

People With Advanced Cancer: The Process of Living Well With Awareness of Dying

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Abstract

Literature suggests that it is possible to live well with advanced cancer but little is known about the process. In this article, we present a secondary analysis of experiences of living with advanced cancer ($n = 22$) that refines the theory of “Living Well with Chronic Illness” for a different context and population. The refined theory explains the experience of living well with advanced cancer illuminating a five-phase iterative process: struggling, accepting, living with advanced cancer, sharing the illness experience, and reconstructing life. These five phases revolve around the core concept of *Awareness of Dying*, which varied from awareness of the possibility of dying, to accepting the possibility of dying, to acceptance that “I am dying.” *Awareness of Dying* led to a focus on living well with advanced cancer and movement towards living a life rather than living an illness.

Keywords

advanced cancer; dying; end of life; palliative; theory; qualitative; secondary analysis; constant comparative analysis; europe

Introduction

Globally there are 14.1 million new cancer cases diagnosed annually, 8.2 million cancer deaths, and 32.6 million people living with cancer (within 5 years of diagnosis) (Ferlay, Soerjomataram, et al., 2013). Cancer incidence is increasing but mortality is decreasing (Ferlay, Soerjomataram, et al., 2013; Ferlay, Steliarova-Foucher, et al., 2013). As new therapies are developed and the disease is diagnosed earlier, people are living longer with cancer than ever before (Tracey, Kerr, Dobrovic, & Currow, 2010). Even patients whose prognosis is limited as a result of advanced disease are living longer (Ruiterkamp et al., 2011), and want to live well, making this issue a global concern.

Patients who are diagnosed with advanced cancer cope with a complex array of factors. These include profound symptoms (Solano, Gomes, & Higginson, 2006; World Health Organization, 2004), prolonged anticancer treatments, side effects from treatment, dealing with the foreign world of the “health system,” and the implications of living with an uncertain prognosis. Being diagnosed with a life-limiting illness often involves significant changes to the ways a person experiences and understands living and dying (MacArtney, Broom, Kirby, Good, & Wootton, 2017).

While there is a growing body of research focused on select aspects of people’s experiences with advanced cancer, there is a dearth of research attending to the process of living with advanced cancer across the trajectory towards death. One exception is the work of Olson and colleagues (Olson, Morse, Smith, Mayan, & Hammond, 2001) who were concerned about the lack of theory linking the living-dying experience of people with advanced disease. These researchers asked the question, “What is the experience of people with illness who expect to die?” and used the answer to modify the Illness Constellation Model.

A recent metasynthesis (García-Rueda, Carvajal Valcárcel, Saracíbar-Razquin, & Arantzamendi Solabarrieta, 2016) resulted in a model that suggests people with advanced cancer desire to live normally while also being aware of the

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closeness of death. Suffering is inherent in the context of advanced cancer, which people seek to reduce and, at the same time, live life with new meaning. This entails a process that has an impact on family dynamics because the sick person not only needs to be cared for but also has the need to care for his or her family. The model addresses the importance of the support network and the health context in which the person lives.

Specific aspects of living with advanced cancer that have been explored include the relationship between spiritual well-being and quality of life (Bai, Lazenby, Jeon, Dixon, & McCorkle, 2015), the phenomenon of living while dying (Colosimo et al., 2018; Cottingham, Cripe, Rand, & Frankel, 2018; Olson et al., 2001), unmet needs for care (Moghaddam, Coxon, Nabarro, Hardy, & Cox, 2016), and psychosocial interventions in the context of advanced cancer (Badr, 2014; Colosimo et al., 2018). Researchers have focused on coping strategies to live with uncertainty about disease trajectory (Lobb et al., 2015) or what it means to cope well when living with advanced cancer (Walshe et al., 2017). The strategies that people use to cope with uncertainty include avoidance, maintaining normality, minimizing the impact of disease, focusing on positive aspects, and focusing on the anticipated outcome of current treatment (Lobb et al., 2015). Walshe and colleagues (2017) emphasized that useful strategies for coping well with advanced cancer are only generated through engagement in the process of living with disease, but that process requires articulation. It is clear that there is a much bigger “story” to the process of living with advanced cancer than we currently understand.

The limited studies transmit the underlying idea that it is possible to live well with advanced cancer but little is known about this process nor how to support it. However, there is a theory that captures the process of living well with chronic illness, developed through grounded theory research conducted with 43 participants who perceived themselves to be managing well with a variety of chronic illnesses (Robinson, 2017). The Theory explains that there is an iterative “Healing Process of Moving On” through which people revisit five interconnected phases (The Fight, Accepting, Living with the Chronic Illness, Sharing the Experience, and Reconstructing Life). The iterative phases revolve around a core category of making hard choices. This model shows a dynamic process that occurs as the chronic condition or the responses to it change and people develop new ways to live well, moving sometimes back and forth between the phases. Multiple chronic illnesses were represented among the participants, which was an intentional decision to enhance applicability.

The first author was familiar with the Theory of Living Well with Chronic Illness and during data analysis for the primary study was struck by possible intersections between the participants’ accounts and the Theory. The

stories of the participants made us reflect on how well the participants lived with their serious illness, which was congruent with the Theory. This was discussed with the team and we became curious about whether the Theory might be relevant to people living with advanced cancer, considering that this stage of the cancer journey is often prolonged and can be considered chronic due to treatment advances (Moghaddam et al., 2016). In addition, we wondered whether the Theory would be applicable within a different culture, that is, Spain versus Canada. This led to the secondary analysis that is reported here. The aim of the study was twofold: (a) to explain the process of living with advanced cancer to enhance understanding and inform the ability to effectively support people when time is both uncertain and short, and (b) to determine the applicability of the Theory of Living Well with Chronic Illness to the more specific scenario of advanced cancer within a Spanish sample and, if appropriate, refine the theory. Theory testing, refinement, and development is recognized as one way to advance applied disciplines such as nursing (Swanson & Chermack, 2013).

