they would not complete their roles as mothers. Yedidia and MacGregor (2001) noted that individuals can be reluctant to relinquish life when desiring to complete certain experiences. Parenting with a terminal illness crystallizes cultural expectations that mothers are central to raising children, which exerts pressure to maintain a normal family life (Bell & Ristovski-Slijepcevic, 2011).

Participants created legacies that, as found by Coyle (2006), were unique and encompassed personal values. Certain participants demonstrated that they were caring parents. They provided emotional comfort to others while establishing after-death identities. Emotional labor did not undermine the authenticity of the person; rather, it reinforced identities (Exley & Letherby, 2001). With the exception of Levina, participants separated their identity from their bodies. As Exley (1999) noted, this is necessary to create after-death identities. They later reconnected with their body. Declining body function will lead to death acceptance (Kearney, 1996). Levina did not create a family legacy. She reported not perceiving physical changes and believed that life would continue. Contrary to other findings (Quinlan & O'Neill, 2009), relatives did not impede the dying process, which may reflect the presence of palliative care.

With regards to the use of external resources, treatment choices centered on cure, hope, quality, and lengthening of life. Coyle (2006) found that individuals undertake a cost-benefit analysis when making treatment decisions. Those who continued treatment desired to increase their lifespan, whereas those who discontinued it were resigned to dying soon. As noted by Camus (2009), treatment was described using military metaphors. This could reflect

terror management theory and an imperative to survive (Arndt et al., 2002). Participants also highlighted treatment side effects. In line with previous research, pain control was paramount. The hospice was reported as important in managing pain, and it did indeed improve quality of life (Broom & Cavenagh, 2011). Seven participants undertook new activities. Tasks can support a sense of control (Reeve et al., 2010). Four participants engaged in alternative therapies. This enables a transition from cure to healing (Broom & Tovey, 2007). Participants who planned home deaths had medical backgrounds.

The importance of social support was highlighted. As noted by McCarthy et al. (2010b), within Irish society there was reportedly a dearth of discourse and education concerning dying. This aligns with Sudnow's (1967) concept of social death. However, participants did not withdraw. They drew on cultural artifacts and purchased wigs to ease tension during interactions. This resonates with Goffman's (1990) concept of "covering." It also challenges Howarth's (1998) assertion that dying involves disengagement. Public interviews of middle-aged individuals were readily available. This could reflect Blauner's (2006) contention that such deaths cause the greatest social vacuum. There was a deficiency of male interviewees. Men, in contrast to women, have an elevated risk of dying from cancer, which is linked to their reluctance to broach medical issues (Clarke et al., 2013).

Participants were immersed in uncertainty. This concurs with a plethora of research (Levine & Karger, 2004; McKechnie et al., 2007; Brennan & Moynihan, 2008). As noted by Zimmermann (2012), time facilitated coping. Seven participants attributed meaning to their dying. Ultimately, as reported elsewhere, each individual's dying experience reflected their coping, external supports, and the context of their life (Kearney, 1996; Yedidia & MacGregor, 2001; Levine & Karger, 2004; Coyle, 2006; McSherry, 2011).

The findings underscore that dying cannot be understood in universal stages, as the individual's context influences the process. Participants had differing methods of coping and distinctively used external resources. McKiernan et al. (2013) highlighted how coping is mediated by numerous factors, including personal and environmental resources. Dying did not instigate the emergence of new meaning to life. Social constructs such as motherhood impacted on experiences. Such dimensions of identity are unaccounted for in psychological theories. Professionals need to support individuals to authentically choose how to die (Farber et al., 2004). Aiding with unfinished business, facilitating life review, goal setting, and comparisons can alleviate pain, yet must be considered in context.

Our findings are not generalizable and arise from a specific context (Carlick & Biley, 2004). The analysis is only one interpretation (Smith et al., 1999). Participants died within 14 months following the final interview. If interviews had been closer to the time of death, we may have obtained different results. Interpretative phenomenological analysis assumes that language provides the means to capture experiences (Willig, 2001). However, interviews are limited in obtaining embodied emotions, and intense pain impedes communication (Reeve et al., 2010). No participant desired a hastened death. Such contexts were not explored. The participants' identities were known, which can induce legitimization of positions.

