Published in final edited form as:
J Palliat Care. 2013 ; 29(2): 76–82.

Living Fully in the Shadow of Mortal Time: Psychosocial Assets in Advanced Cancer

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Abstract

Objective—To characterize the strategies and psychosocial conditions that influence how resilient people live in the face of advanced cancer.

Methods—Grounded theory interviews and surveys of ten resilient people with advanced cancer were collected and analyzed.

Findings—Personal assets including positive relationships, purpose in life, faith, and a sense of mastery contributed to living fully in “mortal time.” Strategies included embracing paradox, reframing time, deepening connections, and aligning actions with priorities. Open-ended interviews yielded rich illness and life stories; many participants requested a copy of the transcript.

Conclusions—Resilient people use a range of strategies to thrive in the face of advanced cancer.

Keywords

cancer; psychosocial aspects; coping; death and dying; grounded theory; quality of life; cancer survivorship

You’re immortal until you find out how mortal you are. ...You’re supposed to live forever. Right? Now you’re facing a definite final time in your life. (Male, AS11)

Such is a common sentiment expressed about “mortal time,” or “the psychological state when humans directly confront the prospect of death.”(1) The shadow of death looms large in our spiritual and literary traditions. Scientific medicine’s attempts to deny and conquer death paradoxically increase existential angst.(2) Advanced cancer challenges death denial and is associated with lower quality of life and greater distress than early-stage cancer.(3)

Yet, positive and negative affect can coexist in the face of terminal illness. (4–6) High profile stories of thriving with cancer celebrate how fighting spirit, self-reliance, spiritual awakening, optimism, and resilience overcome fear, despair, and hopelessness. (7, 8) However, few published stories provide insights into *how ordinary* people thrive with advanced cancer. Positive relationships, purpose in life, self-acceptance, mastery, autonomy and personal growth contribute to resilience. (9, 10)This study explored how ordinary, resilient people live well (or thrive) in the face of advanced cancer. Our research questions were:

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1. What person-level conditions were associated living well with advanced cancer?
2. What did living well with advanced cancer entail?
3. What strategies did people use to live well with advanced cancer?

Methods

Recruitment and Sampling

Recruitment of a purposeful sample occurred at a university comprehensive cancer center according to a Human Subjects Committee approved protocol. Based on their judgment, oncologists and a cancer support group leader invited resilient patients advanced with cancer to participate and referred interested people to the principal investigator (MW) for a recruitment and consenting interview. No one seeking to participate was excluded. Those wishing to participate signed IRB-approved consent forms and completed a self-administered questionnaire. The PI scheduled an interview at home or the research office, per participant preference.

Sampling was guided by grounded theory, where new participants have characteristics that can inform the emerging theory. (11) For instance, early participants had stable Stage IV lung cancer (LC) and were age 65 or more. Finding a high degree of wellbeing, we next asked oncologists to identify younger LC patients (age 35–65) with progressive disease, conditions associated with greater distress. LC patients consistently attributed “doing well” to a lack of physical pain—a condition associated with LC. For comparison, we recruited three middle-aged people with advanced colorectal cancer (CRC), which is associated with lower quality of life. (14)

Data Collection

Data included a quantitative survey and a semi-structured, open-ended interview. The survey included demographic questions and Ryff’s psychological wellbeing (PWB) instrument. (11) PWB is a well-validated, six-point Likert scale with six 14-item subscales: positive relationships, autonomy, environmental mastery, personal growth, purpose in life, and self-acceptance. PWB was used to test whether we had recruited a resilient sample and to inform the question, “What person-level conditions were associated with lived well with advanced cancer?”

The open-ended, semi-structured interview elicited how life was going, strategies they used, and what personal characteristics accounted their doing so well. The interview began with, “What has it been like for you since you were diagnosed with cancer?” Follow-up probes addressed challenges, coping mechanisms, etc. To address how person-level conditions influenced the cancer experience, we asked: “What it is about you that accounts for ... [e.g., your ability to have overcome, to have received so much support...]?” To identify what people learned from their cancer experience, we asked, “Knowing what you know now, how would you advise someone who is just being diagnosed with a similar cancer?” Later, we added a question to explore the emerging strategy of “embracing paradox”: “You (or some people) talked about being able to hold opposite thoughts and feelings, like [both denying and accepting death]? Can you say more about that?” Data saturation occurred at the eighth interview. Interviews were de-identified during transcription.

Data Analysis

Survey data were analyzed with descriptive statistics. Interviews were analyzed with grounded theory, a systemic method to develop a conceptual model of little-understood social phenomena.(13) In phase one we independently coded early interviews line-by-line

and together discussed themes until agreement was reached. We categorized themes per Strauss' coding paradigm: the core category and person-level conditions and strategies that support it. In the next phase, we refined the themes and model by constantly comparing across interviews. In the final phase, we combined and trimmed themes and finalized the conceptual model (See Figure 1).