Method

The study is a secondary analysis of qualitative data originally collected in a phenomenological study designed to gain a deep understanding of the *essence* of the lived experience of having advanced cancer (García-Rueda, 2017). The original study was focused on the “punctual” narrations of experiences and not on the experience as a *process*. Secondary analysis enables the researcher to change the aims and focus of the original study (Heaton, 2008) while capitalizing on the richness of the data (Oliver et al., 2018) that are collected in qualitative research (Hinds, Vogel, & Clarke-Steffen, 1997). This study is an analytic expansion according to Thorne’s (2012) classification. Analysis focused on a new question, the *process* of living with advanced cancer, and used the method of constant comparison (Glaser & Strauss, 1967). Secondary analysis is appropriate for clinical inquiry in nursing, particularly with vulnerable populations, such as those with advanced illness, because it reduces respondent burden (Szabo & Strang, 1997). One of the limitations of secondary analysis is the appropriateness of the data for reanalysis (Hinds et al., 1997). Our new question fitted well with the data as the central concern, life with advanced cancer, was similar for both studies. In addition, during analysis of the primary study, the researchers noted how well the participants lived with their serious, life-limiting illness. The approach that was taken here was to reanalyze all of the data set while attending to a “concept [the process] that seemed to be present but was not specifically addressed in the primary analysis” (Hinds et al., 1997, p. 410).

The original data were collected by the second author in conversational interviews with 22 Spanish adults purposefully selected from three different centers (promoting variation on sociodemographic characteristics) who had been living with advanced cancer for a minimum of 3 months. Twelve participants were men and 10 were women who ranged in age from 45 to 83 years. Nine were married, six single, five widowed, and two divorced. They lived in urban ($n = 15$) or in rural environments ($n = 7$) and most lived with family members (four people lived alone). The time interval between the interview and participant's death varied from 22 days to almost 2 years.

Open-ended questions were used to initiate the interview such as "Would you describe your life with this disease?" and the interviewer then followed the participants' stories, which were audio-recorded. The data for the current study were comprised of 22 verbatim transcripts of interviews, as well as a vignette of each participant's characteristics and story that provided valuable contextual information to facilitate interpretation of the transcript.

Constant comparative analysis was conducted by two members of the research team. One researcher had been involved in the original study and is fluently bilingual in Spanish and English, which enabled culturally appropriate translation of the Spanish transcripts. The other researcher was conversant in Spanish and intimately familiar with the research underpinning the Theory of Living Well with Chronic Illness. This relationship reduced the limitations implicit when there is lack of detailed contextual knowledge about the circumstances of the data collection, in this case, for both studies (Coltart, Henwood, & Shirani, 2013; Seale, 2011).

Both researchers were familiar with the Theory of Living Well with Chronic Illness but set this temporarily aside so as not to impose an analytic framework on the data. The researchers independently read and coded one transcript at a time and then met to discuss the coding before proceeding to the next transcript. Initial open coding was directed by two basic questions: "What is this about?" and "What is going on here [in relation to living with advanced cancer]?" This enabled the data to be fractured and labeled with a name or code that was close to the data (i.e., at a relatively low level of abstraction). The second step of coding focused on comparing the evolving codes with the Theory based on the questions, "Does this code fit the Theory? If so, how? If not, what is going on that is different?" The transcripts were sequentially coded by hand in this two-step fashion and, through consensus, a coding framework was developed by constantly comparing one piece of data with another both within and between transcripts as well as with the Theory. We questioned, tested, and challenged if the coding fit with the phases of the original Theory and whether the Theory provided an adequate, complete explanation for the

process of living with advanced cancer. For example, it was evident that the participants living with advanced cancer had difficulties with the diagnosis and subsequent illness problems. In the original Theory, the first phase is termed "The Fight." This did not seem to fit what we were learning about the beginning of the process of living with advanced cancer. Through careful constant comparative analysis of the transcripts, we came to understand that these participants experienced a unique phase of difficulty that we called "Struggling." Indeed, it was surprising to us that fighting, often viewed as key to living with cancer, was minimally evident. Thus, every code needed to earn its way into the conceptualization of the process. Theoretic memos were used to keep track of ideas, questions, and concerns as the analysis proceeded and a new core category was identified. Finally, the theory was confirmed with two of the primary researchers who had not participated in the secondary analysis. They were asked to judge whether the new theory "resonated" or "fit" with the data and whether the theory presented a credible explanation of the process of living with advanced cancer as a way to enhance the trustworthiness of the findings.

As suggested by Thorne (1998), ethical issues were considered and the secondary analysis was approved by the university research ethics board (Identifier 2016.104).

Findings

Our participants helped us understand that living with advanced cancer is an iterative process comprised of five interconnected phases that revolve around a core concept of *Awareness of Dying*¹ (Figure 1). The five phases are Struggling, Accepting, Living with Advanced Cancer, Sharing the Illness Experience, and Reconstructing Life (Table 1). Each phase is a process within the larger process, which we have named Living well with Awareness of Dying, that is revisited over time as the illness changes and new challenges arise. Despite the fact that the phases are interconnected and interactive, there is a sequence to the larger process of Living well with Awareness of Dying, which is described below. The central, or core concept, of *Awareness of Dying* will then be highlighted.