Future research could consider how place of death relates to educational and socioeconomic status, how the family and public perceive dying, psychotherapeutic interventions, male experiences, transcendence and emotional labor at the end of life, and whether individuals' perceptions of dying alter with contextual changes.

Death is the moment when governance over human existence finds its outer limit (Giddens, 1991). While it cannot be controlled, individuals choose their reactions (Silverman, 2004). Our research illuminates the importance of discovering what is meaningful to us and managing unfinished business long before death (Kuhl, 2002). People are unique, with particular individual and external resources. Consequently, each person marks their dying as their own (Kaplan, 2005). The provision of care reflects broader social values, which are affirmed or weakened (O'Shea et al., 2008). The Department of Health is currently restricting palliative care resources (Health Service Executive, 2013). If society holds to the value of freedom, it is imperative that it support individuals to die authentically while simultaneously meeting their human needs for support, meaning, and transcendence (Cassell, 2004). This has the power to maintain the integrity of the person until the end.

## ACKNOWLEDGMENTS

Thanks to Ms. Vicky Moran and Mr. John Glendon, Archive Researchers at RTE, for granting permission to draw upon the interviews. Thanks also to Mr. Eoin McVey, managing editor at *The Irish Times*.

## REFERENCES

- Armstrong-Coster, A. (2004). *Living and dying with cancer*. Cambridge: Cambridge University Press.
- Arndt, J., Greenberg, J. & Cook, A. (2002). Mortality salience and the spreading activation of worldview-relevant constructs: Exploring the cognitive architecture