Findings

Shown in Figure 1, people were living fully with advanced cancer (core category), which entailed facing death and thereby led to engaging life. Conditions—demographics, challenges, and psychosocial assets—influenced how people lived fully with cancer. Strategies included embracing paradox, reframing time, deepening connections, and aligning actions with priorities.

Person-level Conditions and Sample

Eleven people consented; one declined to participate in the interview providing no reason. The ten participants included 7 men and 3 women; 7 had LC and 3 had CRC. According to survey data, age ranged from 35 to 82 (mean age, 62); 9 had other health conditions (diabetes, sarcoidosis, arthritis, hypertension, cardiovascular disease, Crohn's, other cancers). All were married and had health insurance. Educational levels ranged from <high school to post-graduate. Income ranged from over <\$20,000 to >\$100,000; 2 were working, 3 were on disability, 1 retired since diagnosis; 4 were not employed at diagnosis. PWB survey scores were high (mean 5.0 on a 6-point scale, SD .54, no outliers), indicating were recruited a resilient sample. The interviews identified other assets (e.g., sense of humor, overcoming adversity, engagement in community and world affairs, and faith). Two reportedly were receiving chemotherapy; 3 were in remission. Three with LC and 1 with CRC reportedly had "beat" their odds. All CRC patients had undergone radiation, surgery, chemotherapy, and permanent ostomy.

Living Fully in the Face of Advanced Cancer: The Core Category

There are things that you learn from going through cancer. It puts you in a better place; it changes your life. (AP09)

Facing Death—Advanced cancer made concrete the adage, "We all are going to die someday." Yet, some people danced with death at arm's length; others stared it straight in the eye.

Holding death at arm's length involved realistic denial and mild acceptance of death. Age, remission status, and type of cancer were not influential factors. The oldest patient (age 82 with LC) noted, "I just am taking it for granted that if I do what the doctors say and take the chemo that I will get better," with only a passing acknowledgment to her poor prognosis, "I probably won't [get better], but I am planning on it." (AS2) With a fighting spirit, she had overcome another cancer thirty years beforehand, beat the odds of surviving her current LC by a year; and had a deep engagement with family, local and world affairs. The youngest (age 35, LC) accepted that his cancer was not curable, yet he was still planning for the long-term (e.g., having a family). A remissive CRC patient articulates accepting death while living fully:

The scariest thing at [first] was, 'Am I at the end of my life?' ... But [with recurrence], there has been a lot of growing and maturing. ... I've come to feel as though my life has been rich and full. Death is not as scary a prospect at this point. (Female, AS10)

Staring death in the eye: People in this category acknowledged that the cancer, “will take my life;” that “life is not guaranteed in any way.” Neither remission status, nor cancer type was associated with this category.

Engaging Life—People who held death at arm’s length were engaged in worldly activities (e.g., work, war and peace, public health policy). People staring death in the eye engaged in more immediate family activities, “because there may not be a tomorrow.”

Cancer called upon people to live with more purpose. The type of cancer mattered. CRC and ostomy required overcoming stigma (while having LC did not): “It’s a disgusting thing. You get over it. ... I am still on the sunny side of the turf. ... Once you go through these battles, you have a more meaningful life.” (Male, AS11)

Associated Person Level Conditions: Relationships, especially the spouse, were the most important asset: “Those wedding vows you took a long time ago become more meaningful. You have to endure hardships—and life and death itself to understand their true meaning.” (AS11)

Prior life challenges: Surviving setbacks and tragedies opened hearts and deepened resolve: My boy was in a car accident. ... They didn’t think he’d come out of the coma. But we all came together. We didn’t give up. He did get out of that coma. ... [that] is a beam of hope for me. (Male, AS6)

Strategies for Living Fully

People used four strategies to face death and engage life.

1. Embracing Paradox—Paradoxes, like facing death/living fully, were common. Cancer sucked. It was a wound, a thief. But cancer was also a gift: “Every day’s gravy. ... There’s gonna be hardships. ... I’m happy to have them” (AS11), an adventure, “like going to college;” (Female, AS2), and an opportunity to learn about “having control and letting go.” (Female, AS7) A possible mechanism for holding such paradoxes was described:

When we’re involved in a very intense thing, ... all of our senses are heightened. We, as human beings can’t heighten part of our senses and hold back others. ... We’re tuned into everything, with all of our being. We can see the intensity of the pain, but we also see the intimacy of the life-giving and life-enhancing things. (AS10)

2. Reframing Time—Time—and the poignancy of its passage—truncated hope horizons, such as to see a grandchild born or vote in the upcoming election. People acted on long deferred dreams:

I’m facing the things I feel I should do and things I want to do, because there may not be a tomorrow. ... I want to get out to the West Coast to see my son. I’ve been putting this off for a long time. Now there’s a sense of urgency. (AP8)

Long-term planning was to assure the wellbeing of a surviving spouse. Or, it was tempered by reality—a recently married 35-year-old hoped to have a family—but he acknowledged that it would probably not happen.