Struggling

This was where each participant began their experience with advanced cancer, by struggling with the diagnosis. This was a process of resisting the presence of advanced cancer in one's life that was colored by a sudden awareness of the possibility of dying. Participants described emotional responses of shock, anger, anxiety, and fear. Cognitively, they expressed disbelief and uncertainty while questioning, "Am I dying?" "The first thing you think is that you're going to die." Behaviorally, this was

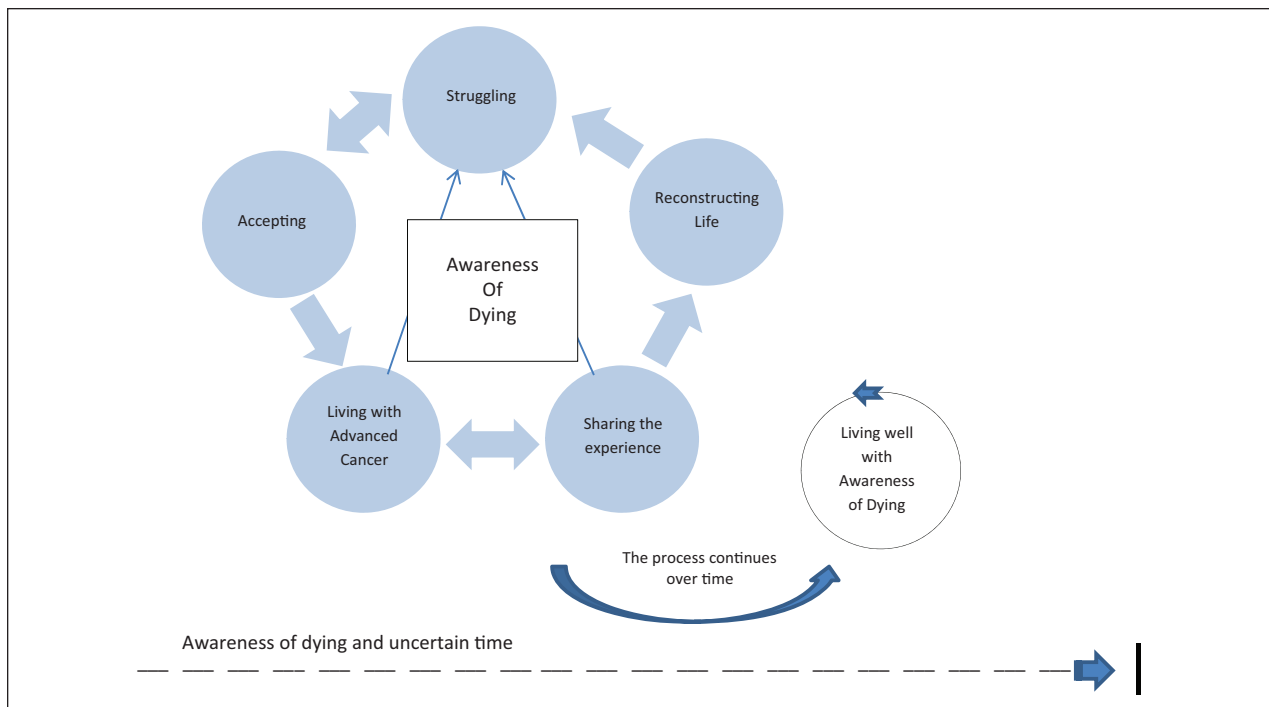


Figure 1. People with advanced cancer: The process of living well with awareness of dying.

accompanied by crying, shouting, and for some, quiet withdrawal.

At first it was worse because I did not understand that this could have happened to me. I felt good . . . and it was a very hard blow. Moreover, what I have is a pretty ugly, serious, serious tumor. . . . So, I was very scared . . . I thought I was going to die the day after tomorrow.

For some participants who were aware that something was wrong, struggling began before the diagnosis.

I knew something was wrong with my body. For example, I could hardly swallow. And it's like you do not want to see. I knew something was wrong, but I was feeling well.

The duration and intensity of struggling varied among the participants; however, there were very few accounts of aggressively fighting the disease. Over time, participants realized that struggling created additional life difficulties and was not useful. In fact, they understood it was counterproductive to moving forward with living, so they made a pivotal choice to let go of struggling. Participants talked about it being the *only* choice and some even talked about there being no choice; however, this realization took time to evolve. They felt stuck in their struggling and needed to stop, which enabled them to move on toward accepting the advanced cancer in some measure.

Well, I did not want to believe it. I'm going to have to mourn and all So it's like that you rebel against cancer, right? That you rebel. I need[ed] my time to internalize, accept.

As discussed, participants chose to stop struggling; however, struggling did not end with this first decision. Instead, over time, when new challenges such as treatment failure or difficult illness problems arose, struggling reoccurred. For example, one participant poignantly described returning to the struggle when physical suffering increased and when *Awareness of Dying* was more present.

And then I start thinking about things I like to . . . avoid . . . to think—I'd rather be dead than be like this. I try to think of things I like, to avoid that thought but I think about it. Imagine if you were really like that every day. I would rather die than be suffering continuously like this, if there is no hope.

Another participant quietly described balancing between *Awareness of Dying* that arose when symptoms increased and “forgetting” he has advanced cancer.

