Cervical Cancer: Patterns of Long-Term Survival

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Key Points . . .

➤ Questions exist regarding the psychosocial consequences of long-term survival from cervical cancer and the individual variability in perceived quality of life.

➤ Targeting the individual variability in responses to long-term cervical cancer survival through open-ended questions and interviews can enhance the understanding of this experience and reveal hidden meanings not evident in quantitative survey data.

➤ Although all study participants felt shock and fear at the time of their diagnosis with cervical cancer, most participants stated that printed information or others with whom to speak about their options, including healthcare professionals, was not readily available.

➤ All of the participants had expected to return to their normal lives and were unprepared for the long-term effects of the disease.

Cervical cancer is the third-most common cause of cancer deaths and second-most common cancer in women worldwide (Jemal et al., 2008), with some 11,150 new cases diagnosed in the United States each year (American Cancer Society, 2007). Cervical cancer is not associated with high rates of mortality in the United States (five-year survival is 70%) largely because of aggressive early identification strategies. The American College of Obstetrics and Gynecology’s (2006) recommendations on use of the human papillomavirus vaccine, targeting females aged 9–26 years, may further decrease the incidence. When diagnosed and treated early, cervical cancer is associated with some minimal disruption to women’s lives (Andersen, 1995; Frumovitz et al., 2005; Jensen et al., 2004) with excellent chances of long-term survival. Later-stage diagnosis can include more complex and invasive treatment procedures and lead to a range of physical and emotional disabilities that can persist for years (Klee, Thranov, & Machin, 2000; Li, Samsioe, & Iosif, 1999). Little is known, however, about the long-term impact of this disease on survivors’ lives.
Questions still exist regarding the psychosocial consequences of long-term survival and the individual variability in perceived quality of life (QOL) (de Groot et al., 2005; Muldoon, Barger, Flory, & Manuck, 1998). Past research has largely focused on short-term survival and identification of variables that put women at risk for a variety of psychosocial outcomes. Issues identified included acute distress with the diagnosis (Andersen, 1995), emotional and sexual difficulties (Andersen, 1996; Cull et al., 1993; Frumovitz et al., 2005; Jensen et al., 2004; Weijmar Schultz, van de Wiel, & Bouma, 1991), and psychosocial issues related to physical effects (Bergmark, Lundqvist, Dickman, Henningsohn, & Steineck, 2002; Klee, Groenvold, & Machin, 1999). Although limited to short-term survival, the research has provided valuable insights for practitioners and researchers. The current study addresses the long-term survival of women with cervical cancer and increases the understanding of how women define and explain their own QOL.

**Literature Review**

QOL has become a focus of study with cancer populations now that cancer is considered a survivable and chronic disease (Ferrell, Dow, Leigh, & Gulasekaram, 1995). The many definitions and conceptualizations of QOL concur with the World Health Organization’s definition of QOL as an individual’s subjective view of a person’s life position in relation to specific goals, expectations, and values (Szabo, 1996). Ferrell et al.’s and Ferrell and Winn’s (2006) work with cancer survivors yields a definition of QOL as a personal sense of well-being encompassing physical, psychological, social, and spiritual dimensions. The psychometric approach used in quantitative QOL research theorizes separate dimensions and often does not take into account the meaning of symptoms to individual patients (Klee et al., 1999). Findings from quantitative studies (Li et al., 1999) indicate that cervical cancer survivors view their QOL as generally satisfactory, with the exception being younger survivors, who exhibited a higher proportion of psychological complaints. No explanation for this experience was provided. Women who remain free of the disease return to their premorbid level of functioning at home and work, despite some long-term effects of pain, fatigue, and incontinence. No clarification was given concerning the underlying differences in women’s experiences that might guide healthcare providers in their follow-up counseling.

In a study of couples’ responses to cervical cancer, de Groot et al. (2005) did not find clinically significant levels of depression, although women reported greater feelings of intrusiveness that interfered with their QOL. No explanations could be derived from the quantitative data to explain the variations in response.

Qualitative research with women who have survived cervical cancer is limited to a few studies. Women who had experienced gynecologic cancer, including cervical cancer, described their sexual adjustment after treatment and its impact on their QOL (Juraskova et al., 2003). They identified intimacy as an important factor in their sexual adjustment and stressed the importance of communication between healthcare professionals and patients with partners in improving outcomes. Killoran, Schlitz, and Lewis (2002) studied 17 survivors of different types of metastatic cancer. Participants described the impact of a life-threatening condition on their life stories. Contrary to published research suggesting that such events may transform individuals (Pelusi, 1997), almost all of the study participants framed their recoveries as being largely unremarkable, raising more questions about the phenomenon of long-term survivorship with cervical cancer. Additional clarification is needed to gain a more critical understanding of the complexities of surviving cervical cancer. No studies to date have asked long-term cervical cancer survivors about their perceptions of their overall QOL following cervical cancer diagnosis and treatment. The purpose of the current study was to ask long-term survivors of cervical cancer to define and explain their QOL and the factors that promoted their adaptation.

