The Transformative Experience of Cancer Survivors

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Examining the concept of transformative experience—defined as an event that changes an individual’s life so as to refocus priorities and self-identity—this chapter begins with the personal transformative experience of one of the authors, followed by the examination of personal interviews with 10 other cancer survivors. The concept’s implications for communication research and action are explored.

I felt a close relationship with other cancer survivors; several individuals that I scarcely knew (one was a total stranger) disclosed to me their own experience with cancer. While sitting in a waiting room to see my doctor or other specialists, I found it easy to talk with other cancer survivors, including those who were ethnically or socio-economically quite different from me. I tried to help other individuals with cancer, aiding them in understanding what they were going through. My general feeling of altruism became much stronger. Having received prayers and other types of support from many others, led me to feel that I should return this assistance to others. My previous focus on career and success faded.

Late Everett M. Rogers
From a diagnosis of kidney cancer in late 2002, to his surgery on January 23, 2003, the author quoted above became one of an estimated 9.5 million cancer survivors residing in the United States. In very recent years, these individuals are receiving increasing attention from the National Cancer Institute and other organizations that support health communication research and action. Cancer survivors (formerly called “cancer victims”) are increasingly well-organized in person-to-person and online support groups, and are gaining medical and political attention.

Many of the cancer support groups function to exchange information, to question medical and other authority, to discuss possible participation in cancer drug trials, and to provide emotional support to fellow cancer survivors and their family members (Ginossar, 2002). Together, such support facilitates the transformation process inherent in individuals’ experiences with cancer.

The objective of the present chapter is to explore the concept of transformation, defined as an event that initiates a process of self-communication within an individual and changes his/her life so as to refocus priorities and self-identity. This concept has received some attention from adult education and from health communication scholars in understanding (1) the re-entry of individuals into higher education, and (2) positive health behavior changes of People Living with HIV/AIDS (Merizow, 1978; Mohammed & Thombre, 2005). However, the concept of transformation has not yet received much research attention from communication scholars, despite its seeming importance in shedding new light in understanding aspects of intra-personal and self-communication processes within an individual. Here we study the individual transformation process for cancer survivors, which resulted from their diagnosis with cancer. Our data are
retrospective reports from a relatively small number of individuals, but suggest the crucial role of transformation in understanding a self-communication process that results in positive and lasting behavior change. Further, the narratives examined in this chapter suggest that spirituality often plays a role in this transformation process.

The author’s cancer experience and the experiences of the cancer survivors interviewed here suggest the nature of transformation, and the several steps or stages that are involved: (1) the triggering event (cancer diagnosis in this case), (2) a catalytic experience (the transformation), (3) immersion, (4) a turning point, (5) integration, and (6) disclosure to others (Merizow, 1978; Mohammed & Thombre, 2005). These stages are detailed later in our analysis of the interview data. To that end, we investigated the following research questions:

1. Does diagnosis with a life threatening disease (cancer) initiate a process of transformation?

2. How do cancer survivors experience a transformation?

2 a: Do a common set of stages occur for individuals in the transformation process?

3. How, if at all, does spirituality emerge into the transformation process?

**Background**

Everett M. Rogers’ diagnosis with kidney cancer in December, 2002 was made on the basis of a CAT scan, ordered as part of a general set of tests for another medical purpose. The photographic plate showed the left kidney had become a large dark mass which was undoubtedly cancerous. It had to be removed as soon as possible. The
diagnosis came as a complete surprise to Rogers; there were no definite symptoms or advanced warnings of this cancer. Rogers’ immediate reaction to the diagnosis of cancer was shock. In his words:

I had been leading an active life and enjoyed my teaching and scholarly work. I wondered, “Why me?” My next thoughts were about how kidney cancer might affect my future life. Would I survive the operation? Then, if my right kidney could not carry the load, what would my life be like, tethered to a dialysis machine? I was beginning to realize that my cancer would change my daily living in very important ways. My wife helped me conduct Internet information searches on kidney cancer diagnosis and treatment.

Over several weeks, Rogers gradually accepted the transformation caused by diagnosis with cancer. Reflecting on the amount of time spent each day considering his “…life and career and speculating about the future.” he stated “I felt that whatever was thrown at me, I could somehow cope. Especially important to me during this period were conversations with my wife, which helped clarify my own thinking.”

The surgery on January 23, 2003, was a turning point in the transformative experience for Rogers. He described it, saying:

I was unconscious during the day-long operation and for three days afterwards while in the ICU (intensive care unit). I spent one week in the university hospital, and then several weeks recovering at home. I slept for many hours each day as my body rebuilt itself. Much of the remaining time was spent in contemplation, reliving my past life experiences and planning future activities.
Gradually, Rogers resumed teaching, student advising, and other university duties in the month or two after surgery. He described the revelation of having been transformed:

I began to understand that the degree to which I could resume my former daily lifestyle was a marker for my degree of recovery. For instance, during the week that I was hospitalized, I was able to get out of bed and walk through the hospital corridors. Nurses and other staff treated me, while walking, as a person. When I lay in bed, they treated me as a patient. I felt like I experienced transformation.