I stand it the best that I can inside, of course, now I give a little more to my head, which before “you have cancer, bah, it will be cured.” But now, seeing myself with less strength and less vitality, well of course you give more . . . a little more thought. But oh, many times I forget that I have cancer eh So either . . . (laughs) No And the truth is that I see that there is a pretty good progression Now it has stopped again, it's stopped by now, for the moment, then when he (cancer) wakes

Table 1. Framework for the Process of Living Well With Awareness of Dying.

Awareness of dying	Phase	Definition	Characteristics	Pivotal Choices in Light of Awareness of Dying
	Struggling	A process of resisting the presence of advanced cancer in one's life; including at various times such things as diagnosis, progression, and prognosis.	Emotional: Shock, anger, anxiety, worry, fear Cognitive: Disbelief, uncertainty; questions such as Am I dying? Why me? Behavioral: Crying, shouting; withdrawing	Letting go of struggling
	Accepting	A process of acceding or coming to some level of agreement about the presence of advanced cancer and the problems it brings.	Some level of peacefulness about the situation	Deciding what to agree to as part of one's life, for example, Do I accept the diagnosis? Do I accept the prognosis?
	Living with advanced cancer	A process of figuring out how to accommodate advanced cancer into one's life.	Accommodating illness problems	Focusing on what matters most by priority setting; hanging on to what matters and letting go of what does not
	Sharing the illness experience	A process of maintaining family and social relationships such that the ill person experiences being supported while also protecting loved ones from unnecessary suffering.	Having someone to count on Protecting loved ones	Deciding about the degree of sharing
	Reconstructing life	A process of moving living into the foreground and advanced cancer into the background. The focus is on living a personally meaningful life versus living an illness.	Focusing outside of oneself and away from illness, even if momentary and transient Living in the moment	Choosing life over illness

up again, until there is no solution. And when there is no solution, what are we going to do? This is . . . This is my life.

Again, as struggling was revisited, it called for a new choice to let go rather than to be stuck in turmoil, which enabled moving forward into the next phase of Accepting.

Accepting

Accepting was a process of acceding or agreeing to the presence of advanced cancer in one's life, along with the problems it brought, to attain some level of peacefulness about the situation. This could only occur after struggling stopped. Most participants used the word "accepting" and described it as the "only choice" because it was viewed as essential to being able to move forward with living.

Why has this touched me? For that God knows. And, and I have accepted it, of course. I have accepted, and also . . . is that I see that this is what I have to do. What do you get not accepting it? If it's there . . . you have it . . . take it to your best (Silence).

Another participant highlighted the hard work of learning how to let go of struggling and move into accepting.

There's no more [struggling]. I'm not very much a resigning person, really, it's not my character, but I learned I guess. I do what I can, and what I cannot do, cannot be done. If it cannot be done, there is no other way than assuming it and taking your best. I do not want not to accept it. I don't want that because I would be embittered all the time.

It is important to recognize that accepting was also a process that was revisited many times when life got challenging because of such things as new information or illness problems. "It is the acceptance of what you have and what you have to do." Depth of accepting varied widely and was navigated over time. It involved coming to some level of agreement about the situation, for example, that there was a diagnosis of cancer, or that the cancer was not curable, or that life might be shorter, or that the person was dying. Achieving some degree of accepting was not only influenced by *Awareness of Dying*, but also it involved it. As illustrated below, participants moved from

awareness of the possibility of dying toward accepting that they were dying.

Now I think more, but I'm not thinking all day that I'm going to die. I mean, that's not it. Because when it has to be, that is . . . No, I do not . . . I mean, it's not that I want to die, no, please. But if it has to arrive, it should arrive.

Accepting, in turn, enabled a degree of peacefulness that contrasted sharply with the turmoil of struggling. Accepting involved making pivotal choices about what to agree to include as part of one's life. For example, several participants talked about not fully accepting that their cancer was incurable. Instead, they hung on to the hope that even though the cancer was advanced, there was still a possibility of cure.

One strategy that facilitated accepting was making sense of one's situation, which enabled answering the hard questions of "Why me?" or "Why now?" or "Did I do something wrong?" or "Is this my fault?" The belief, shared by many of participants, that their situation came from God and God would take care of them, was particularly helpful in making sense of their situation in a way that supported accepting. They described being in God's hands. For some, this was an active choice to turn toward God, while for others it was automatic and a reflection of a strong, ongoing relationship with God. Accepting enabled movement into the next phase of living with advanced cancer rather than against it.

Living With Advanced Cancer

This was a process of figuring out how to integrate advanced cancer into one's life, which entailed working to accommodate or mitigate illness problems so their impact on life and living were minimized, all the while taking *Awareness of Dying* into account. Accepting (to some degree) enabled the development of a negotiated coexistence with advanced cancer because struggling against it had stopped and there was willingness to consider making necessary life adjustments. Illness problems were the everyday problems of living that arose from serious illness, for example, problems moving, incorporating demanding treatment regimens, or difficulty caring for one's children due to pain or fatigue. Taking *Awareness of Dying* into account had to do with the possibility of time being shorter and the need to focus on what mattered most in life.

What happens is that I think of this as a bit . . . a little obstacle race, in which I first said to myself "I'll see if I get to my daughter's communion," and then a little more, and then another . . .

In some instances, living with advanced cancer involved very challenging priority setting and choices. For example, one mother of young children highly valued being a good mother; however, this meant that she needed to let go of having her children close by her because she was not physically able to care for them. She needed to let them go to other family members to receive the care they needed, which was heartbreaking for her but enabled her to hang on to the fact that this is what a "good mother" did. Being a good mother in this way was what mattered most.