**Methods**

This qualitative analysis was part of a national, four-site, population-based survey of QOL in long-term survivors of cervical cancer (Greenwald & McCorkle, 2007; McCorkle, Tang, Greenwald, Holcombe, & Lavery, 2006). Study participants who consented to the larger survey also agreed to be contacted for potential future interviews. Participants in the qualitative arm were provided with a second consent form for the study.

The qualitative study was carried out in the northeastern United States. Women diagnosed with cervical cancer from 1975–1995 who had survived and were aged 18 years and older were identified through a tumor registry. Each physician consent for contacting the patients had been received, letters requesting consent were sent to participants. Of the 793 possible participants, 208 consented and completed the quantitative questionnaires. The data are reported in McCorkle et al.

**Participants and Setting**

Nineteen participants were selected based on the principles of intensity sampling. Patton (2002) defined intensity sampling as cases that are information rich and manifest the phenomenon of interest intensely but not extremely. The purpose of intensity sampling was to select cases that clearly reflect the concept of interest, without being unusual or deviant manifestations (Patton; Sandelowski, 2000). The authors purposely selected participants from the larger study sample to reflect varying patterns of scores on depression, measured by the Center for Epidemiological Studies–Depression (CES-D) scale (Radloff, 1977), and QOL, measured by the Medical Outcomes Study Short Form-36 (MOS-36) (Ware, 1993), and report on long-term complications. Participants with poor QOL and depression scores, participants who reported long-term complications from the cervical cancer, and participants with good QOL and depression scores or who had no reported long-term complications from cervical cancer were invited to take part in the qualitative component of the study. The participants included a largely Caucasian sample ranging in age from 29–64 years. Participants had been diagnosed with cervical cancer 7–28 years prior to interview, and treatment methods included surgery, radiation, and chemotherapy. The reported long-term effects included chronic gastrointestinal disorders, difficulty eating, fatigue, interference with childbearing, sexual issues, and depression.

**Data Collection and Analysis**

Semistructured interviews with open-ended questions were conducted. An interview guide was used to ask the participants questions regarding QOL perceptions and
explanations about their self-assessment. Participants were encouraged to talk about their cancer experience, how long-term complications affected their lives, and what their perceptions of self were.

A member of the research team conducted interviews by telephone or in person, depending on the subjects' wishes. The audiotaped interviews were transcribed verbatim, with the accuracy of the transcripts checked against the taped interviews. The transcribed interviews were analyzed by the first three authors of this article, all experienced in qualitative research methods and analysis. Data were analyzed using qualitative content analysis (Patton, 2002). As defined by Patton, qualitative content analysis entails "data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings" (p. 543). To identify core consistencies and meanings, the researchers read each of the transcripts and identified common themes that cut across the participants' accounts of their experiences (e.g., meaning, impact on self, impact on QOL, coping efforts, future expectations). The themes provided an organizing framework for developing a case summary of each participant's interview. Following the completion of the case summaries, the researchers compared cases to identify variations in how the themes manifested across participants. The final step in the analysis was to identify distinct patterns of response based on a similar manifestation of themes.

The researchers ensured qualitative rigor of the study by establishing the credibility, auditability, and fittingness of the findings (Lincoln & Guba, 1985). Credibility refers to the confidence in the truth of the findings. To achieve this, researchers followed the interview process closely and reviewed all transcripts against the taped interviews to ensure accuracy. Auditability refers to the ability to follow the decision trail of the researchers with data analysis. Authors and methods experts, all familiar with this methodology, reviewed the transcripts and agreed with the descriptions of the main storylines that emerged from the analysis. Fittingness refers to how well the study findings fit the data from which they were generated and their congruence with the context of the phenomenon under study. The findings were shared and discussed with content experts, who supported the descriptions of the results as being congruent with the context of cervical cancer.

**Findings**

The participant characteristics reflected a similar pattern to that found in the quantitative study (see Table 1). Although the majority of the participants experienced long-term complications from their cancer or treatments and experienced some similarities, the meaning attributed to the disease and subsequent view of their QOL differed. The findings are presented with the similarities across the participant accounts provided first, followed by a discussion of the main patterns with themes that emerged from the analysis.