- of terror management. *Journal of Experimental Psychology-General*, 131(3), 307–323.
- Atkinson, S. & Rubinelli, S. (2012). Narrative in cancer research and policy: Voice, knowledge and context. *Critical Reviews in Oncology/Hematology*, 84, 11–16.
- Balducci, L. (2012). Death and dying: What the patient wants. *Annals of Oncology*, 23(3), 56–61.
- Bandura, A. (1989). Regulation of cognitive process through perceived self-efficacy. *Developmental Psychology*, 25(5), 729–735.
- Bell, K. & Ristovski-Slijepcevic, S. (2011). Metastatic cancer and mothering: Being a mother in the face of a contracted future. *Medical Anthropology*, 30(6), 629–649.
- Benzein, E., Norberg, A. & Saveman, B.I. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine*, 15(2), 117–126.
- Bingley, A.F., McDermott, E., Thomas, C., et al. (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.
- Blauner, R. (2006). Death and the social structure. In *Death, dying and bereavement: Major themes in health and social welfare*. K. Doka (ed.), pp. 19–35. London: Routledge.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Breitbart, W. (2002). Spirituality and meaning in supportive care: Spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. *Supportive Care in Cancer*, 10(4), 272–280.
- Breitbart, W. (2006). The goals of palliative care: Beyond symptom control. *Palliative & Supportive Care*, 4(1), 1–2.
- Brennan, J. & Moynihan, C. (2008). *Cancer in context: A practical guide to supportive care*. New York: Oxford University Press.
- Byock, I. (2002). The meaning and value of death. *Journal of Palliative Medicine*, 5(2), 279–288.
- Broom, A. & Cavenagh, J. (2011). On the meanings and experiences of living and dying in a hospice. *Health*, 15(1), 96–111.
- Broom, A. & Tovey, P. (2007). The dialectical tension between individuation and depersonalization in cancer patients' mediation of complementary, alternative and biomedical cancer treatments. *Sociology*, 41(6), 1021–1039.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167–182.
- Byock, I.R. (1996). The nature of suffering and the nature of opportunity at the end of life. *Clinics in Geriatric Medicine*, 12(2), 237–252.
- Camus, J.T.W. (2009). Metaphors of cancer in scientific popularization articles in the British press. *Discourse Studies*, 11(4), 465–495.
- Carlick, A. & Biley, F.C. (2004). Thoughts on the therapeutic use of narrative in the promotion of coping in cancer care. *European Journal of Cancer Care*, 13(4), 308–317.
- Carlson, L., Baker, T. & Halifax, J. (2011). Mindfulness for cancer and terminal illness. In *Mindfulness and acceptance in behavioral medicine: Current theory and practice*. L. McCracken (ed.), pp. 159–186. Oakland, CA: New Harbinger Publications.
- Cassell, E.J. (2004). *The nature of suffering: And the goals of medicine*. New York: Oxford University Press.
- Chan, T.H., Ho, R.T. & Chan, C.L. (2007). Developing an outcome measurement for meaning-making intervention with Chinese cancer patients. *Psycho-Oncology*, 16(9), 843–850.
- Charmaz, K. (1994). Identity dilemmas of chronically ill men. *The Sociological Quarterly*, 35(2), 269–288.
- Chochinov, H.M. & Cann, B.J. (2005). Interventions to enhance the spiritual aspects of dying. *Journal of Palliative Medicine*, 8(1), 103–115.
- Clarke, P. & Black, S.E. (2005). Quality of life following stroke: Negotiating disability, identity and resources. *Journal of Applied Gerontology*, 24(4), 319–336.
- Clarke, N., Sharp, L., O'Leary, E. & Richardson, N. (2013). A report on the excess burden of cancer among men in the Republic of Ireland. Dublin: Irish Cancer Society.
- Clayton, J.M., Hancock, K., Parker, S., et al. (2008). Sustaining hope when communicating with terminally ill patients and their families: A systematic review. *Psycho-Oncology*, 17(7), 641–659.
- Copp, G. (1998). A review of current theories of death and dying. *Journal of Advanced Nursing*, 28(2), 382–390.
- Corr, C.A. (1991). A task-based approach to coping with dying. *Omega: Journal of Death and Dying*, 24(2), 81–94.
- Corr, C.A., Doka, K.J. & Kastenbaum, R. (1999). Dying and its interpreters: A review of selected literature and some comments on the state of the field. *Omega: Journal of Death and Dying*, 39(4), 239–260.
- Coyle, N. (2004). The existential slap a crisis of disclosure. *International Journal of Palliative Nursing*, 10(11), 520–520.
- Coyle, N. (2006). The hard work of living in the face of death. *Journal of Pain and Symptom Management*, 32(3), 266–274.
- Erikson, E. (1950). *Childhood and society*. New York: W.W. Norton & Company.
- Exley, C. (1999). Testaments and memories negotiating after-death identities. *Mortality*, 4(3), 249–267.
- Exley, C. & Letherby, G. (2001). Managing a disrupted life-course: Issues of identity and emotion work. *Health*, 5(1), 112–132.
- Farber, S., Egnew, T. & Farber, A. (2004). What is a respectful death. In *Living with dying: A handbook for end-of-life healthcare practitioners*. J. Berzoff & P.R. Silverman (eds.), pp. 102–127. New York: Columbia University Press.
- Fife, B.L. & Wright, E.R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior*, 41(1), 50–67.
- Fujita, K., Trope, Y. & Liberman, N. (2010). Seeing the big picture: A construal level analysis of self-control. In *Self-control in society, mind, and brain*, R.R. Hassin et al. (eds.), pp. 408–427. New York: Oxford University Press.
- Giddens, A. (1991). *Modernity and self-identity: Self and society in the late modern age*. Cambridge: Polity Press.
- Goffman, E. (1990). *Stigma: Notes on the management of spoiled identity*. New York: Simon and Schuster.
- Greenberg, J. & Arndt, J. (2011). Terror management theory. In *Handbook of theories of social psychology*. P.A. Van Lange et al. (eds.), pp. 398–415. London: Sage Publications.
- Grumann, M.M. & Spiegel, D. (2003). Living in the face of death: Interviews with 12 terminally ill women on home hospice care. *Palliative & Supportive Care*, 1(1), 23–32.
- Health Service Executive (2013). *National service plan*. Retrieved May 1, 2013, from <http://www.hse.ie/eng/services/Publications/corporate/nationaloperationalplan2013.pdf>.

