

The impact of cervical cancer on quality of life: A personal account

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Introduction

The introduction of the Papanicolaou (Pap) test in the United States during the 1950s has significantly decreased the morbidity and mortality associated with cervical cancer [1]; however, cervical cancer continues to impact the quality of life (QoL) of females and their families. A recent manuscript reviewed and succinctly summarized the QoL effects of cervical cancer from diagnosis through treatment [2]. Shock, fear, self-blame, powerlessness, and anger are the most common emotions experienced by women who receive abnormal Pap test results (Table 1) [3]. Oftentimes, women overestimate their likelihood in developing cancer because they do not fully understand human papillomaviruses and their manifestations [2,4], which can lead to increased anxiety about the future. A diagnosis of precancerous lesions or cervical cancer is emotionally traumatic for women (Table 2), and can impact relationships and intimacy with their partners (Table 3) [2,5]. Cervical cancer treatments, such as surgery, chemotherapy, and radiation, can result in a distortion of body image [6]. Obviously, it is important to consider QoL when treating and managing a patient with cervical cancer; “The impact of cervical cancer on quality of life: A personal account” is a first-hand account of Christine Baze’s experience with cervical cancer. She is a survivor, but lives with constant reminders of what her body has been through during her battle with cervical cancer.

Cervical cancer: A patient’s perspective

As a patient, I only knew that I should see my gynecologist once a year, sit in the stirrups, take a deep breath, and stare at the

ceiling while he did something to me under a sheet. I did not know anything about my cervix or what the Papanicolaou (Pap) test was supposed to detect. I was 31 years old when my gynecologist told me I had an abnormal Pap test in March 2000.

I went back for a colposcopy, and as my doctor was taking biopsies of my cervix, he started talking about dysplasia in my cervix. I was diagnosed with invasive cervical cancer with extensive lymphatic invasion on April 18, 2000. Ten days later, doctors performed a radical hysterectomy. I kept my ovaries because I wanted to keep my hormones and possibly have a biological child through a surrogate mother. One month later, doctors confirmed lymphatic invasion and performed laparoscopic surgery to move my ovaries out of my pelvic area to prepare my body for radiation. I started five weeks of pelvic radiation (Monday through Friday) concurrent with four rounds of chemotherapy. After that, I had three more rounds of internal radiation. My last radiation treatment was on July 27.

In just three months, I went from singing, songwriting, and playing with my band to surgeries, nausea, and a goal of trying to make it to the bathroom on time. I could not believe this was my life. I did not even recognize myself anymore. Physically, I was dramatically different; I lost 22 pounds and my hair was dull and thin. Emotionally, I was consumed with fear, anxiety, horror, disbelief, anger, and sadness. I cried a lot throughout my treatment. I did not know how to let others in on my experience with cancer, and I shut out the people who were closest to me, including my husband, Robert. Robert tried to cope by pretending everything was normal; nothing was normal anymore, and we both knew it. Eventually I turned to individual and group therapy, antidepressants, acupuncture, Reiki, and yoga to ease my depression.

I felt ashamed that I acquired an oncogenic human papillomavirus (HPV) infection from sex. Robert and I had been

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Table 1
Effects of abnormal cervical cytology on quality of life

Clinical trial	Participants (N)	Assessment tool(s)	Outcomes
Lerman et al. [7]	224	Self-assessment questionnaires	Elevations in worries about cancer, impairments in mood, daily activities, sexual interest, sleep patterns
Maissi et al. [4]	1376	S-STAI-6, self-report questionnaires	Elevated anxiety, emotional distress; worries about sexual health
McCaffery et al. [8]	428	S-STAI-6, cervical screening questionnaire (CSQ), Likert Scale	Elevated anxiety and psychological stress
Campion et al. [9]	105	Self-assessment questionnaire	Decreased sexual arousal, frequency of intercourse, and orgasm

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Table 2
Impact of diagnosis or treatment of precancerous lesions (CIN) or cervical cancer on quality of life