Four strategies facilitated the phase of living with advanced cancer when time may be short: making life adjustments, maintaining a positive attitude, normalizing, and hoping. *Making life adjustments* occurred to accommodate illness problems or treatments. For example, one couple living in a small village found social interactions on the street with neighbors to be a problem because of the constant focus of others' concerns on the illness. The couple adjusted their life by going to the next village for coffee, allowing them a pleasant outing together where they could attend to life rather than illness. Many participants spoke of the need to balance dependence and independence in making necessary life adjustments, which was a tricky endeavor. It was important to accept assistance but, at the same time, it was essential to maintain a sense of being worthwhile and to reduce the perception of being a burden. As one participant explained, "You depend on someone when you have never depended on anyone, and now need to (Silence). And that's the most complicated."

Maintaining a positive attitude was often expressed as "choosing to see the positive," which facilitated living well. This strategy enabled participants to choose where they put their attention. For example, one participant was no longer able to work but this was quickly dismissed with expressions of gratitude for the small things that were still possible, such as being able to shop for groceries, enjoy a coffee with friends, or see beautiful flowers. Another participant emphasized it this way: "There is no need for big things, the little things of everyday life . . . [I] depend on those. . . . Well I guess you learn to value things every day, right?" Maintaining a positive attitude was recognized as a powerful influence on the experience of living with advanced cancer by all the participants and, at the same time, many acknowledged that sometimes it was difficult, which caused them to return to struggling from time to time.

Normalizing was also a focusing strategy. Like the lens of a camera, participants focused on the "normal" aspects of their life, setting aside the "not normal" aspects by ignoring them, which minimized the impact of advanced cancer on everyday life.

I make an effort to continue having a normal life like any person. I achieve it and it gives me strength to say "I'm normal" as my life is like the one of any other person. I feel alive in the sense that I make a normal life, as any person who is not sick.

I understand that this disease is very present in our society and I happened to get it. And I accept it in the sense of normalizing it, trying to live with the disease, not denying it or not to be angry all day because it has touched me, but try to cope and become a little friend of what I carry with me. . . . I mean to accept, to normalize it, to cope with it.

Significant illness problems, such as treatments or being unable to work, which could not be put aside, were reconstructed as one's new normal, again minimizing their impact. Some participants even spoke explicitly about the normality of their own death and dying (*Awareness of Dying*), constructing this as a natural part of life.

Before I did not think. It seemed that you were going to last forever, or you did not have death in mind, but now it's a matter of course that you think about that. And there are times when you talk about it normally and other people are not prepared to speak with that normality.

Another participant stated it this way: "I told the doctor the other day that I know we were born to die."

The final strategy was *hoping*, which involved being open to possibilities. This was particularly important when normalizing was not possible, for example, during extended hospitalization, when holding onto the hope of feeling better, leaving hospital, and resuming enjoyable activities was critical. As one participant explained, if one treatment did not work there was the possibility that another one would. "I take . . . strength from myself. I choose to hold onto possible treatments, being thankful for treatment options."

Sharing the Illness Experience

This piece of the puzzle of living well with advanced cancer and *Awareness of Dying* involved maintaining family and social relationships such that the ill person experienced being supported. Having a sense of being loved and accompanied in the experience was critical but needed to be balanced with protecting loved ones from unnecessary suffering. Participants deeply appreciated that family members also experienced *Awareness of Dying* and that this generated suffering, therefore they made pivotal choices about how much information to share and with whom. We have called the two characteristics of this phase of sharing the illness experience as (a) having someone to count on and (b) protecting loved ones (Table 1).

Having someone to count on to share the experience was highly valued and generated immense gratitude as

well as a sense of well-being despite serious illness. Participants counted on different people for different things, often expanding their circle of support beyond immediate family. The caring physical presence of family was central to the participant feeling accompanied and did not necessarily include talking together about the situation. As one participant explained,

My life is now calmer. My wife is here all day. . . . Every night remains one of my children. Every night! . . . which is very nice for me. It is bad to have the disease, but it is . . . very nice things that come with it.

Sharing the experience and having someone to count on often meant relationships deepened. However, the participants worried about the fact that suffering was also shared and they were concerned about being a burden, which led them to protect those they love.

Protecting loved ones was primarily focused on selective communication that involved carefully choosing what to tell, how to tell, and who to tell; setting limits aimed at preventing or alleviating suffering. Most participants talked about limiting sharing as a way to protect in the moment and a way to enable loved ones to continue on over time. As illustrated below, while *Awareness of Dying* may have been shared with family members, discussion of this awareness was not.

From the first day I knew it was this bad disease. What will I say? If I already know what it is . . . I have not wanted to ask a lot, so they [family] do not suffer. I do not want them to suffer (gets excited). Because every time I raise the issue they say "Forget it, forget it. That's not going to come." It's the only thing . . . what am I going to tell him? (Interviewer: Would you like to talk about it?). . . . It would hurt me to have to say "Son, I'm going to die of this." It is an uphill . . . struggle. It would be a hard time . . . Do you get me? This is complicated for me. They already know, because we are not fools, as I know, they know it.

Thus, participants used two strategies: (a) balancing giving and withholding information, and (b) relying on themselves as much as possible, such as in problem solving or doing self-care. For example, one participant who needed to talk about his illness situation but did not want to burden his family explained that he turned to others who were diagnosed with the same disease without fear of increasing suffering. Participants were resourceful in their caring for self and others.

