

Qualitative Health Research

<http://qhr.sagepub.com/>

"Unremarkable" Recoveries: Normalizing Adversity and Cancer Survival

Moira Killoran, Marilyn Jean Schlitz and Nola Lewis

Qual Health Res 2002 12: 208

DOI: 10.1177/104973202129119847

The online version of this article can be found at:

<http://qhr.sagepub.com/content/12/2/208>

Published by:



<http://www.sagepublications.com>

Additional services and information for *Qualitative Health Research* can be found at:

Email Alerts: <http://qhr.sagepub.com/cgi/alerts>

Subscriptions: <http://qhr.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

Citations: <http://qhr.sagepub.com/content/12/2/208.refs.html>

>> [Version of Record](#) - Feb 1, 2002

[What is This?](#)

“Unremarkable” Recoveries: Normalizing Adversity and Cancer Survival

Moira Killoran
Marilyn Jean Schlitz
Nola Lewis

Much of the existing popular literature suggests that survival from life-threatening diseases encourages a process of self-transformation. Seventeen long-term survivors of metastatic cancer were interviewed about the impact of a life-threatening condition on their life stories. Contrary to the existing literature, which suggests such an event greatly transforms the individual, nearly all of those interviewed for this study framed their unusual recoveries as being largely unremarkable. Traditional North American cultural values, which normalize adversity, appear to bolster the participants' beliefs that one can have control over one's health and can even resist a recurrence of cancer.

The search for the meaning of a serious illness—the “why me” question—is a common response following an undesirable life event (Silver & Wortman, 1980). A number of studies have looked at answers to this “why” question in terms of attributions of causality (Abrams & Finesinger, 1953; Bard & Dyk, 1956; Gotay, 1985; Linn, Linn, & Stein, 1982; Moses & Cividali, 1966). Other studies have examined the cognitive appraisals and coping styles in different cultural beliefs for the causes of illness (Baider & Sarell, 1983; Kohli & Dalal, 1998).

In addition to the *why* question, recent research has explored how people respond, including different coping styles. These studies have examined positive, negative, and neutral responses to undesirable life events. For example, research has explored how a traumatic experience may shatter a person's belief that the world is meaningful and benevolent (Janoff-Bulman, 1989). On the other hand, Taylor (1983) proposed that many people experience positive changes in their lives following a cancer diagnosis. Although the way people respond to an illness has been

AUTHORS' NOTE: The Brenden O'Regan Fund generously supported this research. Cancer incidence data used in this publication were collected by the Northern California Cancer Center under contract N01-CN-65107 with the National Cancer Institute, National Institutes of Health, and with support of the California Cancer Registry, a project of the Cancer Surveillance Section, California Department of Health Services, under subcontract 050M-8701/8-S1522 with the Public Health Institute. The content of this publication does not necessarily reflect the views or policies of the Northern California Cancer Center, the California Public Health Institute, or the U.S. Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. government. In particular, we would like to thank Dee West, Eva Glazer, and Sue Brown of the Northern California Cancer Center.

QUALITATIVE HEALTH RESEARCH, Vol. 12 No. 2, February 2002 208-222
© 2002 Sage Publications

extensively analyzed in terms of how they search for meaning and cope, little is known about how people describe—how they “narrate”—their response to illness in terms of their overall life story.

Various researchers have analyzed how narratives influence understandings of health and illness in a number of arenas (e.g., Crepeau, 2000). For example, personal narratives provide insight into how major events might be viewed as having a causative sequence and how meaning is created (Linde, 1993; Robinson, 1990). Many scholars have researched how the narrative form offers a means to examine the way people think about the origins of illness (B. J. Good & Good, 1980; Kleinman, 1980). Others have studied how people understand pain (Garro, 1992; M. D. Good, Brodwin, Good, & Kleinman, 1992; Jackson, 1994), disruption (Becker, 1997; Reissman, 1990), illness (Kleinman, 1980; Robinson, 1990), and death and aging (Rubinstein, 1995) through narrative.

M. J. Good, Munakata, Kobayashi, Manningly, and Good (1994) extended literary forms, such as narrative, to anthropological observations of clinical encounters between oncologists and patients. They argued that the act of constructing a “virtual plot” of what people remember from the past and what they imagine for the future shifts constantly as “the action progresses” (p. 855). The act of ordering a set of events, or *emplotting*, is a “crucial imaginative response of those who face sudden threat of an illness such as cancer” (p. 855). We would add that such emplotting is also of crucial importance for people who have survived advanced cancer for a long time.

Although an extensive psychosocial literature exists on coping strategies, social support, and related concerns among long-term survivors (see Reifman, 1995), *long-term* is usually defined as little more than 5 years. With the exception of numerous biographies that have celebrated the lives of long-term cancer survivors (e.g., Halvorson-Boyd & Hunter, 1995; Nepo, 1994) and a popular account of long-term survivors (Hirschberg & Barasch, 1995), we are unaware of research that has examined the experience of cancer, particularly an advanced diagnosis, in the life stories of very long-term survivors (e.g., more than 20 years).

In this article, we develop these lines of inquiry, examining how the event of a metastatic¹ cancer diagnosis, and the cancer experience generally, is emplotted or ordered in the overall life story for people who have survived advanced cancer for an unusually long time. The major finding of this study indicates that nearly all of the participants characterized the event as largely unremarkable. The typically traumatic diagnosis of metastatic cancer apparently provided little plot—no evident tension or suspense—within their overall life stories. Why would this be the case?