Rogers led an active transformed teaching and research life conducting research in the health arena, directing masters and doctoral dissertations. He resumed traveling and speaking engagements. However, in May 2004, Rogers’ cancer recurred and in late October 2004 he passed away with complications of cancer. During his last days Rogers devoted extensive time to reading and contemplating about the transformation process and expressed that understanding transformation is key to understanding lasting health behavior change process.

**The Concept of Transformative Experience**

The concept of transformative experience (also called transformative perspective) was first studied by scholars of adult education, who investigated the circumstances leading adults to return to school. A pioneering study dealt with the transformative experiences that encouraged adult women to enroll in a community college (Mezirow, 1978). In recent years, scholars, mainly in adult education, extended the study of transformative experiences to individuals diagnosed with HIV (Baumgartner, 2002; Courtenay, Merriam, & Reeves, 1998).
A transformation mainly arises from a “disorienting dilemma” (Mezirow and Associates, 2000) that an individual faces in life. This dilemma could be triggered by diagnosis with a life threatening disease, by a life changing happy event like marriage, birth of an offspring, graduation, or getting a job, or by a sad event like losing a job, divorce, death of a family member, or a serious personal injury in a car accident. The positive or negative experience (the disorienting dilemma) sparks a process of self-reflection and contemplative thought in an individual, leading to transformation.

Baumgartner (2001) identified lead markers in the transformative experience include the following. First, the individual experiences a heightened sensitivity to life and its meaning that is a direct result of contemplation and thought about why the disorienting dilemma occurred to him or her and not to others. Here the person undergoes a stage of silence for a period of time, perhaps rarely talking to anyone, followed by adjustments to his/her existing and new perspectives. Second, after the realization period, an individual is open to change his or her existing viewpoints. Such realization leads an individual to establish a somewhat new identity. In the case of HIV/AIDS, the deep contemplation process helps individuals accept their new HIV-positive status (Baumgartner, 2001). In the case of cancer, survivors become aware of changes that need to be undertaken in their post-cancer life.

Third, the new identity is further centralized after the individual is comfortable to disclose to others his for her condition. Immersion in the new community of cancer survivors is accompanied by a desire to educate others and to provide support to others. The individual makes personal behavior changes, urges others to do the same, and influences others to do the same by sharing his/her experiences. Mezirow and Associates
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(2000) studied the “disorienting dilemma” of diagnosis with HIV/AIDS and found that the transformative experience leads an individual to self-examination, and thus to a new frame of reference.

Fourth, a transformative experience creates an immediate need for information about various alternatives. For example, cancer survivors and their family members typically make extensive searches of Web sites in an attempt to learn more about their cancer and treatment alternatives, and these individuals join both online and person-to-person support groups with other people who have experienced the same cancer (Ginossar, 2002). The transformative event leads people into group communication with other cancer survivors.

Fifth, cancer survivors wholeheartedly narrate their experiences to others in this stage of the transformation process. The purpose of sharing personal experiences with others is to change their behavior which is a result of the transportation effect of the narratives. This effect is likely to be especially strong when the narrative of a cancer survivor is exchanged with other survivors, as in face-to-face support groups or online. Despite various studies documenting the power of narrative, however, little research attention has been given to behavior changes caused by narratives (Green & Brock, 2000).

Past research on transformative experience indicates that the resulting changes are in fact long lasting. Mezirow (1978) found in his research of female adults returning to school that transformative experiences are stable over time. An individual seldom returns to a previous perspective once a transformation has occurred. The transformative experience lasts over time. As another example, Baumgartner (2002) re-interviewed 11
respondents in 1995, 1998, and 1999; their transformative experience, resulting from
diagnosis as HIV-positive, remained stable.

Mohammed and Thombre (2005) analyzed 164 self-reported HIV/AIDS stories
on the World Wide Web for evidence of a transformative perspective. Sixty percent of
the 164 narratives demonstrated a first stage of transformative experience: Shock, fear,
denial, and relief resulting from the triggering event (the disorienting dilemma). A
distinct catalytic experience, a second stage of transformation, was demonstrated in 48
percent of the stories. The authors coded four other markers in the transformative
experience: (1) immersion in the HIV/AIDS community, (2) educating others, (3) the
centrality of HIV identity, and (4) an adjustment in perspectives. Evidence was also
found for (5) making a meaningful contribution to life, (6) heightened sensitivity to life,
and (7) a desire for undertaking service to others (altruism), especially to other
individuals living with HIV/AIDS. Thus, diagnosis of an individual as HIV-positive
frequently brought about major behavior changes in that individual’s life, which in turn
affected others.