- Howarth, G. (1998). Just live for today: Living, caring, ageing and dying. *Ageing and Society*, 18(6), 673–689.
- Hubbard, G. & Forbat, L. (2012). Cancer as biographical disruption: Constructions of living with cancer. *Supportive Care in Cancer*, 20(9), 2033–2040.
- Irish Cancer Society (2013). *Cancer statistics*. Retrieved May 1, 2013, from <http://www.cancer.ie/about-us/media-centre/cancer-statistics>.
- Kaplan, K.O. (2005). Footprints on the sands of time. *Death Studies*, 29(8), 759–767.
- Kastenbaum, R. (1996). A world without death? First and second thoughts. *Mortality*, 1(1), 111–121.
- Kastenbaum, R. (2000). *The psychology of death*. New York: Springer Publishing Company.
- Kearney, M. (1996). *Mortally wounded: Stories of soul pain, death and healing*. Dublin: Marino Books.
- Kissane, D.W., Clarke, D.M. & Street, A.F. (2001). Demoralization syndrome: A relevant psychiatric diagnosis for palliative care. *Journal of Palliative Care*, 17(1), 12–21.
- Kreuter, M.W., Green, M.C., Cappella, J.N., et al. (2007). Narrative communication in cancer prevention and control: A framework to guide research and application. *Annals of Behavioral Medicine*, 33(3), 221–235.
- Krikorian, A., Limonero, J.T. & Maté, J. (2012). Suffering and distress at the end of life. *Psycho-Oncology*, 21(8), 799–808.
- Kübler-Ross, E. (1969). *On death and dying*. New York: McMillian.
- Kuhl, D. (2002). *What dying people want: Practical wisdom for the end of life*. New York: Public Affairs.
- Levine, A. & Karger, W. (2004). The trajectory of illness. In *Living with dying: A handbook for end-of-life healthcare practitioners*. J. Berzoff & P.R. Silverman (eds.), pp. 273–296. New York: Columbia University Press.
- Marrone, R. (1999). Dying, mourning, and spirituality: A psychological perspective. *Death Studies*, 23(6), 495–519.
- McCarthy, J., Donnelly, M., Dooley, D., et al. (2010a). *The complete ethical framework for end-of-life care*. Dublin: The Irish Hospice Foundation.
- McCarthy, J., Weafer, J. & Loughrey, M. (2010b). Irish views on death and dying: A national survey. *Journal of Medical Ethics*, 36(8), 454–458.
- McCreadie, M., Payne, S. & Froggatt, K. (2010). Ensnared by positivity: A constructivist perspective on being positive in cancer care. *European Journal of Oncology Nursing*, 14(4), 283–290.
- McGrath, P. (2003). Religiosity and the challenge of terminal illness. *Death Studies*, 27(10), 881–899.
- McKechnie, R., MacLeod, R. & Keeling, S. (2007). Facing uncertainty: The lived experience of palliative care. *Palliative & Supportive Care*, 5(3), 255–264.
- McKeown, K., Haase, T., Pratschke, J., et al. (2010). *Dying in hospital in Ireland: An assessment of the quality of care in the last week of life*. Dublin: The Irish Hospice Foundation.
- McKiernan, A., Steggles, S. & Carr, A. (2013). Understanding how people cope with cancer: A review of theories. *The Irish Psychologist*, 39(8), 218–223.
- McSherry, C.B. (2011). The inner life at the end of life. *Journal of Hospice & Palliative Nursing*, 13(2), 112–120.
- Mikulincer, M., Florian, V. & Hirschberger, G. (2003). The existential function of close relationships: Introducing death into the science of love. *Personality and Social Psychology Review*, 7(1), 20–40.
- Murray, E. (2013). *Access to specialist palliative care services and place of death in Ireland*. Dublin: The Irish Hospice Foundation.
- Murray, M. (1999). The storied nature of health and illness. In *Qualitative health psychology: Theories and methods*. M. Murray & K. Chamberlain (eds.), pp. 47–63. London: Sage Publications.
- Neimeyer, R.A., Currier, J.M., Coleman, R., et al. (2011). Confronting suffering and death at the end of life, the impact of religiosity, psychosocial factors, and life regret among hospice patients. *Death Studies*, 35(9), 777–800.