As anthropologists, we analyze these people’s characterization of their life stories as “unremarkable” in the specific context of (a) traditional North American cultural values, such as individual will, self-reliance, and control, that normalize adversity and (b) a North American master narrative about cancer (and illness generally) that emphasizes positive thinking, hope, and the “right attitude” generally as having curative power. Apparently, to view a serious diagnosis as life altering, to make it a plot within their life story, would have destabilized the participants’ sense of control over their survival. To admit that they have survived a major threat would mean to acknowledge their great vulnerability, which might open a wound best left untouched. Thus, the significance of the event was downplayed so as to not allow for the possibility of further ill health or a recurrence of cancer. Evidently, a belief in

the importance of individual will was emphasized to maintain control over one's health (see Kluckhohn & Strodtbeck, 1961).

Recently, Becker (1997) examined in great detail the narratives that people create to locate meaning and order for disruptions in their lives. In a similar vein, Tishelman and Sachs (1998) contributed to the literature on normality, arguing that people attempt to construct order as a means of coping with a disruptive situation. We build on such understandings, examining ways in which normality represents for this population that they have been "cured,"² in part due to their individual will, self-control, and self-reliance.

METHOD

In 1997, in collaboration with the Northern California Cancer Center, we identified 237 individuals who were diagnosed with metastatic cancer between 1973 and 1976, had survived at least 20 years, and were alive at last contact. Of this group, the research team was able to locate the original address and/or phone number for 99 individuals. After sending out letters explaining the study to this group of 99, we were able to contact 35 individuals who still lived in the San Francisco Bay Area. Seventeen agreed to be interviewed, and the other 18 refused participation. (Of the 61 we were unable to contact, 7 had died, 11 had moved out of the San Francisco Bay Area, and 46 had moved and an exhaustive search recovered no forwarding address.)

The group interviewed was predominantly female (12 women and 5 men),³ and the median age was 72. Fifteen of the 17 participants identified themselves as White.⁴ The majority (11 of 17) had at least a college education and another 11 out of 17 self-identified as being from a middle-class socioeconomic background.⁵ The majority were also Christian or at least raised Christian (15 of 17).⁶ Five of the 17 had had at least one recurrence of cancer. There were 10 types of metastatic cancer: testicular (2), prostate (1), nasopharynx (1), breast (2), ovarian (3), uterine (1), placenta (2), kidney (1), lymphoma (3), and Hodgkin's (1).

Statistically Speaking, How "Remarkable" Were These Recoveries?

In the 1970s, for those diagnosed with metastasized prostate, ovarian, uterine, and kidney cancer, there was less than a 10% chance of survival beyond 5 years (Gloeckler Ries et al., 1997). Those with breast cancer and cancer of the nasopharynx had a less than 18% chance of survival beyond 5 years (Gloeckler Ries et al., 1997). Thus, 9 of the 17 had less than an 18% chance of survival beyond 5 years. As these people had survived for 20 years, they clearly were exceptional. Survival rates for the remaining 8 are less clear (American Cancer Society, 1998). Data are either unavailable or are unavailable for an advanced stage of the particular disease.

After participants received a letter outlining the goals of the study, telephone contact was made to set up an interview. As the majority began to talk about their life stories on the phone (after agreeing to participate in the study), detailed notes were taken. The first author conducted 2- to 3-hour semistructured interviews in the participants' homes. Audiotaped recordings of the interviews were transcribed

verbatim, along with field notes recorded after the interview. Fictitious names were used for all the participants for both record keeping and public presentation.

The interview guide included both structured and open-ended questions. It began with a request for a brief life story. A series of questions focused on the participants' experiences of the diagnosis and illness, the meaning that the illness experience had in their lives, beliefs as to the cause of the illness and the reason for their unusual survival, and related questions.

After the interviews were completed and measured, careful readings of the interview transcripts were conducted to analyze the text for narrative components, common themes, and patterns. For example, broad themes in the brief life history given at the outset of the interview were refined and confirmed through additional examples and cases in contrast to the remainder of the interview.

The consistent and core theme of an "unremarkable" recovery—the role of advanced cancer in one's life story—was discerned through an analysis of the narrative structure of three versions of the same incident. These three renditions were elicited in each interview during (a) the participants' initial descriptions of themselves, which they volunteered at the time of the first phone contact; (b) a short description of their life stories asked at the onset of each interview (prior to any other exchanges); and (c) their descriptions of the role of metastatic cancer in the context of their overall life stories.

There were three subthemes to the core theme of unremarkable recovery that were evidenced in the majority of the interviews. These three characteristics represented the way the entire cancer experience was incorporated into the larger context of the participants' life stories. The participants tended to (a) view the diagnosis as insignificant; (b1) question the severity of the illness, disbelieve the diagnosis, and (b2) not worry; (c1) not question the cause but explain the "cure" in terms of faith in medicine, spirituality, and personal volition or (c2) explain both cause and cure in terms of biomedicine and personal volition. These various features are described below in further detail.