Based on the above past research and theorizing, we seek in this chapter to
understand a cumulative set of stages that may occur for individuals in the transformation
process, especially for diagnosis with cancer.

**Methods**

We examined the nature and extent of transformative experiences by conducting
in-depth interviews with 10 cancer survivors in 2003. We gained access to these
participants through Bernard Lash, a volunteer with People Living Through Cancer
(PLTC), and with Priscilla Lash, administrative assistant at PLTC. PLTC is a large cancer
support group (with 7,000 members) in Albuquerque, New Mexico. An in-depth interview was also conducted with Lash (2003) himself, a survivor of tonsil cancer for the past 23 years. Each cancer survivor was interviewed if they expressed willingness to share their experiences in coping with cancer. One respondent was re-interviewed four months after our initial interview.

In-depth interviews lasting an hour to an hour-and-a-half were conducted with each cancer survivor. A semi-structured open-ended interview guide was used (Appendix A). Extensive hand-written notes were taken during each interview, and each interview was taped recorded. The authors then examined the data for emergent themes concerning the transformation experience related to self-reported intra-personal communication after diagnosis with cancer.

Results

Each cancer survivor narrated experiencing a process of self-communication and deep contemplation. Intrapersonal communication is an important part of transformation. A common question asked by individuals experiencing a disorienting dilemma (cancer diagnosis in this case) to themselves is: Why me? (R. Q. # 1). This stage sparks a process of intense information search, a first step towards making positive behavior changes by the individual. The process leads the individual to take control of the post-cancer life situation, and later manifests into a new cancer survivor identity. The identity change is followed by a desire to educate others in a similar situation and to inspire them in making positive behavior changes (see Table 2). Each cancer survivor that we interviewed described undergoing a transformative experience (Table 1), although three of the ten respondents described their transformation as slight.
R. Q. # 2 asked: How do cancer survivors experience a transformation? Each individual underwent a unique response to the reality of being diagnosed with cancer, but nevertheless followed certain common patterns in the transformative experience process. The stages of shock/disbelief, surprise, and anger were commonly reported by our respondents. The phase typically lasted only a week or two. Respondents quickly advanced into active information-seeking behavior, thus taking control of their situation and orienting themselves toward a new cancer identity.

Most respondents reported they were deeply self-reflective about their cancer diagnosis and the meaning of their world in the larger scheme of things. A certain amount of anxiety about the success of their cancer treatment and whether they would survive surgery, radiation or chemotherapy existed. At this phase, they started questioning their physicians, seeking support by joining a cancer support group and gathering still more information.

R. Q. # 2a asked: Do a common set of stages occur for individuals in the transformation process? and

R. Q. # 3 asked: How, if at all, does spirituality emerge into the transformation process?

The examination of data from in-depth interviews revealed several themes relating to a common set of six stages that were found in the transformation process for our respondents (Table 2). Different themes relating to spirituality emerge as an essential part of the transformation process in our respondents’ disclosures. We begin with Donald and two additional interviewees who perceived their transformation as slight. We
continue with “Gordon” and the remaining seven interviewees who considered their transformation more pronounced. Only the first names of respondents are used in order to maintain their anonymity and protect their identity.

Donald, a prostate cancer survivor, suspected in advance of diagnosis that he might have this cancer. Even then, the actual diagnosis was a shock. He trusted his medical doctor completely and accepted his new medical situation. “I was not going to wait and die. I said okay, I have cancer. Now tell me how I can get over it.” His transformative experience resulted in a firm belief in a higher power. Donald explained:

I was pretty spiritual all my life and after cancer I realized that by the grace of God, I am alive. There is a higher power and I have given myself to that power. I live 24 hours a day, not yesterday or today. If someone with cancer calls me, I give 100 percent of my time to help that individual. I enjoy everything of life and now have a closer relationship with life.

[Put Table 2 about here].

Notably, spirituality was advanced as a key component of Donald’s transformation. He professed to have always been a spiritual person and framed his post cancer experiences in terms of a strengthened sense of meaning or spiritual reawakening. Again, transformative experiences can be linked to spiritual experiences leading to transcendence and thus more meaningful relationships and greater freedom in the spiritual sense (Newman, 2000). These factors are considered an expansion of consciousness.
Compared to other cancer survivors interviewed for the current study, however, Donald professed having experienced a relatively slight transformation. We would suggest two possible reasons for this. First, it may be that because Donald was already “highly religious” prior to his diagnosis, he didn’t view his transformation as one where the spiritual aspects of his life had changed appreciably. Second, and perhaps more importantly, Donald’s slight transformation may be explained by the relative brevity of his cancer experience. Donald received early treatment for his cancer, and perceived it as mild. Analysis of transformative experience might therefore include consideration of an individual’s prior spirituality or religious faith, as well as the severity of an individual’s illness and time spent coping with the illness and its treatment.