**Similarities Among Participants**

The researchers identified several similarities that emerged from participants' accounts, including the time surrounding the diagnosis, their view of healthcare providers, and the coping strategies they used to deal with the diagnosis, treatments, and complications when applicable. The participants all reported on the shock and fear they felt at the time of their diagnosis. They remembered very detailed information, the context, the words spoken, and what was happening the day of their diagnosis. One of the participants diagnosed nine years prior to the interview reflected on the vivid recall of the experience.

I was at work and they said there was something abnormal showing still on the Pap smear . . . . They called me back and said that what is showing is signs of carcinoma and I was so shocked. I couldn’t talk and that’s what they said to me on the phone and they just said that it’s like cervical cancer . . . . and I just had an emotional breakdown.

Healthcare providers played a significant role in participants' stories. Physicians and nurses were viewed as either positive or negative aspects of their experience. Four participants stated that they felt like a number, with the doctor telling them their diagnosis over the telephone in an impersonal manner. Others described their physicians and nurses as wonderful and generally supportive. Many participants spoke of the need for healthcare providers to be more compassionate and to offer more information to help the women cope with the disease and effects of treatment. One participant, diagnosed eight years prior to the interview, had advice for healthcare providers.

I need to know that, when you look at me, you understand who I am and that we can focus on a level that will make me feel comfortable with you. So reach out to that person and make sure they have the best understanding of the knowledge you give them because there’s some people who don’t understand and some people won’t be advocates for themselves; they’ll rely on what you know. And, as intelligent as you are and as intelligent as you may speak, some people may not understand you. If you can make yourself as accessible and understanding for each individual, as hard as that may be, that would help a lot of people and hopefully make them understand that people are understanding.
The participants had expected that they would return to their normal lives and reported that they were unprepared for the long-term effects of the disease in their lives, including debilitating genitourinary and gastrointestinal complications.

All participants spoke of either family or friends providing the social support that helped them to cope and get through the difficult times. Individual coping strategies ranged from meditation, exercise, guided imagery, humor, information, and prayer to strategies that included noncancer support groups, retreating from social contact, and keeping it all in or to themselves. One woman spoke of keeping herself surrounded by positive people and staying away from people who brought her down. The need to keep a positive perspective and energy around themselves was expressed by several of the participants.

Three distinct patterns were identified from the analysis (see Table 2). The first pattern was one of moving on from the cervical cancer experience, the second pattern focused on a renewed appreciation of life, and the third pattern centered on the ongoing struggles some participants still endured from the cervical cancer experience. No differences were reported in symptom severity or complications among subjects in the last two patterns.

Moving On

Four of the participants expressed a sense of having moved on from the cervical cancer experience. They had been diagnosed 9–24 years prior to the interviews. They did not attribute any special meaning to the experience for their lives at present. Three reported no long-term complications from their treatments, although they still had some worries about potential recurrence. They viewed their cervical cancer as an awful experience from their past that they had left behind. One woman stated, “I feel fine now and it’s been 15 years . . . that’s awful experience from their past that they had left behind. One...

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<tr>
<th>Theme</th>
<th>Illustrative Quote</th>
<th>Meaning</th>
<th>Impact on Self</th>
<th>Implications on Quality of Life</th>
<th>Coping Strategies</th>
<th>Future Expectations</th>
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<tr>
<td>Moving on</td>
<td>I just go about what I do every day and I don’t really dwell on it. You know I don’t think about it. Like I said, the only time I think about it is when I go for my Pap smear every November.</td>
<td>No meaning was noted. The participant’s disease was treated and cured, and she has moved on.</td>
<td>The participant still has some vaginal discharge that is more of a nuisance than anything else.</td>
<td>The participant feels that her overall quality of life has not been affected.</td>
<td>Her husband and family helped during a difficult treatment period.</td>
<td>The participant worries about recurrence once a year—during her Pap smear. She is older now and keeps busy with her daily activities.</td>
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<td>Renewed appreciation of life</td>
<td>So as I grew and I dealt with cancer ... it has actually caused me to change my whole outlook on life ... something good.</td>
<td>The participant feels she has received a second chance and has an obligation to live a better life.</td>
<td>The participant has a renewed determination and resolve.</td>
<td>Recurrent depression, bladder issues, and sexual dysfunction have plagued her.</td>
<td>Family support, exercise, and activity were crucial.</td>
<td>The participant has no concerns about her future and focuses on living a full life.</td>
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<td>Ongoing struggles</td>
<td>I was taking medication for the depression. I got into a divorce and I was losing my job . . . I knew that my life was never going to be the same again. To me I feel a void . . . a fear.</td>
<td>The participant has struggled longer than 10 years to overcome a sense of loss of control and that her life was no longer what it had been.</td>
<td>The participant realized that she is strong enough to cope with anything.</td>
<td>The participant has depression, impaired sexual function, and bowel issues and feels physically mutilated.</td>
<td>A self-help group provided the participant with needed coping skills.</td>
<td>Considerable fear exists about the future, including fear that cancer will return. She is concerned about entering a new relationship.</td>
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Table 2. Qualitative Themes and Patterns