(a) Viewing the Diagnosis as Relatively Insignificant in One's Life Story

In the popular mass media, cancer diagnoses provide dramatic themes for soap operas, newspaper headlines, and television news stories (Lupton, 1994). Yet, in the life stories of this unusual population of survivors of advanced cancer, the diagnosis evidently provided no plot: Most participants reported that their diagnosis was not a major event in their lives. Characteristically optimistic attitudes, reflecting traditional North American values (Arensberg & Niehoff, 1975) and the belief that "no news is good news" were emphasized over any particular sense of drama. To illustrate, a 74-year-old woman named Alice began the description of her life story with a quick, easy smile and an emphatic (perhaps almost defensive), "I have had a *wonderful* life." When asked why she did not mention her metastatic cancer in her otherwise highly detailed life story (which included an in-depth description of a "horrendous" divorce), she replied that the advanced cancer was "just . . . another adventure in my life." Other participants explained that other major life events, such as a spouse's death, had greater significance, or even that "the cancer didn't bother me a bit."

Some respondents described the illness during the initial phone contact (prior to the interview) in terms of a plot in their life story. However, during the actual interview, their descriptions indicated that having advanced cancer did not ultimately play a significant role in their lives. For example, a 78-year-old woman named Elizabeth described initially on the phone that her survival from metastatic ovarian cancer was thanks to "a religious experience." She described strangers "witnessing for Christ" who stumbled on her home looking for directions. Of particular significance to her was the fact that this happened on the last day of her cancer treatment. These strangers "prayed to God to cure every cell" in her body. During the course of the interview, she repeated this story with considerable passion, but later acknowledged that "I didn't think of it at the time as a life-threatening illness." She now realized that "it would have killed me. It's known as the 'silent killer'" (she had less than a 10% chance of survival), but she did not think it was serious 20 years earlier, when she was being treated.

Although Elizabeth recognized the severity of her condition, she clearly did not deem it significant in her overall life story. In comparison to other life events, such as having had a condition akin to narcolepsy that nearly made her suicidal, the cancer "didn't bother [her] a bit." Near the end of the interview, she observed that interviewing people like her "would be boring" because there would be no plot. This suggests that she may have provided the story of the religious experience narrative as a "hook" to justify or even spice up the interview (even though she later discounted its significance). On reexamining notes from other participants, it became apparent that such a hook was evident in several of the interviews. Again, however, in the context of the overall life story, the hook straightened out into a seamless flow of a relatively normal life without drama. One of the possible explanations for this practice of normalizing the illness experience became lucid after an interview with a 53-year-old African American man named Ray.

In the initial phone conversation, he was very reluctant to be interviewed, explaining, "I'm a sort of covert person." The first thing he said before letting the interviewer in was, "As soon as I got off the phone with you, I got a cold." He claimed that his cold had progressed to pneumonia and the doctors could not understand why it persisted. In fact, it became evident that Ray chose not to see his advanced cancer as particularly significant in that it provided no plot to his overall life story—as that could disrupt his sense of control over his own health. He stated,

I'm a "wellness" guy. Part of that is [pause] very holistic. And it's very much [pause] "no sickness allowed." . . . I don't tolerate anything that constitutes leaning toward weakness. I cut off the peaks and the valleys for survival. . . . They kill you.

According to Ray, his belief in the strength of his own will keeps him alive. He viewed talking with an interviewer about his cancer and thereby being more vulnerable as potentially making him unwell, perhaps even causing his mysterious case of pneumonia.

Although Ray's fear that he could make himself vulnerable through discussing his illness was the most extreme example of a need to protect and normalize unusual recoveries, a similar current ran throughout nearly all the interviews. Another way in which such a belief system was evident was in the second characteristic of normalizing adversity through an unremarkable recovery, disbelieving ever

having had cancer and/or questioning the severity of the diagnosis (b1) or not worrying (described in b2).

(b1) Questioning the Diagnosis or Disbelieving the Severity of Illness

Jocelyn, an 83-year-old woman, was one of the people interviewed who provided a plot or "hook" during the initial phone contact. Prior to being interviewed, Jocelyn said (on the phone) that "*they* called it cancer—to this day I *don't* call it cancer." After she was diagnosed with metastatic breast cancer, her doctors told her that they could not guarantee her more than 6 months to live. Yet, during the interview she said that she was "very, very doubtful" that she ever had breast cancer.⁷ She believed that she had "pre-cancer cells." In her discussion of her treatment for metastatic cancer, she reiterated her disavowal of her metastatic cancer diagnosis. She declared that the doctors thought that "it looked cancerous." In addition to her incredulous tone, her choice of the word *look* as opposed to *was* (cancerous) was significant, as it allowed for the possibility that it was not cancerous.

Grace, an 88-year-old woman, was diagnosed with metastatic ovarian cancer when she was 63 years old. She expressed disbelief throughout the course of the interview that her cancer had metastasized. Grace asserted that she had had chemotherapy because "they never know whether it has affected other parts of the body." The doctors believed her cancer was metastatic and had indicated her diagnosis as such on her medical records, which a pathologist from our research team also confirmed. Grace, however, interpreted the reason for doing the chemotherapy treatment as a "possibility" that it had spread: "They were never very sure, and I had no signs of cancer . . . the cancer could have metastasized to other parts of the body. But I didn't feel that at all."

Grace's personal belief in her own ability to know "the truth" is given much greater weight than the truth-telling potential of biomedicine. She valued her own ability to read her own body as "normal" over other forms of knowledge.