Louise, a 71-year-old lung cancer survivor, had faith in God and believed that whatever happened, God would take care of her. She recalled a voice that she heard when she was lying on a bed before her surgery. The voice said she was going to be all right.

I believe that God loves me and he is always with me. If I am still here, there must be a reason for it. I now believe that there is something that is bigger, which controls us. I help anybody who comes for advice about cancer and tell them not to live for cancer. Do whatever you want to do, and live life to the best of your ability. Cancer is extraneous. I do not worry and get into stressful situations. If I find there is a difficult situation and if I can do nothing about it, I get out of it straight away. I try to learn a new skill, something which I do not know, like I learned to keep the books [accounting] on the computer. That helps in getting my mind off of my cancer and getting excited about simple things.
Louise tells others to enjoy others’ company, joke with each other, be able to forgive, go on with life, and to demonstrate a willingness to change. She has a mission in her life to help others, to be kind, loving, and generous. “I have learned to appreciate that some people are different and are not going to be like me, but we can still appreciate each other.” These experiences of Louise are close to the spiritual realm as she reveals an active, hopeful approach to life, as well as a connection to others.

Like Donald, Louise also admitted to experiencing a slight transformation. Louise, before being diagnosed with cancer, suffered a mild brain tumor. Her tumor was removed successfully. In addition, she had had a series of medical experiences since early childhood, including the removal of her gall bladder. She was also a chain smoker since her 30s, and was well aware that she might be diagnosed with cancer. And, similar to Donald, she described herself as always having been very spiritual. She explained:

I lived in Gallup, a small community which had families from different cultures: Chinese, Japanese, Navajo, Zuni and Hispanic. My upbringing and interaction with individuals from different cultures made me accept different situations. So being diagnosed with cancer and accepting it was not that hard.

Louise therefore considered cancer as an extraneous condition, and said further, “You’ve got to live life to the best of your ability in all situations and that is what I did.”

In addition to again considering the impact of an individual’s previous spiritual and religious experience on the transformation process, Louise’s prior medical experiences and her expectation that a cancer diagnosis was likely suggest the importance of considering the impact of an individual’s medical history as well. Specifically related to the characteristics of spirituality outlined in chapter one, (M. Wills, this volume), it
may be that an individual’s ability to engage hope and optimism are compromised by a history of illness. As such, the potential for transformation may be affected.

The third interviewee, Judith, was diagnosed with colon cancer in 1991. She was taken aback when she learned about her cancer. It was a shattering experience. But she believed in her doctor and did exactly what he told her to do. She realized that she was fortunate to be alive. Judith offered:

I do not put off things now. Life is too short and cancer changed me as a person. I do feel fortunate. My mind is more active and I appreciate my life. I realize the shortness of life, and I always did my contribution to the world by helping others in whatever way I could. I am more conscious of time now.

Like Donald and Louise, Judith does not explicitly focus on spirituality per se but talks about her transformation in terms of a greater appreciation of life and being more helpful to others. In terms of spirituality, she demonstrates being more “active” and more “connected” to others.

Judith also seems to have experienced a relatively slight transformation. She explained that she first experienced cancer first when her husband was diagnosed with prostate cancer. She nursed him for five years, but he did not survive and had a painful death. Later, when Judith herself was diagnosed with colon cancer, she recalled the shattering experience of her husband and took her diagnosis in stride, prepared for the worst. Fortunately, her daughter nursed her and she survived to appreciate life more after her experience with cancer. She became a volunteer in a cancer support group where she could share her experience with newly-diagnosed individuals. However, her cancer experience did not manifest into a total reorientation in her perspective on life.
The fact that Judith had witnessed first-hand her husband’s cancer-related tragedy begs the question of how prior experience with cancer-diagnosed individuals affects one’s level of optimism concerning one’s own cancer diagnosis. Similar to Louise, then, Judith’s ability to engage hope may have been compromised. Analysis of transformative experience might therefore include not only consideration of an individual’s own medical history, as previously suggested, but also the individual’s prior experience with the illness of significant others.

Turning to an examination of those survivors whose transformation experience was more pronounced, Gordon, a 67-year-old pancreatic carcinoma survivor, was a spiritual person from childhood. He never imagined himself as being diagnosed with cancer. He was not angry or worried, but the diagnosis completely surprised him. His cancer was detected in 2002. After he accepted the reality of the cancer diagnosis, he immediately began an extensive information search. He believed his doctor’s recommendations, and shared information about treatment options with his family members. He did not argue about his new situation, feeling it would be futile.