Renewed Appreciation of Life

A group of nine participants all expressed a renewed appreciation of life as a result of the cancer, regardless of the presence or absence of complications. They had been diagnosed 8–28 years prior to the interviews. Many saw the meaning of the cancer experience as a rebirth, a wake-up call, or a second chance at life. One participant, 12 years after diagnosis with no long-term complications, addressed this feeling.

[Cervical cancer] brought a lot of different things into my life. It gave me a different perspective on life, the way you live it, and you have more appreciation for life. It was a learning and growing experience for me because it really changes my whole life. You’ll never be that same person again. You’re a whole different person when you go through this experience. It does something to you physically, mentally, and spiritually. It brings a new light to your life.

The complications that affected the most women in this group included depression, gastrointestinal and genitourinary difficulties, sexual issues, pain and swelling in the lower extremities, and emotional worries. One participant, eight years after diagnosis and reporting a high QOL, still experienced severe gastrointestinal issues, decreased bladder function,
and difficulty eating and could not return to her activities of daily living. However, she linked the cancer experience to an increased appreciation of life.

I have this timeline . . . life before cancer, life after cancer. It’s not before I got married or after I got married. It’s before cancer and after and the sad part about it is I think it took cancer to make me realize a lot of things in my life, to appreciate a lot more of the things that I didn’t appreciate before, and I said this to my mother the other day. I said that I wish I could just pick everybody up and say, look, I don’t want you to go through what I went through but I want you guys to see what I see now. Start appreciating everything. If it wasn’t for the cancer I would never . . . teach the scuba program to kids. Those are my kids.

The participants had renewed their appreciation of life because of cervical cancer. One woman, 13 years after diagnosis with good QOL but still experiencing gastroinflamatory issues, stated, “I can cope with anything now if I know the worst and I can take it from there. I have a different outlook now and an appreciation of life. I don’t give up.”

Participants talked about how the cancer had made them stronger, more resilient, and more sensitive to what was important in their lives.

Ongoing Struggles

Six participants ascribed a negative meaning to their cervical cancer experience, often saying it was a struggle just to live. All had been diagnosed 11–15 years prior to the interviews and struggled with the long-term effects, including depression, severe gastrointestinal issues, difficulty eating, sexual issues, and swelling in the lower extremities. The long-term effects interfered with their activities of daily living. Participants saw their lives as ruined. One woman, 15 years after diagnosis with a low QOL, had a very morose view of her future. She was fatalistic and started smoking again. She felt that her health could be no worse. She struggled to deal with her long-term complications and felt less able to cope with other life challenges.

The radiation pretty much killed me . . . has ruined my life and still, it’s 15 years later . . . it haunts me. It left me with chronic diarrhea and I live my life around my guts. It’s really tough you know, when you have two, two-and-a-half hours every morning before you can start your day, running back and forth to the toilet. When you can’t go out for dinner with friends. When you can’t go for lunch because you’d spend the whole afternoon in the bathroom. I eat once a day—at night. The diarrhea has ruined me. I struggle every day of my life and you get to the point where struggling is normal.

The participants reported a change in their lives that did not bring them any renewed appreciation or awakening to a deeper meaning, instead focusing on the lives they had lost. One woman, 11 years after diagnosis with low QOL, still struggled with severe lymphedema in her lower extremities, limitations to her diet, severe gastrointestinal pain, and limited activity. She said, “I really miss the fact that I can’t just walk out the door and go and do my shopping . . . that’s over, you know. I just never thought anything would happen to me.” She reported that she should value life more but did not know if she could value her own. She reported suffering from depression and had been taking antidepressants for years.