Other participants also placed a greater weight on their own beliefs and their own sense of normalcy over the medical prognosis that they were given. Sometimes this took the form of a belief in a positive medical statement, despite a poor prognosis. Joan, a 57-year-old woman, was relieved when told that they "caught it early . . . [and] got it all out." She had been informed that she had only 6 months to live after she was diagnosed with metastatic renal cell carcinoma. But she expressed her feelings by saying,

I didn't believe 'em. . . . I didn't *dwell* on it. It went in one ear and out the other. . . . At the moment that they told me 6 months, I don't even remember what my reaction was. . . . And I guess because I felt that they caught it early, and I was told they got it all out, I guess in my dumb little mind I felt safe. You know, ignorance is bliss.

This "I'm-not-going-to-worry, I'm fine" was a theme common to many of the interviews. For example, a 63-year-old man of East Indian descent stated that when you have "some problem, you worry a little." Significantly, he downplayed having had metastatic cancer, saying that "sickness had nothing to do with" his life. Sickness did not qualify as a problem.

(b2) Not Worrying

Elizabeth, the 78-year-old woman who had been diagnosed with metastatic ovarian cancer, was asked if she worried. Like Joan, she semimocked herself in reply, saying, "I was just plain ignorant." Her self-mockery indicates that she thought she should have worried: "I didn't know, you know. And the odd thing is—it's in the family. I should have." Clearly, though, the diagnosis was still not something she thought much about. She acknowledged this tendency to deny the severity of an event when she said,

In our family, we have a tendency to put things out of our mind that we don't want to think about. And sometimes it can be dangerous because my mother did that, and so she didn't have treatments, and that's why she died.

Elizabeth viewed the diagnosis in terms of just doing the treatment, as a task to complete: "They just told me I had to do it, so I went ahead and did it." She did not think it was life threatening or serious; she just thought that her treatments were something that she needed to take care of. She seemed to retain some distance from her illness, like her mother, but instead of not taking care of the illness through treatments, she just incorporated this activity into her coping style.

Many of the respondents tied their "not worrying" strategy to beliefs in their own ability to affect the course of their lives. They described their state of mind as they followed their doctor's treatment plans with statements like "I never thought I wasn't going to be cured" or "I wouldn't let anything take my spirit down." Overall, personal will—be it through faith or personal abilities—was the dominant theme for this group. This is the third characteristic of these "unremarkable" recoveries: either not questioning the cause for their illness and understanding the cure in terms of their own faith, or explaining the cause and the cure in biomedical terms but taking personal responsibility for their cure.

(c1) Not Questioning the Cause for the Illness and Explaining the "Cure" in Terms of Faith in Medicine, Spirituality, and Personal Volition

Nearly all participants expressed a desire to not question or analyze what caused their illness. For example, Grace, the 88-year-old woman with ovarian cancer (mentioned earlier), asserted that she never wondered and did not know what caused her cancer. When her doctors suggested to her that it was hereditary, she disagreed. Her explanations illustrate her belief that her own personal volition to be healthy kept her healthy. She also invoked other related North American values, such as acceptance, perseverance, and optimism (see also Becker, 1997):

I didn't think about dying. . . . I still feel the same way. I still feel that something wonderful is going to happen tomorrow. And it usually does. There's hardly a day that something doesn't happen, some little thing, that I don't feel that God is watching over me.

This somewhat unruffled attitude or approach was also mirrored in the responses to how the participants explained their "cure."

All of the participants who did not question the cause for their illness had some explanation as to why they were cured. Their explanations were grounded in strong expressions of faith—be it an emphatic faith in Western biomedicine, such as “I had great belief it would work, there was no other option,” and/or a belief in the “grace of God,” and/or more personalized expressions of faith, such as “it wasn’t my time.” They all acknowledged some sense of spirituality and personal determination. For example, Ray expressed his belief as to what caused his remission in the following fashion:

I just think it’s the will. I *really* do. . . . It’s the will. It’s not *my* will, mind you. It’s the will of a God force. . . . I lived it. I have this all of the time. And I see it in people that didn’t survive. . . . My brother—I felt a definitive sense in the last year, and I told you that last year was our 3rd-year bell curve. Like, if you get over this you’re okay. Otherwise, out you go. And he went out. I felt the resignation that I *never* had. I felt him go, like, “Gee, I’m a little tired.” Or, “Maybe it’s over.” And, you know, it kind of scared me because I didn’t. . . . You know, I’m trying to be supportive but I wanted to tell him, like, you know, I’m not going to feel like that.

Ray expressed a nonsecular belief in a person’s will, a personal will that is also beyond the individual, a “God force.” Yet, he believed in a person’s freedom to act as they chose. Although he initially described his survival in terms of fate (“It’s the will of a God force”), he also admitted that he saw himself as choosing to not feel resigned, willing himself to live, unlike his brother. It is almost as if he was somewhat ashamed to admit that he held himself responsible for his own survival, so it was framed as a simultaneous belief in both a supernatural and personal volition. Many people would see prognostic odds as providing little sense of control (Becker, 1997, p. 43), but Ray interpreted his brother’s not surviving beyond the 3rd year as a result of his lack of a will to go on, something Ray chose not to do. Jocelyn also explained her survival in terms of her belief in her will and its connection to a God will:

And I kept just believing that your faith in what God . . . can do. And I was sure that there is enough something—a force, a power, in this world, for life to go on, not to be crushed. That I must have some part of that. I must have access to that same power that the little tiny weed that grows between the cracks of the cement, and it comes up and it finds a way to come up and grow. . . . I’m not saying that I didn’t need the medicine. . . . Whatever help you can get is fine. . . . Well, that’s faith when you just believe and say, “It’s going to be all right, it’s going to happen, I’m going to be fine.” That is taking it on faith. What else is it? Nobody could *guarantee* me anything, so it had to be.