Gordon described his feelings,

A feeling of complete peace is hard to explain. I learned about love more than ever before. Family and friends are the only things that are important in this life. One thing that I learned was that God is not of one faith. Spiritual development has always been my goal and this experience [cancer] taught me how important it is. I feel religion is man-made, and spiritual development and faith are not. I know that we need to accept all faiths and religions, because truly there is only one God.
This experience [cancer] helped me grow in my faith, and I know that we need to accept and honor all religions and faiths. Gordon’s spiritual nature, it seems, enhanced his transformative experiences. He admitted that experiencing transformation after being diagnosed with cancer resulted in his faith being pushed to a deeper level. He admitted to being more reflective than he might have otherwise been and helping other cancer patients. He regularly volunteered to share his survival experiences in the frequently held counseling sessions. Gordon’s experience thereby suggests that the nature of transformation is potentially intertwined with the notion of spirituality (M. Wills, this volume). Transformation is an active process, at its best a hopeful process, and clearly a process of connection well akin to that characteristic of spirituality.

James, a lung cancer survivor, recalled that fighting cancer represented a new awakening for him. When diagnosed, he was in shock and cried. It was difficult to accept the diagnosis, as there was no reason for his having cancer. He calmed down and said to himself: “Everything is going to be fine. I always had an attitude about life, i.e., I believed in the survive option. Faith is going to win.” James displayed a transformation in his changed perception of life. His transformation relating to spirituality manifests as having greater connection to others, to a higher power, to life (M. Wills, this volume). He explained:

I help everybody. Give a hug, say ‘Hi’ and treat everybody like humans. I am now more connected to people. I believe that we need more people with cancer so that this experience can change them and make them realize the goodness of life. I found out from cancer what I am made of. I am a survivor.
Dodd was diagnosed with prostate cancer in 2002. He was unusually healthy for his age (63 years) and so the cancer diagnosis came as a shock. He read and searched for information about his cancer condition. After studying the options, he decided on surgery. Dodd’s transformative experience manifests itself into what he himself calls a new belief that magic does not happen, but that miracles do happen in life. He said:

Life is very short and the cancer experience is vivid in my memory forever. Life is very seductive and pulls you back into doing certain things. However, I made a commitment to myself that I will cherish life. Now to me my old life seems foolish, a waste of time. I am clear about what and how I am going to spend my time and what I am doing now. It is an experience which is non-cognitive, and I am unable to explain it fully.

Dodd’s embracing of unique change in lifestyle after coping with cancer is evidence that transformative experiences lead to a lasting behavior change process. Dodd admitted also to being helpful to others which is a direct result of contemplating what happened to him, resulting in a desire that he does not want others to suffer like he did. The non-cognitive experience that he admitted to undergo can be termed as being close to spirituality.

Jacqueline, who worked as an administrative assistant for a pediatrician, was angry and cried for a week when she was told that she had breast cancer in October, 1995. Her doctors told her that she had ductal carcinoma; the cancer had spread to her ducts which secrete milk. She was further told that there might be a chance that she would have to undergo a lumpectomy. “I went through the phase of why should the cancer happen to me? What did I do wrong?,” Jacqueline disclosed. Her husband was
very supportive and together they went to the local library searching for information. The National Cancer Institute helped direct them to an oncologist and a surgeon.

Jacqueline underwent surgery, which at first was not successful. She explained, “My options were to have a two-hour surgery which also included the reconstructive surgery. However, two days after the surgery, the doctors told me that I would have to undergo radiation as they did not get clean margins.” Two years after the radiation, she had a recurrence of the cancer in the lymph system. “This time I was mad; I threw the phone down, was disappointed, angry and could not believe it,” she said. She went through a series of bone and CAT scans, and was told that there were only 20 percent survivors. Given those odds, Jacqueline said, “I decided to be in the 20 percent. I cleared my calendar, did meditation, yoga and planted a garden.”

She was recommended for treatment at a well-known cancer center in Texas and experienced a strange feeling when she arrived there: “I felt that what was being done to my body was not good. As they were taking me into the operating theatre, I decided that I would have to leave this place.” Jacqueline returned to Albuquerque and opted for chemotherapy which controlled her cancer.

Jacqueline acknowledged being more spiritual and engaging in intra-personal communication. She admitted to being compassionate and connecting with others and being more connected to life itself. “My attitude to life was different. I could feel that God has communication with me. He will direct me to the right path. I kept saying to myself whatever happens to me will be right. That gave me strength,” said Jacqueline. She described her transformation experience:
I have developed compassion for the next person. I know what is going on in life now, the purpose of everything in life. There is surely a reason for everything that happens. I do not hold on to grudges. I do not get angry. My attitude has changed. The cancer experience has taught me how to live.