Clinical trial	Participants (N)	Assessment tool(s)	Outcomes
Bradley et al. [10]	241	FACT-G-4, QOLI; CES-D (depression); POMS-SF (mood)	Increased depression, anxiety, anger and confusion
Andersen et al. [11]	147	Profile of Mood States (POMS); Dyadic Adjustment Scale; Katz Adjustment Scales	Elevated depression, anxiety, confusion, and anger
Cull et al. [12]	83	Self-assessment questionnaires	Anxiety, depression and stress were elevated, as was fear of recurrent disease
Andersen et al. [11]	122	The Sexual Arousability Inventory; The Heterosexual Behavior Hierarchy—Female Form; Diagnostic and Statistical Manual of Mental disorders (DSM-III)	Inhibited sexual desire, decreased orgasm
Cull et al. [12]	83	Self-assessment questionnaires	Significantly poorer sexual function, pain with intercourse
Bergmark et al. [13]	606	Self-assessment questionnaire	Insufficient vaginal lubrication for intercourse, a shortened vagina, insufficiently elastic vagina

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Table 3
Quality of life issues experienced by women and their partners

Clinical trial	Participants (N)	Assessment tool(s)	Outcomes
Lalos, A [14]	134 (60 women and 47 spouses)	Semistructured interviews, check-lists of psychological symptoms	Male spouses were given the news of their diagnosis of cervical cancer by their ill partner. This way of being informed provoked anger and bitterness among the spouses.
Zacharias et al. [15]	80 (40 couples)	Quality of life cancer version scale, coping scale	Patients were more inclined to do something positive to alleviate their situation, whereas spouses tended to hope that problems would go away. Patients reported significantly more use of cognitive restructuring and threat minimization than spouses.

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monogamous for over 10 years, and neither of us had many sexual partners prior to meeting when I was 21. I was confused. The intimacy issues that followed my hysterectomy and treatment were embarrassing and made me feel like less of a woman; the emotional impact of battling cancer was overwhelming for my husband and me, and ultimately destroyed our marriage. Neither of us knew how to recreate the intimate side of our relationship, and the inside of my vagina felt like raw nerves. I felt damaged and unfixable. Robert and I avoided each other, and eventually the emotional and physical gap between us became too wide to cross. As I battled my depression, I started to ask questions — Why did this happen to me? Did I do something wrong? How many people have had the same experiences?

The stigma associated with HPV is real. I was consumed with fear and guilt — I thought I was being punished for doing something wrong and I was going to die. Nobody wants to talk about HPV or cervical cancer. But I do, and I will, because I do not want one other woman to lose her fertility or her life to cervical cancer. I learned that HPV is a very common virus, and that most women (80%) will acquire HPV by the time they are 50 years old. I learned that you can get HPV from having sex once, and HPV is not a sign of promiscuity or infidelity. Doctors know that HPV infections cause cervical cancer, and they have screening tools to detect HPV infections and precancerous lesions in their early stages. Now, women can protect themselves with cervical cancer vaccines.

Inspired by an uplifting scene in the movie, “Harold and Maude,” I started making music again, but this time my lyrics had a different tone. I jumped right back into life and decided to live every minute of every day, but my husband was still consumed with fear that my cancer would come back. I created a non-profit organization to support and educate other women about HPV and cervical cancer. Through The Yellow Umbrella Tour (www.theYELLOWUMBRELLA.org), my concert series,

I use my lyrics and my story to break down the silence surrounding this ubiquitous infection. Consuming my time with cervical cancer awareness and prevention became a way to heal. I became more independent, more vocal, and more confident, but I could not fix my marriage. My story is making a difference. I see it in women's eyes when they hug me after a concert, or when I read an email from a husband who lost his wife to this unnecessary and preventable disease.

The reality is that I will never have a biological child, and I have side effects from my treatment that affect me today and possibly for the rest of my life. The radiation damage in my intestines, bowel, and bladder, the atrophy of my vagina, and my scars are constant reminders of what my body has gone through. I live with the fear that my cancer is coming back every time I cough or have a pain. I am lucky that I did not lose my life to cervical cancer, but the disease was devastating to my marriage. After being together for 17 years, my husband and I could no longer find common ground or a connection, and we separated. I am not saying cervical cancer is fully responsible for our pending divorce, but I can say that it changed us dramatically. I changed physically, but cancer changed the way both of us see and operate in the world. At the end of the day, there are things we can control and things we cannot. I cannot go back to the life I had before cancer, but I can go forward, share my experiences, and be myself. I am just one woman with one story, but I believe women are listening because they want to protect themselves against HPV and cervical cancer. I believe men are listening because they love their mothers, wives, and daughters. Doctors have tools available to prevent and, hopefully, eliminate cervical cancer in the future; women just have to use them.

Conflict of interest statement

CB has no conflicts of interest to disclose. BJM has served on the Speakers' Bureaus of GSK, Merck and Digene. TJH has received honoraria from Merck, GSK and Hologic.

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