Jocelyn’s faith was in her ability to have access to life in the face of adversity (a “weed growing between the cracks”). It was her faith beyond medicine, and her determination to access that power, that, she believed, sustained her. Jocelyn not only did not question the cause for her illness but also did not believe the initial diagnosis. Of greater importance were a sense of faith in biomedicine (despite her disbelief) and her belief system. Although about half the group did not question the cause of their illnesses, all who did explained this in biomedical terms and, more important, also expressed that their own personal will was significant in their survival.

(c2) Explaining the Cause and Cure in Biomedicine and a Sense of Personal Volition

The participants who attributed the cause for their cancer to medical/scientific explanations, such as hereditary factors or environmental hazards, also attributed their cures to their own personal volition, their belief in their own ability to influence their health. For example, Alice, the 74-year-old woman mentioned earlier, expressed her faith as a symbiotic relationship between medical science and her own belief system. She had no beliefs as to what caused her cancer because "they [medical science] don't know", but she believed that she had been cured because of her strong faith and belief in science. This belief in science was familial, as her father and brother were both scientists: "Oh, I think it was scientists. My brother's a scientist, my father was a scientist—medical science is wonderful." Alice said that she personally never questioned that her treatment would be successful because "I think *science* was the reason for the cure. . . . But, yes, I think positive thinking helps make you better."

A number of the respondents initially credited medical science and then added that they believed they were cured due to being "good" patients because, for example, they "followed the doctor's directions to a 't'" or they followed "all the rules." Jocelyn, the 83-year-old breast cancer survivor, said,

I'm sure what the doctors did was okay, but I don't think that would have cured me by itself. . . . I didn't just make up my mind that I was going to change my attitude or anything. I think I always had that kind of attitude. I think I always believed that somehow I was just a lucky person and things always turned out for me good.

Some participants believed that personal determination was part of their cure. For example, Amelia, a 47-year-old woman, went so far as to say that although medical science "cured" her of her cancer, during emergency surgery for complications, "there was a point where I knew that I could decide whether I was going to live or die."

DISCUSSION

There are two common images of cancer in popular culture: (a) the sense that a cancer diagnosis is a "death sentence" that causes some people to respond with an overwhelming sense of fear for themselves or for others and (b) the understanding that a diagnosis of cancer is transformational—a second chance at living, or a "wake-up call" to what is important in their lives (Weiss, 1997). These images speak to common beliefs in North American popular culture that the best means to overcome this fear is with a "fighting spirit" and a positive attitude so that one can "conquer and defeat the battle" against cancer (B. J. Good, Good, Lind, & Schaffer; Lupton, 1994).⁸

These images abound in our popular culture. For example, the back-cover endorsement for Rena Blumberg's (1982) book *Headstrong* describes her fight against cancer and states that "she won through determination and stubbornness" and is a "living proof that feisty women live longer" (p. 32). Implied in this endorsement is the belief that the "feisty" win and live, and the calm and complicit lose and

die. There is also a semiacademic, semipopular literature with a similar perspective. Psychologists Temoshok and Dreher's (1992) work on the "cancer personality" (described as a tendency to be "unfailingly pleasant, appeasing and—most important—unable to express emotions, especially anger" [p. 93]) has received a fair amount of public exposure. Norman Cousins's (1983) recounting of his "laughing" recovery from illness is a well-known example of the "transformative potential" of a life-threatening diagnosis.

A large number of academic publications also explore these themes in great detail. Some document the positive changes in people's lives following a diagnosis of cancer. For example, in a study of how breast cancer survivors adjusted to their diagnosis, many of the respondents claimed new insights into themselves and their lives, believed that they were emotionally better adjusted, and experienced positive changes in their priorities and values (Taylor, 1983).

Carter (1990, 1993) and Pelusi (1997) have written on the transformative potential of a breast cancer diagnosis. They documented psychological and/or social phases or stages of recovery from breast cancer. A dominant theme in Carter's (1990, 1993) studies was that the survivors experienced a period of going through the survival process and the resulting emergence of a more authentic self. In a similar vein, Pelusi (1997) spoke of breast cancer survivors facing uncertainty and growing into a journey of enlightenment and self-transcendence.

Given this popular and academic context, the major finding of our study—that 20-year survivors of metastatic cancer characterized their experience as essentially unremarkable—stands out in rather bold relief. As people who had been given very slim chances for recovery, it was surprising to find that the majority expressed a calm and detached approach to their illness. Why would this be?

At first glance, the most obvious explanation for our study population's unremarkable recovery stories might be that the majority came of age in the 1940s and 1950s (median age was 72), a time prior to the mainstreaming of psychology within American culture (Pipher, 1999), and thus were less influenced by the 1970s "me decade," when Americans are said to have become more interested in their own psyches (Wilkinson, 1988). For baby boomers who grew up during this era, it is easy to see how a "death sentence" would be seen as psychologically transformative, whereas for those that have lived through the Depression, a tragedy such as a cancer diagnosis might be viewed within the realm of possibility and "the hard knocks of life" (see also Patterson, 1987).