Fifty-six-year old Gail, who holds a doctorate in communication, was diagnosed with metastasis breast cancer in January, 2001. The cancer was in its fourth stage, rapidly spreading to her bone and liver. Gail’s doctors gave her three months time to live. Her initial reaction was shock and grief:

I went straight to the church after the appointment and prayed. After I got home, I held on tight to my teddy bear and cried from the depth of my heart. I did not want to sleep. I tried to watch a funny movie but could not.

We interviewed Gail in October, 2003. She said that she did not waste time in thinking about why she was a victim. She and her husband started gathering information on the stage of her cancer. She was told immediately to go into chemotherapy which, she added, was painful. She disclosed having experienced the transformation perspective, saying,

I am more conscious and appreciative of simple things in life now. Having come out of death, I feel very much blessed. I will do anything possible to help those who have been diagnosed with cancer. I always had faith in God but now it has increased even more.

When re-interviewed in February, 2004, she was still undergoing chemotherapy but had returned to her normal routines. Nevertheless, she disclosed that her transformative experience lasted over time. She offered:
My health is getting better each day even though I have to eat the pills. Each day that I am alive makes me happy. I have a deep love for friends. I want to be an example to others to make positive changes. I do not want others to lose hope and give up.

Bill, a rocket scientist, found out about his prostate cancer during a routine physical examination in April, 2003. His PSA (protein specific antigen), which is a marker of prostate cancer, was 9.5.

I was upset for weeks. Why did this happen to me? I was in good shape and exercised often. I had a fulfilling life as a pilot, then a researcher, and was thankful for it. But I had never thought of mortality. I told myself: I have a lot of learning to do. I need to resolve this.

To that end, he embarked on an information search, referencing books, online sources and talking to prostate cancer survivors.

Bill had successful surgery in August, 2003. Describing his transformative experience, Bill said,

The cancer has changed me. I came face-to-face with mortality. I have become a little different, more philosophical. I started thinking what are the things that I wanted to do and how much time do I have? Earlier, I used to concentrate on material things but that now were insignificant. I attribute my survival to the many blessings of people close to me and to the good wishes of my children and grandchildren. I realize that I need to help others who have cancer. I give my telephone number to them and volunteer to talk to them any time of the day. I feel more connected to my family. I tell people to have a right state of mind and a
positive attitude. My advice is to find ways to eliminate stress, and to eat the right food.

Bill’s transformation intersects with spirituality as he described an active approach to coping—taking a major role in the pursuit of his wellbeing, along with seeking greater meaning and purpose in his life. He describes also a hopeful approach to coping—“…having a right state of mind and a positive attitude.” And, clearly, his transformation reflects the third defining characteristic of spirituality (M. Wills, this volume), or connection, as he recounts a stronger connection to his family and his openness to help others.

Along similar lines, Mike described his transformation process as active, hopeful, and as one that inspired a greater connection to others and to the universe. When he was diagnosed with prostate cancer in May, 2003, he felt numb. “I was shocked but not surprised. The diagnosis with cancer made me extremely introspective,” said Mike. He engaged in information-gathering, did research on his condition and gained knowledge about treatment options. “I not only read books but joined a support group, talking to prostate cancer survivors. That really helped and gave me confidence to go for surgery,” said Mike.

Mike framed his transformation experience similar to other interviewees. He said:

I realize the worth of life now. I had a simple life but now I realize even more how important it is to enjoy every moment of life. Existence has become a bigger purpose for me. I want to help others and contribute in a small way to making this place a little better. I offer to help whoever is in need within my circle of
friends and support group and am very proactive in this. I always had animals in my house. I have started loving them more now.

Discussion: Transformation of Cancer Survivors

All ten respondents reported undergoing a transformative experience, and displaying fairly common stages. They exhibited considerable information-searching about their cancer. A cancer diagnosis typically stimulates an intense hunger for information. Their doctor provided them with certain information, but they were seldom satisfied with it. Ginossar (2000) noted, the medical encounter is usually quite short, and cannot cover many patient questions. As such, individuals diagnosed with cancer may demand a second or third medical opinion. They read available material about their individual condition. They want to have control over their new situation. They talk to their immediate friends, family members, and to people who have survived cancer. They listen and ask many questions, especially how to avoid medical treatment. Many individuals search for alternative treatment procedures and options. These information-seeking processes involve considerable commitment of time and effort by the cancer patient and his/her family members in order to reach the survivor stage.

As an individual’s information level about his or her cancer increases, a process of change is initiated, amounting to adjusting to a new lifestyle, which includes changes in diet, work schedule, exercise, alternative living, and deep thinking about their condition. A self-reflective process of contemplation about the meaning of life and of the individual’s personal cancer condition usually occurs. This positive thought process helps in making a reassessment of material, emotional and psychological options. Possibilities of medical treatment, alternative treatment and other choices are considered.
By now, the person has centralized his or her new identity as a person living through cancer. His or her future life will be different, even if the cancer is successfully treated. At this stage, the individual faces a need to make decisions. The person synthesizes all the available information and options. He or she is willing to do whatever is needed to stay alive and to live a better life.