Reconstructing Life

In this phase, termed *Reconstructing Life*, living moved into the foreground and advanced cancer moved (or was pushed) into the background. The focus was on living a

personally meaningful life, albeit in moments, rather than living an illness. Many participants reported actively choosing life over illness rather than waiting for a break from the illness or illness problems. For example, one participant chose to delay treatment to take a holiday from being sick.

I need a vacation from all this. As I said, every day I think on this, always having to do something related to the disease. . . . We will postpone the treatment. It's not going to change anything and being one week of complete vacation will be helpful.

Reconstructing life occurred in the context of *Awareness of Dying* and recognition that time was precious. There were two characteristics or facets to this phase: (a) shifting attention outside of oneself and away from illness, and (b) living in the moment. Participants *shifted attention outside of themselves* by continuing to make personally meaningful contributions to family, community, and society. In this way, they supported their valued human identity that was not defined or limited by sickness. Some participants talked about contributing to society by leaving their body to science, some simply continued to help others as they had done before, and some planned for the well-being of their family after their death.

All this story (saying goodbye to my family) I started to ruminate when I thought I was dying and I told my wife, "There is something that has to be done with you and with the children," because I had heard somewhere that they helped prepare for the death. And I said, "Look, if I'm going to leave now, you're going to cry, but the next step is to move on." And then, that's what I tried to transmit to them. Even if it was tough, what they had to do was seek help to continue. And then almost without realizing it, I raised the idea of doing the farewell. And I liked it a lot (Silence).

Living in the moment was a way of maximizing precious time, given *Awareness of Dying* and the desire to live as fully as possible. It involved two strategies: (a) being intentionally present to attend to moments of joy or beauty, and (b) controlling thoughts. Participants explained being present in several ways:

People who have been sick, I think, have a different joy.

There are times when you think you're going to die, you already have an expiration date. You say, "I'm going to die from this but I will try to be as late as possible, and that the time is, use it, live well . . . live happy and calm." Enjoy every day because you never know if tomorrow will come (Silence).

Controlling thoughts involved actively stopping thinking, particularly about the disease and dying. In addition,

thinking ahead was curtailed. Troubling thoughts related to death and dying were particularly intrusive and persistent, which resulted in a return to struggling for some. It required energy and determination to control these thoughts to live life rather than live illness. Poorly managed symptoms and pain or hospitalization interfered with reconstructing life because of their intrusiveness.

Deep accepting facilitated reconstructing life because there was little struggle with the realities of the situation. For example, one participant accepted that he was dying and viewed it as a meaningful opportunity to be a role model for those he cared about. In this case, reconstructing life occurred with dying a close companion rather than being in the background.

The theory of Living well with *Awareness of Dying* captures the five-phase process these participants, diagnosed with advanced cancer, engaged in to live as well as possible within the constraints of serious illness and shortened life expectancy. As has been noted, the iterative process revolved around, and was influenced by, the core concept of *Awareness of Dying*, which varied from awareness of the possibility of dying, to accepting the possibility of dying, to awareness, and, for some, acceptance that "I am dying." This core concept will be discussed below.

Awareness of dying. *Awareness of Dying* was a process within the larger process and, as has been discussed, influenced all the phases. For example, struggling could involve resisting *Awareness of Dying* even if advanced cancer was accepted. Participants' *Awareness of Dying* changed in relation to two dimensions, the first being time and the second being the position of the awareness in relation to the finitude of self. Time was about whether dying was viewed as close or far away. While time was always uncertain, and something that participants struggled with, there were aspects of the experience that brought *Awareness of Dying* into the near rather than distant future. Dying took on more immediacy in the circumstances of increased intensity of illness and hospitalization. However, the ability to make meaning of the situation, such as the illness being within God's hands, eased struggling and facilitated accepting.

How the participants positioned their *Awareness of Dying* determined how it influenced the process of living well with advanced cancer. Sometimes, the awareness was foreground, occupying their day-to-day thoughts and actions. In this situation, some participants struggled against the awareness while others were motivated to plan for their families' well-being by preparing wills or negotiating child care. Envisioning a future for their family that was characterized by their absence brought *Awareness of Dying* firmly into the foreground. The pain and preoccupation that participants experienced when envisioning their absence resulted in actively putting the

Awareness of Dying in the background where thinking about it could be avoided at least for a time. This active and pivotal choice took energy but enabled a focus on living and living well as time was perceived to be short and precious. Finally, some participants seemed to carry the *Awareness of Dying* comfortably beside them, which arose with deep accepting that supported reconstructing life. For all the participants, *Awareness of Dying* led them to focus on living well with advanced cancer; they were aware that did not have time to lose.

Limitations

The original Theory of Living Well with Chronic Illness was based on family interviews and, therefore, represented the family perspective. The study being reported was based on interviews with individuals diagnosed with advanced cancer, and represents the perspective of the person with advanced cancer, although frequent references were made to family. Family clearly played an extremely important role for the participants but the theory does not reflect a family perspective. It is well recognized that the diagnosis of advanced cancer affects and is affected by family (Badr, 2014). Furthermore, the Spanish cultural context is relatively homogeneous. It would be interesting in future studies to explore the family perspective and different cultural contexts to further assess theory applicability and support theoretical development. In addition, the data were comprised of a single interview with each participant. We note that Olson and colleagues (2001) utilized multiple interviews and found a stage of Enduring to Die, which was characterized by withdrawal that was not represented in our data. Therefore, where possible, repeated interviews over time may be helpful to further refine the conceptualization of the process of Living Well with Awareness of Dying.