Discussion

The present study uncovered three key differences than those reported in the literature to date. Most studies showed that the majority of women with cervical cancer ‘moved on’ and returned to their premorbid levels of functioning. Only a small subset of 4 women of the 19 in this study described themselves as having moved on from their cervical cancer experience. Killoran et al. (2002) described this process as normalizing the adversity experienced with cancer. Their qualitative study participants downplayed the significance of the cancer event in their lives, similar to that reported by the current study’s subset. Killoran et al. suggested that, by normalizing adversity, the participants reflected the North American values related to belief in self and strength of will to move on.

The second unique finding was that two-thirds of women in the current study reported good QOL despite worries or complications from cervical cancer. This may have been attributed to their choice to view the cervical cancer experience in a positive, transforming way. Studies with different cancer populations have described this transformative process as one of survival that results in a wake-up call and renewed appreciation of life (Carter, 1993; Pelski, 1997). The reflections and personal insights gained from experiencing cervical cancer reaffirm the importance of life and a need to live the rest of life to its fullest potential.

The third finding that differed from much of the literature was related to the participants who reported ongoing struggles, in contrast to most published studies of cervical cancer populations that report no long-term morbidity (Andersen, 1996; Cull et al., 1993; Juraskova et al., 2003; Li et al., 1999). The complications that have been reported to date largely focus on sexual dysfunction (Bergmark et al., 2002; Frumovitz et al., 2005; Jensen et al., 2004). Not only did the current study’s participants report ongoing complications, but they were unable to identify any positive outcomes related to their cervical cancer, being consumed in many instances by its debilitating complications. Eisemann and Lalos (1999) observed that the women in their study, who had high QOL and sense of wellness before their cervical cancer and were still struggling with complications after, were reacting to the drastic change in their lives.

Regardless of the experience of long-term cervical cancer survivorship, most of the study participants reported a perceived lack of information provided to them about the disease and potential for treatment complications. They were unprepared for the possibility of long-term complications that might change their daily lives. Participants stated that they expected to hear this from their healthcare providers, find information themselves, or find someone to talk to—a finding that is still evident today (National Academy of Sciences, 2007). A systematic review of information needs of patients with cancer (Rutten, Arora, Bakos, Aziz, & Rowland, 2005) identified information about treatment and side effects as the most commonly cited need. Healthcare providers in the current study were viewed as either very helpful and supportive or impersonal. Participants made a plea to be seen as individuals, to have their level of understanding addressed, and to not be assumed to be one.
Conclusions and Implications for Practice and Research

Cervical cancer survival brought some degree of long-term complications for most of the study participants. However, the attitude and the meaning they attributed to the experience varied. Future research should identify the factors that can facilitate this attitude change or a reframing of the traumatic experience to optimize QOL. Knowledge about post-traumatic stress syndrome (Passik & Grummon, 1998) treatments can be used to teach women how to block out their negative thoughts and replace them with positive ones (Schover, 2000). Cognitive reframing is one of several psychosocial interventions identified in a meta-analysis by Graves (2003) as being effective in influencing QOL for patients with cancer and depression. A patient’s ability to cognitively process life-threatening events into more manageable events is at the core of the intervention. Mishel et al. (2005) developed an effective multipronged intervention that used cognitive restructuring with long-term breast cancer survivors to manage the uncertainty that accompanied their recovery.

The cognitive reframing model shows promise for clinicians working with long-term cervical cancer survivors.

Healthcare providers in this study were viewed as both positive and negative to participants’ experiences. Some were described as supportive, providing needed information. Others were distant, giving the subjects their diagnosis over the telephone with no follow-up information. A systematic review of information needs of patients with cancer (Rutten et al., 2005) identified healthcare providers as significant sources of information that could help to alleviate patient concerns. Although physicians were mentioned most often, nurses also can provide more specific information regarding the treatments, potential side effects, and range of support that might improve patients’ QOL (Ferrell & Winn, 2006). Families and friends also provided much-needed social support for patients in this study and need to be included in interventions targeting cancer survivors (Grey, Knafl, & McCorkle, 2006).

Despite the limitations of the study findings being generalized beyond this specific group of participants, the results provide a wealth of insights for healthcare providers and researchers. The use of purposive sampling and mixed-method design were strengths of this study in selecting the range of participants who reported a broad array of difficulties and successes. These long-term survivors of cervical cancer differed in their perceived experience of cervical cancer, and the qualitative data provided a more nuanced understanding of participants’ experiences from quantitative survey results. Using a mixed-method design to help uncover some of the embedded meanings identified in quantitative research can lead to the development and testing of more effective interventions that help cervical cancer survivors live fuller, meaningful lives with improved QOL.

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