Bernard Lash (2003), who provided access to our respondents and who himself is a cancer survivor, recalled his experience with tonsil cancer in 1980. His doctor gave him two to three months of life. He noted, “I took the medical options which were rather negative and painful, but I knew that I was going to stay alive. However, it meant a complete change in my lifestyle.”

Most cancer survivors do change their lifestyle in significant ways (Ginnosar, 2000; Lash, 2003). As the narratives from our ten participants exemplify, cancer survivors potentially become (1) more spiritual and, relatively, (2) more altruistic in helping others, especially fellow cancer survivors. Lash (2003), however, drawing on his extensive counseling experiences, suggested that while individuals do change their lifestyle, most do not effectively cope with cancer. He estimated, "Only about 20 percent of all cancer-diagnosed people cope effectively with their illness." Thus, along with an overview of the stages of transformation in the final section of the chapter, we suggest future avenues of research that could prove important to cancer-diagnosed individuals and their health providers as they seek effective means for coping with this disease.
Conclusions

The present study substantiates that most people who experience cancer report experiencing the multi-stages of transformation. Author Rogers’ personal challenge with cancer and the consequent self-reflection and intrapersonal communication that he underwent is supported generally by the similar experiences of ten other cancer survivors. A major behavior change process is stimulated by diagnosis with a serious aliment like cancer. Concrete behavior change arises out of the transformative process and is long lasting, over a considerable period of time. A cancer diagnosis is, therefore, much more than just a medical decision; it is a major socio-psychological and spiritual upheaval for the individual cancer survivor. Generally individuals de-emphasize their career and materialistic life, become more positive in behavior, and stress enjoying everyday simple experiences. In other words, they may become more engaged in the realm of being spiritual. These changes lead to more self-efficacy and self-control of their health behavior.

Each of ten cancer survivors described undergoing a transformation. Each cancer patient undergoes a unique response to the reality of being diagnosed with cancer but nevertheless follows certain common patterns in the transformative experience process. The exact nature of an individual’s transformative experience in response to a cancer diagnosis may include shock/disbelief, surprise, and anger. This initial phase, however, lasts only a week or two. Respondents quickly advance into gathering active information. They take control of their situation and start orienting themselves to a new post-cancer identity.
We also found general support for the stages of transformation suggested in previous research by Merizow and Associates (2000): (1) diagnosis, (2) a catalytic experience/transformation, (3) immersion with others who are surviving cancer (such as in a support group), (4) a turning point, (5) integration, and (6) disclosure of the individual’s cancer experiences to others. The stages of transformation explicated in the present chapter can also be compared with the stages-of-change model (Proshaka et al., 1992).

A major behavior change process is stimulated by a cancer diagnosis. However, many health behavior change programs have been ineffective because the participants’ stage-of-change were not taken into full consideration (Prochaska et al., 1992). How can cancer prevention and treatment programs better utilize an understanding of transformation? For example, do cancer survivors have higher credibility than oncologists in communicating preventive health behavior change messages to other cancer survivors?

What is the most appropriate research methodology for studying transformation? The present study relied on relatively unstructured interviews with cancer survivors. Past studies used content analysis of narratives to obtain evidence of a transformation perspective, with data gathered in personal interviews. Mohammed and Thombre (2005) demonstrated that self-reported narratives on the World Wide Web may also be appropriate data for analysis about transformative experiences. One future method of data-gathering might be repeated interviews with cancer survivors undertaken at frequent time intervals of several weeks or months through the transformation process. Another approach to studying transformative experiences would be to interview key informants.
Interviews with doctors treating cancers and expert informants (for example, Lash, 2003) can provide valuable data about transformation.

The present study used in-depth personal interviews with ten survivors who experienced some degree of transformation. We did not take into account the experiences (1) of non-survivors, or (2) cancer-diagnosed individuals who do not seek effective treatment. What could be done to increase the proportion of successful survivors by an improved understanding of transformation? Research needs to be undertaken (1) on the importance of social support from family and friends in an effective transformative experience, and (2) the potential role that the Internet could play in the information-gathering process that leads to transformation.

The significant role that spirituality plays in the transformative experience also is of interest for future research. The aspects outlined by the present data indicate the spiritual experiences transcend any religious experiences. It would be useful to analyze the dimensions of these spiritual experiences and their importance in formulating the process of lasting health behavior change in individuals. And, as previously suggested, transformation researchers might consider individuals’ reported spirituality and/or religious faith prior to a transformation, as well as their past experiences of their own and others’ illness.