Discussion

The aim of the study was twofold: (a) to explain the process of living with advanced cancer to enhance understanding and inform the ability to effectively support people when time is both uncertain and short, and (b) to determine the applicability of the Theory of Living Well with Chronic Illness (Robinson, 2017) to the more specific scenario of advanced cancer within a Spanish sample and, if appropriate, refine the theory. We found that the Theory of Living Well with Chronic Illness was indeed useful to understanding this situation but required refinement to adequately explain the process of Living Well with Awareness of Dying. The adjusted theory illuminates a five-phase iterative process (Struggling, Accepting, Living with Advanced Cancer, Sharing the

Experience, and Reconstructing Life) that revolves around *Awareness of Dying*, which captures the challenges as well as resilience of the participants as they grappled with life-limiting illness and the desire to live life fully (Table 1).

As Walshe et al. (2017) have recently suggested, the strategies for coping well with advanced cancer, which are the focus of several studies (Coyle, 2006; Dale & Johnston, 2011; Lobb et al., 2015; Sand, Olsson, & Strang, 2009; Walshe et al., 2017), are only generated through engagement in the process of living with disease, which is a “bigger story” than has previously been put forward. This study offers one explanation of the process of living well with advanced cancer that addresses the bigger story and enables us to understand the findings of previous research in a new and integrated context.

Awareness of Dying is the core category around which the larger process revolves and, like each of the phases, is a process unto itself that was revisited over time. Awareness shifted from initial recognition of the possibility of dying to ultimately, for some, accepting that “I am dying.” *Awareness of Dying* centers on the meaning participants gave to being sick with advanced cancer—it meant that time was uncertain and more limited than they had imagined, which colored the process of living. The time between the crisis of diagnosis of advanced cancer with accompanying knowledge of death, and the point of death, which has been termed the living-dying interval, may be months to years due to medical advances (Colosimo et al., 2018).

In this context of a prolonged living-dying interval, double awareness broadly refers to the capacity of individuals with advanced cancer to sustain and negotiate the dialectical tension that arises between remaining engaged in the world, while preparing for impending death. (Colosimo et al., 2018, p. 1)

This double awareness was clearly evident for the participants in our study, whose primary focus was on remaining engaged in the world of the living. The tension that Colosimo and colleagues so aptly describe resulted in struggling and required some degree of accepting to move more fully into living rather than dying. However, as these authors point out, the tension was negotiated or navigated and was not resolved. Based on our findings and the work of others, awareness should not be viewed as a stable attribute (Field & Copp, 1999; Mamo, 1999); rather, it varies over time, which challenges the more traditional idea that awareness that one is dying is relatively stable (Glaser & Strauss, 1965). Our theory contributes to understanding the nuances and dynamic nature of awareness within the concept of double awareness. Furthermore, it highlights the centrality of the process within the larger process of living well with advanced cancer. People diagnosed with advanced cancer are confronted with their

mortality in a way that does not allow for evasions and requires hard work to find a way to live without a clear future (Coyle, 2006; Willig, 2015). The heightened concern about living and dying accompanying a diagnosis of advanced cancer creates an existential plight or crisis that requires time to adjust (Bai et al., 2015). Our findings address the gap identified in the literature about the ways in which the dying person engages with the challenges posed by the living-dying interval (McSherry, 2011; Willig, 2015).

The larger process began with Struggling and was characterized by discomfort, emotional distress, as well as suffering, which has also been identified by research conducted by Olson and colleagues (2001). Participants were challenged with uncertainty about the future (Etkind, Bristowe, Bailey, Selman, & Murtagh, 2017; Shilling, Starkings, Jenkins, & Fallowfield, 2017) but did not get stuck in Struggling and give up as found by Olson et al. (2001) or put plans on hold for an extended period to live one day at a time, as found by Shilling et al. (2017). Loss of control (Etkind et al., 2017; Shilling et al., 2017) was not a significant focus for the participants in our study. Instead, they moved past Struggling and into Accepting by making an active choice to stop resisting the illness and *Awareness of Dying*.

Accepting entailed coming to some level of agreement about the presence of advanced cancer in one's life. It is important to note that we have used the term *accepting* rather than "acceptance" to emphasize that accepting is a process that can occur in many forms and in relation to many facets of the experience (such as accepting the diagnosis, the worsening of the situation, or dying). Accepting is embedded in the findings of Olson et al. (2001) but not explicitly identified as critical to moving past the initial phase of distress. This is one of the contributions of the new theory. Through Accepting, suffering was mediated (Thompson et al., 2009) and our participants gained a sense of peace that has been identified as an important contributor to quality of life for people with advanced cancer (Bai et al., 2015). Furthermore, Accepting was facilitated by spiritually making meaning of the illness, which also positively influences quality of life (Bai et al., 2015). The importance of Accepting is supported by the research of Nipp and colleagues (2017) who found that accepting the reality of the situation, something that many of our participants emphasized, was associated with enhanced quality of life and mood.

Accepting enabled movement into the next phase of Living Well with Advanced Cancer where participants got to know the illness and made adjustments to accommodate both the illness and illness problems in their daily lives. Olson and colleagues (2001) have conceptualized this phase as Enduring to Live: Keeping Going. Our participants seemed more focused on living a life than

enduring to stay alive by fighting death (Olson et al., 2001). As already noted, there was very little evidence of fighting in our data, although participants did return to struggling from time to time when significant challenges arose, so this phase may be more akin to Stage 5 of the Illness Constellation Model, learning to live with the altered self. The importance of living a meaningful and productive life *now* has been identified as critical for people with advanced cancer (Cottingham et al., 2018). These researchers term it "Living in the face of death." Maintaining a positive attitude, one of the strategies that participants emphasized, is akin to positive reframing or looking for something good in the situation, which has been associated with enhanced quality of life and mood (Nipp et al., 2017). This supports the notion that the participants in this study were indeed living well with advanced cancer and *Awareness of Dying*.