Life review was not our research aim, yet people used vivid vignettes—of eloping to illustrate independence, or how early life poverty instilled a work ethic—to exemplify how life experience had contributed to their current wellbeing. One hard-living man (AS3), who had survived multiple health crises despite his doctors having given up, told a cathartic and

vivid life story of struggle (shot down in war), loss and redemption from alcoholic, multiply divorced and unemployed to a successful, happily married Alcoholics Anonymous sponsor. He summarized: “It all boils down to two things: ... Accept your higher power and you gotta take responsibility.” Some people asked for the interview transcript as a keepsake to share with others.

3. Deepening Connection With Others and Spiritual Forces

“I tell her that I love her many, many times a day. ... I say it a lot more, with purpose. With meaning!” (AS11)

People trimmed their social networks to the most important people and openly expressing affection:

The most important things are just the simple things—your family, the wife and kids, grandchildren. ... You have to spend more time with people you care about and tell them how you feel. ... It’s letting the other person know they are special. (AS9)

Cancer prompted everyone to connect with something bigger. Whether through religion or non-denominational perspective, the sentiments were universal: “The most important things are actually pretty simple. Make peace with the Good Lord. Make peace and be honest with yourself. Be thankful for what you have and live your life to the fullest.” (AS6) “On a basic philosophical level, I feel as though our jobs as a human being is to get in touch with what’s important and what we have to offer to the world while we’re here.” (AS10)

4. Aligning Actions with Priorities

“Everybody that’s had major surgery or heart attacks or cancer, they all tell you ... It’s what becomes important to them after they’re diagnosed.” (AS9)

In our sample, it came down to having more time and things yet to do.

Getting more time: Perceived suboptimal initial care at a community hospital awakened people’s fighting spirit to find better healthcare and to maintain hope. When her local oncologist suggested, “I can sign you up for hospice,” one woman responded, “I’m a fighter,” (AS2) and switched to an academic comprehensive cancer center. Another concluded, “People should not be afraid to switch doctors.” (AS5) A mid-50ish man and his wife both quit their jobs, left their social network behind and relocated near the comprehensive cancer center: “My primary doctor pooh-pooed me when I told him I had rectal pains.” (AS12) Taking action to switch doctors opened the door to realism-tempered hope:

The best thing you can hope for is a complete cure. If they can’t cure it, then I’m hoping they can slow it down. If they can’t slow it down, I’m hoping they can just keep it where it is as long as possible. And if they can’t do that, then I just hope there isn’t a lot of pain. (AS9)

Things left to do involved leaving a meaningful legacy. Vocational and avocational goals provided a sense of connection, mastery, purpose, legacy, or a way to explore cancer: “I love my job, I love my coworkers; I love my boss; I love what we do as a [non-profit] organization. It is something I can achieve and do very well—disease or not.” (AP5) One woman acknowledged growth as her artwork shifted to pro-social imagery to convey the “barbarism” of colostomy and the sorry state of CRC treatment and research. Another hoped to complete his furniture-carving project for his son. “It is something I can do something about. ... You don’t have to worry about the cancer.” (AP8) Two men facing death at close range were fixing up the house and getting the finances in order for their wives. These

productive activities suggested that purpose in life was linked to responsibility to others, that relationships would be their legacy—the love they had created would in turn provide peace to close out a life.

Discussion

We explored dimensions and strategies associated with thriving with advanced cancer and the influential person-level conditions. We interviewed ten patients with advanced cancer, selected by their oncologists for their resilience. Dimensions of living well were facing mortality and engaging fully in life. Strategies entailed holding paradox, reframing time with regard to planning ahead and reflecting back, deepening connection, and aligning their actions with their newfound priorities. Several person-level conditions influenced the dimensions of and the strategies for living well. Among the strongest were positive relationships, a sense that their lives had meaning and purpose, and a sense of competence and mastery.

Interpretation of Findings

People were able to live fully with their advanced cancer by facing death and thereby engaging in and appreciating ordinary life activities. Eastern and Western religious traditions, existential philosophy, and the contemporary dying well literature all reflect these concepts. (15–22) Strategies that facilitated living fully included holding paradox, reframing time, deepening connections and aligning actions with priorities.