The role of individual self-efficacy in a transformative experience needs analysis as well. The total numbers of U. S. cancer survivors increases daily, and they are becoming increasingly well-organized. Their voice is heard now more than ever (e.g., the Susan B. Konen Foundation for Breast Cancer). Cancer survivors are becoming more influential participants in the cancer policy-making process. The National Cancer
Institute now supports research on cancer survivors and provides funding to projects to answer crucial questions: Why do some people survive, while others do not? Does transformation contribute to a more successful survivorship? Why do differences in survival rates exist for individuals by socio-economic status and ethnicity? What kind of continuing medical treatment and education is needed for cancer survivors? Some of the answers could be found in the transformative experiences of survivors and could suggest future research directions.

The present study sought to explicate the importance of transformation in cancer survivorship. The study of transformation by communication scholars is at an early stage. Future researchers should look for the commonality of patterns in the transformative experiences resulting from cancer, HIV, and other diverse events like divorce, marriage, and others. Many people who have various health problems (cancer in this case) do not experience an effective transformation. A very large number drop out of treatment programs (Alpha Institute, 1993). An important question thus arises: What efforts could be undertaken to help these individuals experience a more effective transformation? Given the significant role of spirituality in the transformative experience, the search for answers to this critical question invites further investigation of spirituality in the health behavior change process.
Acknowledgments

The authors thank (1) Dr. Shaheed N. Mohammed of Marist College for calling their attention to the concept of transformative experience, and stimulating the present research, and (2) Bernard Lash, People Living Through Cancer, Albuquerque, NM, for helping the authors gain access to their respondents.

References


Appendix A

Interview guide for cancer survivors demonstrating transformation perspective

1. When was your cancer detected?

2. What was your initial reaction?

3. Who did you look to as information sources for knowing more about cancer?

4. Do you recall your first experiences in searching for cancer information?

5. When were you comfortable in disclosing your cancer to others?

6. Did you undergo any transformative experiences? (Define transformation for the respondent.)

7. Did you participate in any support groups?

8. Did you feel a change in your perception about life as a result of your cancer diagnosis?

9. Did you feel a need to help others with cancer?

10. Did you experience a change in orientation towards life?
Table 1. The Degree of Transformation for 10 Cancer Survivors in New Mexico.

<table>
<thead>
<tr>
<th>Identification</th>
<th>Type of Cancer</th>
<th>Age</th>
<th>Date of Cancer Diagnosis</th>
<th>Intrapersonal Self-Communication Reported</th>
<th>Self-Reported Transformation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. “Gordon”</td>
<td>Pancreatic</td>
<td>67</td>
<td>2002</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>2. “Donald”</td>
<td>Prostate</td>
<td>73</td>
<td>2003</td>
<td>Yes</td>
<td>Slight</td>
</tr>
<tr>
<td>3. “Louise”</td>
<td>Lung</td>
<td>71</td>
<td>1992</td>
<td>Yes</td>
<td>Slight</td>
</tr>
<tr>
<td>4. “Judith”</td>
<td>Colon</td>
<td>70</td>
<td>1991</td>
<td>Yes</td>
<td>Slight</td>
</tr>
<tr>
<td>5. “James”</td>
<td>Lung</td>
<td>68</td>
<td>2003</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>6. “Dodd”</td>
<td>Prostate</td>
<td>63</td>
<td>2002</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>7. “Mike”</td>
<td>Prostate</td>
<td>58</td>
<td>2003</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>8. “Gail”</td>
<td>Breast</td>
<td>56</td>
<td>2001</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>9. “Bill”</td>
<td>Prostate</td>
<td>58</td>
<td>2001</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>10. “Jacqueline”</td>
<td>Breast</td>
<td>47</td>
<td>1995</td>
<td>Yes</td>
<td>Yes</td>
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</table>
Table 2. Stages of Transformation Exhibited by 10 Cancer Survivors in New Mexico.

<table>
<thead>
<tr>
<th>Respondents/Themes</th>
<th>Shock/disbelief</th>
<th>Information searching</th>
<th>Self-reflection</th>
<th>Orienting to a new identity</th>
<th>Finding a new meaning of life</th>
<th>Contribution to others</th>
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</thead>
<tbody>
<tr>
<td>1. “Gordon”</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes (profound)</td>
</tr>
<tr>
<td>2. “Donald”</td>
<td>Yes</td>
<td>Yes (short)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>3. “Louise”</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>4. “Judith”</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>5. “James”</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes (profound)</td>
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<tr>
<td>6. “Dodd”</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>7. “Mike”</td>
<td>Yes</td>
<td>Yes (short)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>8. “Gail”</td>
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<td>Yes (short)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>9. “Bill”</td>
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<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>10. “Jacqueline”</td>
<td>Yes</td>
<td>Yes (long)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes (profound)</td>
</tr>
</tbody>
</table>