Sharing the Illness Experience comprised the next phase. Here, participants highlighted the importance of family relationships, which have been linked to a sense of belonging and enhanced quality of life (Nipp et al., 2017; Peoples, Nissen, Brandt, & La Cour, 2018). Social belonging is nurtured through shared emotional connections and the ability to contribute to the lives of others (Peoples et al., 2018), both highly valued by participants. Shilling and colleagues (2017) noted that people with advanced cancer and their family caregivers seldom discussed their concerns about an uncertain future with each other (see also Olson et al., 2001). Our theory offers one way to make sense of this phenomenon (at least from the perspective of the person with advanced cancer)—that constraining conversation is protective and aimed at limiting suffering. This challenges the assumption that "complete" open awareness is the most adequate way of dealing with Awareness of Dying (Glaser & Strauss, 1965). Lack of open awareness has been perceived as an indication of nonacceptance (Thompson et al., 2009), as a barrier to adequate planning of dying careers (Seale, Addington-Hall, & McCarthy, 1997), and as a negative influence on the quality of life of the dying person (Lokker, Van Zuylen, Veerbeek, Van Der Rijt, & Van Der Heide, 2012). However, Timmermans (1994) challenged the original concept of open awareness, proposing a subcategorizing to include (a) Suspended open awareness where the patient or family has heard information about the terminal condition but do not believe it, (b) Uncertain open awareness where information is given about the terminal illness but it is qualified by expressions of uncertainty to make room for hope, and (c) Active open awareness where the patient and family understand the situation fully. We propose that perhaps rather than these being different kinds of awareness, they represent different phases of awareness that occur over time and may be revisited. Limited sharing enabled the participants to

balance the need to be supported and the need to protect loved ones. People with advanced cancer may need assistance achieving a supportive balance between communicating and protecting that does not perpetuate a conspiracy of silence and also respects varying needs within the family.

The next phase in the theory is Reconstructing Life where life and living fully in the moment was foreground and illness as well as *Awareness of Dying* was background. Participants experienced joy and beauty in moments of being fully present to life and the tension inherent in the living-dying interval was temporarily suspended. These five phases of living well with advanced cancer were revisited as illness progression and *Awareness of Dying* along with uncertain time shaped the process of living with advanced cancer.

This study offers an integrative explanatory theory of living with dying and refines the Theory of “Living Well with Chronic Illness: The Healing Process of Moving On” (Robinson, 2017). It is clear that in both chronic illness and advanced cancer, living well involves an iterative process that is revisited over time. One difference is that quite quickly the participants with advanced cancer chose to let go of Struggling to move into Accepting because they experienced the negative consequences of resisting a situation that could not be changed. Resisting got in the way of living, which became more urgent in the context of *Awareness of Dying* and knowledge that time might be short. The other phases of living well are similar for advanced cancer, including the same underlying ideas but with nuances. In the case of the people with advanced cancer, accepting entailed making space for the *Awareness of Dying*, which was a new core category and not a facet of the original theory. Current study participants did not identify themselves and were not selected based on the idea of living well. Instead, the data supported the idea that the participants wanted to live and to live well. *Awareness of Dying* underpinned moving on toward living a life rather than living an illness. It may seem incredible from the perspective of someone who is not in this situation how well these people lived with advanced cancer; but as one of the participants said, “It’s not that I’m a brave, I’ve never been.” They helped us understand that living with advanced cancer involved a process requiring deep engagement, time, and effort—and that it is indeed possible to live well even if it is in moments.

Implications for Practice

Several things stand out in terms of potential implications for practice. It is evident that accepting is key to moving forward in the process of living well with advanced cancer; it may be tempting to promote accepting and to judge lack of accepting negatively. However, accepting takes

time and, as has been explained, can take many forms. Furthermore, it is not stable over time. It is conceivable that prematurely focusing on accepting might interfere with building a supportive therapeutic alliance. Careful assessment of where the ill person is in the process based on an understanding of the phases and levels of awareness will likely be most useful to effective therapeutic alignment.

Maintaining a positive attitude (e.g., finding the positive in the situation) was a helpful strategy for living well and should not be viewed as an indication of lack of *Awareness of Dying*. The participants in this study worked hard to live a life rather than live an illness, all the while being aware of dying, so the implication here is to support the positive. It has been found that hoping for a cure when cancer is advanced is also not evidence of lack of awareness—it can be a choice in focusing on positive possibilities (Robinson, 2012).

It also must be noted that *Awareness of Dying* was pervasive and was something that participants were willing and able to discuss. Early introduction of palliative care (Temel et al., 2010) along with advance care planning (Bernacki & Block, 2014) has been shown to enhance quality of life for people with advanced cancer. *Awareness of Dying* and willingness to discuss it will likely facilitate acceptance of palliative care and serious illness conversations.

Finally, the importance of family love and support cannot be underestimated. This should be assessed and supported. In particular, people with advanced cancer may need assistance balancing the sharing and withholding of information in relation to their desire to protect loved ones from suffering.

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Note

1. We have used “Awareness of Dying” because it is the label that best represents the experience of our participants. This term was first used by Glaser and Strauss (1965) but the term has been taken up by other researchers and evolved over time. We provide an explanation of the label as we use it because it is not the same concept as in the work of Glaser and Strauss.

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