In our study, however, there were baby boomers for whom this illness had relatively little significance. For example, one 44-year-old man had not even informed his grown sons about the advanced cancer, even though his body had been physically altered from the treatment. He commented that he had simply dealt with the advanced cancer and "moved on," allegedly never worrying about dying. With the exception of one woman who described her diagnosis as "transformative," all the others—the baby boomers (6 of 17) and those in their early 60s through late 80s (10 of 17)—described their diagnoses and recoveries as unremarkable.

Similarly, the generational difference theory would not explain the transformational healing described in Taylor's (1983), Carter's (1990, 1993), and Pelusi's (1997) studies of breast cancer survivors, as all of the participants in these studies were of generations older than baby boomers, approximately the same age as most of the participants in our study. The majority of women for all of these studies were White, Christian, and from middle- to upper-income brackets, again, very similar to

the participants in our study. The women in these studies, therefore, were similar demographically yet expressed very contrary views of the role of the cancer experience in their life stories. For earlier studies, it was transformational; for ours, insignificant.

The most obvious differences between our study and other studies are the length of time since treatment and stage of cancer at the time of diagnosis.⁹ In Taylor's (1983), Carter's (1990, 1993), and Pelusi's (1997) studies, the respondents were fairly recently diagnosed—they had survived an average of only 2.6 years (Taylor), 7.6 years (Pelusi), or 10.6 years (Carter)¹⁰ and were not survivors of advanced metastatic disease.¹¹ Thus, this unremarkable characterization cannot be explained away by differences between generations, either in terms of our study, which included both generations, or other studies, which included generations earlier than baby boomers.

Would the fact that our study population consisted of very long-term survivors (more than 20 years) of an advanced stage of the disease greatly influence their characterizations of their experience as conventional and utterly ordinary? Perhaps their desire to preserve their sense of self, which had not been identified with a serious illness, coupled with the severity of their diagnosis and accompanying vulnerability, led to an emphasis on the insignificance of the experience with metastatic cancer.

Martha Balslem (1993) has written one of the few full-length ethnographic monographs on North American cultural beliefs about cancer.¹² In it she examined lay and professional attitudes toward cancer prevention and working-class beliefs about cancer causation. Balslem described an underlying cultural belief in the work of public health professionals that individuals are responsible, through lifestyle choices, for their illness. The study also indicated that the working-class community greatly resented being blamed for their illness (by public health professionals) but did believe that one's attitude causes cancer, whereas none of the individuals surveyed believed that one's attitude causes heart disease.

However, these individuals also believed that to think about or try to prevent cancer is to tempt fate. Thus, they referenced stories of "defiant ancestors," who stayed healthy by keeping a positive attitude and refusing to acknowledge symptoms. The beliefs that the wrong attitude can cause cancer and a positive one can cure it are pervasive in North American culture. Although they are often thought of as specific to Americans of European descent of a middle-class background, they are part of the North American cultural belief system about cancer and, as Balslem (1993) demonstrated, are also applicable to other cultural and class levels within North American society.¹³

CONCLUSION

In this study, we have described how long-term survivors of metastatic cancer attempted to normalize their unusual experience within the North American cultural context by downplaying any significance of the event in their life stories. Contrary to the popular and scholarly literature, which insists that survival from life-threatening diseases encourages life transformation, these life stories suggest that the North American cultural values that normalize adversity have greater resonance for this population.

For individuals who have some distance from their disease and are experiencing decreased uncertainty, of greater importance to them is a sense of normalcy, demonstrating that they were "cured" through self-control and self-reliance. This references the North American cultural belief that individuals bear the responsibility for curing their own illness through positive thinking, hope, belief in God, and having the right attitude. Downplaying the metastatic cancer diagnosis and characterizing themselves as normal individuals with strong wills and good attitudes, people who were "believers," be it in religious faith or biomedicine, managed to maintain a sense of control over their health and disallow any further vulnerability to cancer.

This practice was distinguished by three characteristics: (a) viewing the diagnosis as insignificant; (b1) questioning the severity of illness, disbelieving the diagnosis, and (b2) not worrying; and (c1) not questioning the cause and explaining the cure in terms of faith, medicine, and individual will or (c2) explaining both cause and cure in terms of biomedicine and personal volition.

Our analysis uncovered stories without life transformations, stories of unremarkable recoveries. We believe that the length of time since the diagnosis, coupled with the severity of their condition, may have shifted the participants' focus toward North American cultural values that normalize adversity and protect the individual from further trauma. Many respondents acknowledged a felt cultural stigma in our society associated with having cancer. To be unremarkable is to be healthy; to be remarkable is to be unhealthy and metaphorically connected with all of the negative images and the stigma associated with cancer in our society (Lupton, 1994; Sontag, 1990).

This stigma may arise from being seen to have the opposite of the highly regarded traditional North American cultural values of strength, fortitude, and invulnerability, that is, being weak and vulnerable (see Wilkinson, 1988). Such a stigma may be due to one's being seen as defeated, a quitter, which goes against the spirit of "try, try again" and "never say die" (DuBois, 1955). Finally, and perhaps most crucially, this stigma may be due to being seen as losing control and thus relinquishing the individual's ability to alter his or her own fate (Becker, 1997; Kluckhohn & Strodtbeck, 1961).

NOTES

1. Metastatic cancer is considered very advanced and life threatening because the cancer has spread beyond the original site, such as a primary tumor, to other organs of the body.