Research confirms that existential issues are critical for people with advanced cancer and that some people paradoxically live more fully in the face approaching death. (18, 19) Like others, our participants recognized beauty within the ugliness and suffering of cancer, especially CRC. (20) Narrative, end of life and lifespan development literatures informed our interpretation of the findings. Many artistic, intellectual and spiritual traditions suggest being able to integrate apparent opposites. Integrating the intuitive/emotional (mythos) with the logical (logos) is a sign of wisdom. (21) People who tell polyphonic, or many-voiced, illness narratives cope better than people who tell simpler consistent linear stories. (22, 23) With regard to many-voicedness, symbolic interactionism, the theory that informs grounded theory method, assumes that people continuously construct their “self” as they interact in different social contexts. (24)

Consistent with Carstensen’s theory of socioemotional selectivity, our participants who were living with a shorter time perspective focused on emotionally meaningful goals; chose carefully who they spent time with; and were living in the “now.” (25)

Our in-depth interviews resulted in two forms of narratives and both pointed to the high levels of resilience. The cancer narratives were grounded in the present with a tempered hope for the future. According to Ezzy, such narratives promote an appreciation of ordinary daily events, unlike hopeless stories with an “empty” present. (23) People also engaged in dignity-enhancing life review, which is a natural and healthy life integration and end-of-life activity. (6, 26, 27)

People turned toward death by having conversations with their loved ones, and their higher power about emotional, existential and spiritual issues after a life of giving and receiving love, contributing to the greater good. (14, 15) Living well was associated with the eudaimonic orientation (purpose and contribution) versus a hedonic orientation (pleasure), encompassed the dimensions of psychological well-being: A meaningful life includes the assets of our participants: self-acceptance, positive relationships, competence and mastery, contribution to the social greater good, having hopes and goals even at the end of life, and a

sense of humor or irony. (10) Holding paradox, reframing time as it runs out, and deepening connection to spiritual or humanistic ideals seemed to spur personal growth in the face of death. Relationships, especially the scope, depth and growth of the spousal relationships, were the most profound dimension of coping with cancer.

Limitations

This study has its limitations. Results from this small, Caucasian resilient and happily married sample cannot be generalized. The single interview caught only one frame in the respondents' experience. Future research might benefit from follow-up interviews.

Implications for Practice

How do we build an assets focus into interventions that typically assess and address the needs and concerns of cancer patients? eHealth interventions with salient information, guided activities, and chat groups can be helpful at the end of life within an already-established online community.(28) Yet, we found that advanced cancer patients guarded their limited time and energy to spend it in meaningful ways with their loved ones. They were limiting and deepening their social connections, not expanding them. We thus question whether computerized assessment, feedback, and resources oriented towards problem solving or getting support with anonymous others would advance their *existential* goals.

Our accidental discovery was that the in-depth research interview itself might have been a meaningful intervention. People thanked the interviewer for the opportunity to tell the story and requested a copy of the transcript. Some noted, "This is the first time I've spoken about this." Although this discovery is anecdotal, life review is a positive life integration activity to make meaning of their life.(26, 27) Chochinov found that providing hospice patients with a well-honed life story developed from a life review interview reduced distress.(27) We also collected people's cancer narrative, which encouraged them to appraise their situation, identify options, reflect on strengths and challenges, articulate goals, appreciate paradox, and celebrate the complexity inherent in living a rich life.(8, 22, 23) Based on these findings, we conducted a feasibility test with cancer patients of an telephone-based life review and illness narrative intervention and online education to facilitate revising and sharing the story with his or her close social network.(29) A randomized control trial of My Living Story, a life review and social networking intervention, was recently completed with advanced cancer patients.

Conclusions

We found that there was a lot of life in the shadows of mortal time. People diagnosed with cancer can thrive despite a challenging cancer diagnosis, guarded prognosis and difficult treatment. How? By mobilizing assets, such as relationships, the ability to create meaning and purpose in life in the face of difficult circumstances, and acceptance coupled with a desire for personal growth. Strategies included embracing paradox, reframing time, deepening connections, living their priorities and leaving a meaningful legacy. By encouraging patients to enlist their assets and use these strategies, they might be able to live more fully in the face of advanced illness. The very act of constructing the story within the research interview seemed beneficial. Further research into the therapeutic use of narrative within standard cancer and palliative care should be pursued.

Acknowledgments

This research was funded by a pilot grant from the Center for Health Enhancement Systems Studies, University of Wisconsin-Madison's NCI-funded Excellence in Cancer Communication Research (P50 CA095817-0181). Mindy A. Smith, MD, MS provided editorial review. Mary Stone, University of Wisconsin Department of Family Medicine, provided editorial and bibliographical assistance.

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Figure 1.
 Model of Living Fully with Advanced Cancer