- Nissim, R., Rennie, D., Felming, S., et al. (2012). Goals set in the land of the living/dying: A longitudinal study of patients living with advanced cancer. *Death Studies*, 36(4), 360–390.
- O'Shea, E., Murphy, K., Larkin, P., et al. (2008). *End-of-life care for older people in acute and long stay care settings in Ireland*. Dublin. Hospice Friendly Hospitals Programme and National Council on Ageing and Older People.
- Pattison, E.M. (1977). *The experience of dying*. Englewood Cliffs, NJ: Prentice Hall.
- Pinquart, M., Frohlich, C., Sibereisen, R.K., et al. (2005). Death acceptance in cancer patients. *Omega: Journal of Death and Dying*, 52(3), 217–235.
- Quinlan, C. (2009). Media discourses on autonomy in dying and death. *Irish Communications Review*, 11, 37–49.
- Quinlan, C. & O'Neill, C. (2009). *Practitioners' perspectives on patient autonomy at end of life*. Dublin: The Irish Hospice Foundation.
- Reeve, J., Lloyd-Williams, M., Payne, S., et al. (2010). Revisiting biographical disruption: Exploring individual embodied illness experience in people with terminal cancer. *Health*, 14(2), 178–195.
- Silverman, P.R. (2004). Dying and bereavement in historical perspective. In *Living with dying: A handbook for end-of-life healthcare practitioners*. J. Berzoff & P.R. Silverman (eds.), pp. 128–149. New York: Columbia University Press.
- Smith, J.A. & Osborn, M. (2003). Interpretative phenomenological analysis. In *Qualitative psychology: A practical guide to research methods*. J.A. Smith (ed.), pp. 51–80. Thousand Oaks, CA: Sage Publications.
- Smith, J.A., Jarman, M. & Osborn, M. (1999). Doing interpretative phenomenological analysis. In *Qualitative health psychology: Theories and methods*. M. Murray & K. Chamberlain (eds.), pp. 218–240. London: Sage Publications.
- Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage Publications.
- Sudnow, D. (1967). *Passing on: The social organization of dying*. Englewood Cliffs, NJ: Prentice-Hall.
- Talwar, V., Harris, P.L. & Schleifer, M. (2011). Children's understanding of death: From biological to religious conceptions. New York: Cambridge University Press.
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. New York: Open University Press.
- Willig, C. (2009). Unlike a rock, a tree, a horse or an angel: Reflection on the struggle for meaning through writing during the process of cancer diagnosis. *Journal of Health Psychology*, 14(2), 181–189.
- Willig, C. (2011). Cancer diagnosis as discursive capture: Phenomenological repercussions of being positioned

- within dominant constructions of cancer. *Social Science & Medicine*, 73(6), 897–903.
- Willmott, H. (2000). Death, so what? Sociology, sequestration and emancipation. *Sociological Review*, 48(4), 649–665.
- Wilson, S. (2007). When you have children, you're obliged to live: Motherhood, chronic illness and biographical disruption. *Sociology of Health & Illness*, 29(4), 610–626.
- Wong, P.T. & Tomer, A. (2011). Beyond terror and denial: The positive psychology of death acceptance, *Death Studies*, 35(2), 99–106.
- Wright, K. (2003). Relationships with death: The terminally ill talk about dying. *Journal of Marital and Family Therapy*, 29(4), 439–453.
- Wrubel, J., Acree, M., Goodman, S., et al. (2009). End of living: Maintaining a lifeworld during terminal illness. *Psychology & Health*, 24(10), 1229–1243.
- Yedidia, M.J. & MacGregor, B. (2001). Confronting the prospect of dying: Reports of terminally ill patients. *Journal of Pain and Symptom Management*, 22(4), 807–819.
- Zimmermann, C. (2012). Acceptance of dying: A discourse analysis of palliative care literature. *Social Science & Medicine*, 45(1), 217–224.