2. The word *cure* is placed in quotation marks to indicate awareness that this is not a medically correct term but was used by most participants.

3. This is similar to the original sample of 99, which contained 34 men and 65 women.

4. The remaining 2 participants identified themselves as Black and Indian, respectively.

5. Of the remaining 6 participants, 1 identified as upper-middle class, and 5 identified as lower-middle class.

6. The remaining 2 participants identified themselves as Jewish and Hindu, respectively.

7. Although we do not have access to information on how the diagnosis was communicated to Jocelyn, we were able to obtain her medical records, and a pathologist from our research team confirmed her original diagnosis.

8. A large number of both academic publications and popular references promote the idea that a "fighting spirit" is an effective coping style that enhances adjustment and cancer survival outcomes (see,

for example, Classen, Coopman, Angell, & Spiegel, 1996; Greer, Morris, & Pettingale, 1979; Spiegel, 1993; Watson, Haviland, Greer, Davidson, & Bliss, 1999).

9. Some might also argue that because these women were all breast cancer survivors and thus endured a major physical transformation (mastectomy) that is heavily laden with cultural values in the North American context, this in itself would encourage a sense of self-transformation.

10. Taylor's (1983) findings were specific to women who were 2-year survivors of breast cancer, the range being 1 to 60 months; Pelusi's (1997) study involved women who were on average 7.6 years posttreatment, with a range of 2 to 15 years. Carter's (1990, 1993) sample targeted 25 "long-term survivors," defined as women with between 5 and 26 years of survival time but whose mean survival time was just 10.56 years.

11. The exception is 18% of Taylor's (1983) sample, who were diagnosed with metastatic cancer.

12. Many researchers have examined North American knowledge and beliefs about cancer. However, the studies are generally written from a public health perspective, in which knowledge tends to mean how much people know about biomedical beliefs, as opposed to beliefs as folk models. Anthropologists tend to view these terms not as contrary but as having differing meanings. See Pelto and Gretel (1997) for an interesting discussion of this topic.

13. *Middle class* is itself a problematic term in that "the general feeling in America is that you are middle class if you say so" (Wolfe, 1999, p. 2). However, we are using the term in the sense that Wolfe (1999) suggests: as a *mentalite*—a cluster of attitudes, beliefs, practices, and lifestyles.

REFERENCES

- Abrams, R. D., & Finesinger, J. E. (1953). Guilt reactions in patients with cancer. *Cancer*, 6, 474-482.
- American Cancer Society, California Division, and Public Health Institute, California Cancer Registry. (1998). *California facts and figures, 1998*. Oakland, CA: Author.
- Arensberg, C. M., & Niehoff, A. H. (1975). American cultural values. In M. A. Runkievich & J. P. Spradley (Eds.), *The Nacerrima* (pp. 363-378). Boston: Little, Brown.
- Baider, L., & Sarell, M. (1983). Perceptions and causal attributions of Israeli women with breast cancer concerning their illness: The effects of ethnicity and religiosity. *Psychotherapy and Psychosomatics*, 39, 136-143.
- Balshem, M. L. (1993). *Cancer in the community: Class and medical authority*. Washington, DC: Smithsonian Institution Press.
- Bard, M., & Dyk, R. B. (1956). The psychodynamic significance of beliefs regarding the cause of serious illness. *Psychoanalytical Review*, 43, 146-162.
- Becker, G. (1997). *Disrupted lives: How people create meaning in a chaotic world*. Berkeley: University of California Press.
- Blumberg, R. (1982). *Headstrong: A story of conquests & celebrations . . . living through chemotherapy*. New York: Crown.
- Carter, B. J. (1990). *A phenomenological study of survivors of adult cancer*. Unpublished doctoral dissertation, University of California, San Francisco.
- Carter, B. J. (1993). Long-term survivors of breast cancer: A qualitative descriptive study. *Cancer Nursing*, 16, 354-361.
- Classen, C., Coopman, C., Angell, K., & Spiegel, D. (1996). Coping styles associated with psychological adjustment to advanced breast cancer. *Health Psychology*, 15, 434-437.
- Cousins, N. (1983). *Anatomy of an illness as perceived by the patient*. New York: Bantam.
- Crepeau, E. B. (2000). Reconstructing Gloria: A narrative analysis of team meetings. *Qualitative Health Research*, 10, 766-787.
- DuBois, C. A. (1955). The dominant value profile of American culture. *American Anthropologist*, 57, 1232-1239.
- Garro, L. (1992). Chronic illness and the construction of narratives. In M. D. Good, P. E. Brodwin, B. J. Good, & A. Kleinman (Eds.), *Pain as human experience: An anthropological perspective*. Berkeley: University of California Press.
- Gloeckler Ries, L. A., Kosary, C. L., Hankey, B. F., Miller, B. A., Harras, A., Edwards, B. K. (Eds.). (1997). *SEER cancer statistics review, 1973-1994* (Pub. No. 97-2789). Bethesda, MD: U.S. Department of Health and Human Services, National Institute of Health, National Cancer Institute.

- Good, B. J., & Good, M. D. (1980). The meaning of symptoms: A cultural hermeneutic model for clinical practice. In L. Eisenberg & A. Kleinman (Eds.), *The relevance of social science for medicine* (pp. 165-196). Boston: D. Reidel.
- Good, B. J., Good, M. D., Lind, S. E., & Schaffer, C. (1990). American oncology and the discourse on hope. *Culture, Medicine and Psychiatry, 14*, 59-79.
- Good, B. J., & Del Vecchio Good, M. J. (1994). In the subjunctive mode: Epilepsy narratives in Turkey. *Social Science & Medicine, 38*, 835-842.
- Good, M. D., Brodwin, P. E., Good, B. J., & Kleinman, A. (Eds.). (1992). *Pain as human experience: An anthropological perspective*. Berkeley: University of California Press.
- Good, M. J., Munakata, T., Kobayashi, Y., Manningly, C., & Good, B. J. (1994). Oncology and narrative time. *Social Science & Medicine, 38*, 855-862.
- Gotay, C. C. (1985). Why me? Attributions and adjustment by cancer patients and their mates at two stages in the disease process. *Social Science & Medicine, 20*, 825-831.
- Greer, H. S., Morris, T., & Pettingale, K. W. (1979). Psychological response to breast cancer: Effect on outcome. *Lancet, ii*, 785-787.
- Halvorson-Boyd, G., & Hunter, L. K. (1995). *Dancing in limbo: Making sense of life after cancer*. San Francisco: Jossey-Bass.
- Hirshberg, C., & Barasch, M. (1995). *Remarkable recovery*. New York, NY: Riverhead.
- Jackson, J. E. (1994). The Rashomon approach to dealing with chronic pain. *Social Science & Medicine, 38*, 823-834.
- Janoff-Bulman, R. (1989). Assumptive worlds and the stress of traumatic events: Applications of the schema construct. *Social Cognition, 7*, 113-136.
- Kleinman, A. (1980). *Patients and healers in the context of culture*. Berkeley: University of California Press.
- Kluckhohn, F. R., & Strodtbeck, F. L. (1961). *Variations in value orientations*. Evanston, IL: Row Peterson.
- Kohli, N., & Dalal, A. K. (1998). Psychological recovery of women with cervical cancer: The role of cultural beliefs. In W. J. Lonner, D. L. Dinnel, D. K. Forgays, & S. Hayes (Eds.), *Merging past, present, and future in cross-cultural psychology* (pp. 348-364). Lisse, the Netherlands: Swets & Zeitlinger.
- Linde, C. (1993). *Life stories: The creation of coherence*. New York: Oxford University Press.
- Linn, M. W., Linn, B. S., & Stein, S. R. (1982). Beliefs about causes of cancer in cancer patients. *Social Science & Medicine, 16*, 835-889.
- Lupton, D. (1994). *Medicine as culture: Illness, disease and the body in western societies*. London: Sage.
- Moses, R., & Cividali, N. (1966). Differential levels of awareness of illness: Their relation to some salient features in cancer patients. *Annals of the New York Academy of Science, 125*, 984-994.
- Nepo, M. (1994). *Acre of light: Living with cancer*. Greenfield Center, NY: Greenfield Review.
- Patterson, J. T. (1987). *The dread disease: Cancer and modern American culture*. Cambridge, MA: Harvard University Press.
- Pelto, P. J., & Gretel, H. (1997). Studying knowledge, culture, and behavior in applied medical anthropology. *Medical Anthropology Quarterly, 11*, 147-163.
- Pelusi, J. (1997). The lived experience of surviving breast cancer. *Oncology Nursing Forum, 24*, 1343-1353.
- Pipher, M. (1999). *Another country: Navigating the emotional terrain of our elders*. New York: Riverhead.
- Reifman, A. (1995). Social relationships, recovery from illness, and survival: A literature review. *Annals of Behavioral Medicine, 17*, 124-131.
- Reissman, C. K. (1990). Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science & Medicine, 30*, 1195-1200.
- Robinson, I. (1990). Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis. *Social Science & Medicine, 30*, 1173-1186.
- Rubinstein, R. L. (1995). Narratives of elder parental death: A structural and cultural analysis. *Medical Anthropology Quarterly, 9*, 257-276.
- Silver, R. L., & Wortman, C. B. (1980). Coping with undesirable life events. In J. Garber & M.E.P. Seligman (Eds.), *Human helplessness: Theory and applications*. New York: Academic Press.
- Sontag, S. (1990). *Illness as metaphor and AIDS and its metaphors*. New York: Doubleday.
- Spiegel, D. S. (1993). *Living beyond limits*. New York: Fawcett Columbine.
- Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist, 38*, 1161-1173.
- Temoshok, L., & Dreher, H. (1992). *The Type C connection: The behavioral links to cancer and your health*. New York: Random House.
- Tishelman, C., & Sachs, L. (1998). The diagnostic process and the boundaries of normality. *Qualitative Health Research, 8*(1), 48-60.

Watson, M., Haviland, J. S., Greer, S., Davidson, J., & Bliss, J. M. (1999). Influence of psychological response on survival in breast cancer: A population-based cohort study [See comments]. *Lancet*, 354, 1331-1336.

Wilkinson, R. (1988). *The pursuit of American character*. New York: Harper & Row.

Wolfe, A. (1999). *One nation, after all*. New York: Penguin.

Moira Killoran, Ph.D., is an associate research scientist at the Prevention Research Center, Berkeley, CA.

Marilyn Jean Schlitz, Ph.D., is director of research at the Institute of Noetic Sciences and senior scientist at the Complementary Medicine Research Institute at the California Pacific Medical Center.

Nola Lewis is the associate director of research at the Institute of Noetic Sciences.