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ladder cancer presents a treatment challenge because of the tendency of bladder tumors to recur or progress. Whether the bladder tumor is superficial or invasive, risks of disease progression or mortality are ever-present, especially within the initial 5-year postoperative interval. Cancer therapies may pose daunting prospects to women requiring drastic surgical procedures, exhausting radiation therapy sessions that may damage normal tissue, and a course of chemotherapy that is likely to result in nausea, weakness, increased susceptibility to infections, and marked fatigue. While these interventions hold out the best prospect for complete recovery, main and side effects of cancer treatment may be difficult to endure. If surgery and subsequent treatments are successful and cancer does not recur, women with re-established continence will always need to diligently monitor for postoperative changes or other symptom development.

For many, cancer has both an acute and a chronic phase in which experiences of nursing care shifts from postoperative pain and difficulty managing numerous tubes, external drains, and dressings, to initiating participation in catheterization. Both phases of treatment are important to recovery aimed at supporting and enhancing resumption of life tasks and roles.

Bladder cancer is often considered an exclusively white male phenomenon; however, disproportionately more women die annually from bladder cancer (Mungan, Kiemeney, van Dijck, van der Poel, & Witjes, 2000). The reasons for this vary; however, trends indicate that women tend to present to health care providers in a later stage of this disease and have a worse prognosis. Women with invasive stages of disease have a 5-year survival rate of only 50% (Baniel, 1999). This trend is disturbing since the rates of bladder cancer are rising (Stephenson, 1998), and increasing numbers of women are diagnosed annually (American Cancer Society, 2003; Mungan et al., 2000). The American Cancer Society (ACS) estimates that there will be 57,400 new cases of bladder cancer in the United States in

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### Purpose
The purpose of this study was to gain an understanding of what it means to live with bladder cancer following surgery to re-establish urinary continence.

### Method
Hermeneutic phenomenology was used to reveal the meaning of the lived experience of undergoing surgery to re-establish urinary continence after cystectomy.

### Results
Transformation was the main theme revealed. Sub-themes included unknowing, awareness overlaid with suffering, loss of self, the insider view, metamorphosis, restoration, and the unfolding path.

### Conclusion
An understanding of the lived experience of surgery to re-establish continence after cystectomy for bladder cancer will help nurses promote effective nursing care for these patients.

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**Lived Female Experience of Chronic Bladder Cancer: A Phenomenologic Case Study**

Edith L. Hilton
Lesley J. Henderson

The purpose of this phenomenologic case study was to disclose the lived experiences of a woman survivor of invasive bladder cancer who underwent reconstructive surgery resulting in re-established urinary continence. Data revealed the chronic nature of managing re-established urinary continence, the uncertainty of long-term survival, and the complexity of the sudden loss of urinary continence.

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Invasive malignancy of the bladder is the most common reason for radical cystectomy and compulsory urinary diversion. Urinary continence may be accomplished with externally applied collection devices, or surgically re-established with continent diversions (Kock, Indiana, or Florida pouch) or neobladders constructed from gastrointestinal tissue; either method presents specific management issues and may pose substantial challenges to women (Bernier, 2001). Besides the considerable difficulties of managing surgically re-established urinary continence, women with invasive bladder cancer face an additional burden: recurrence of malignancy in 50% to 60% of all surgically treated cases (Baniel, 1999).

There is a dearth of contextual information about women’s experiences with this complex phenomenon. Lived experiences of women with this condition are essential to disclose because of the chronic nature of managing surgically re-established urinary continence after bladder cancer, the increased likelihood of disease recurrence in this population, and the uncertainty of long-term survival. Loss of urinary continence is a multifaceted issue that is greatly influenced by the ways in which women perceive themselves. Nursing recognizes high-level wellness as an achievable goal for patients who are disabled or chronically ill and strives to assist clients to manage physical disabilities, maintain optimal autonomy, and create the best lives possible. To these ends, nurses identify risk factors associated with chronic diseases and anticipate complications arising from acute conditions superimposed on chronicity (Hilton, 2001). Bladder cancer is an example of this notion. According to Davidhizar and Shearer (1997), nurses should build on the client’s positive attributes and work to reduce negative factors. Despite altered continence, women survivors of bladder cancer may achieve excellent functional outcomes and enjoy a good quality of life. The study provides information and insights enabling better understanding of re-established urinary continence in a chronically ill or disabled population.

Review of Literature

Bladder cancer and women. Bladder cancer is the tenth most common cancer among women (ACS, 2003). Although mortality from bladder cancer declined 8% between 1980-1995, the incidence increased 36% from 1956-1990 (National Program of Cancer Registries, 1999; Shenkman & Lamm, 1998). Bladder cancer presents a treatment challenge because of the tendency of bladder tumors to recur or progress. Whether the bladder tumor is superficial or invasive, risks of disease progression or mortality are ever present, especially within the initial 5-year postoperative interval. In addition to disease-caused problems such as gross hematuria, diagnostic and therapeutically based problems such as cystoscopy and biopsy may create additional problems including pain, infection, and increased bleeding.

Bladder cancer as a chronic illness. In the invasive stage, cancer cells penetrate bladder and surrounding tissues necessitating radical cystectomy, surgical construction of a urinary diversion, and possible additional surgical procedures (Falvo, 1999). Surgical reconstruction is required to provide an alternative means of urinary drainage. Continent urinary diversions enable individuals to avoid external collection devices and enable minimal changes in body image (Falvo, 1999). Nevertheless, body image is affected by extent and type of disease, surgical procedure, recovery from surgery, and sequelae that stipulate lifelong altered urinary continence. Limitations and restrictions imposed by altered continence and recurrent bladder cancer have an obvious potential for disrupting affected women’s lives and adversely for affecting their ability to cope with both acute and chronic aspects of their condition. Coping abilities may be severely taxed during sustained illness (Hilton, 2001).

Contextually, altered urinary continence may pose extensive limitations and restrictions on women thereby limiting their options in employment, social and leisure-time activities, functional capabilities, and overall health and quality of life. Impact on quality of life is subjective and is influenced by cultural, ethnic, spiritual perspectives, and attitudes of those in the environment (Falvo, 1999; World Health Organization, 2003). Altered continence may challenge femininity, attractiveness to others, or inhibit role relationships. Further, the impact of bladder cancer on the individual’s ability to control her life circumstances may also adversely affect perceived quality of life. Self-concept and body image are closely linked to physical appearance and body function. Urinary continence is one of the most fundamental, important, and private bodily functions. Decreased ability to manage urinary continence may cause substantial worry, decreased self-concept, and promote social isolation.

Women with disability or chronic illness. According to Schaefer (1995), chronically ill women fear the unknown related to their future, and they fear loss of self. Some women dread being regarded as a disease instead of the woman they still are. For some, receiving a diagnosis eliminates the mystery of the unknown, and provides a sense of hope that the diagnosed illness may prove curable. Others experience a sense of relief resulting from diagnostic validation of their condition establishing it as authentic. Emotional aspects of chronic illness include feelings
of fear, rage, powerlessness, anger, hopelessness, guilt, and despair, anxiety, and depression (Morse & Carter, 1995; Schaefer, 1995). Psychological changes associated with chronic illness include both acute and chronic depression, regressive behaviors, anxiety, and manifest a negative, defeated, demoralized attitude. Physical symptoms of chronicity include decreased endurance fatigue, malaise, and insomnia (Miller, 1992). Each of these responses to disease may adversely affect recovery.

Comparison of surgical procedures. Invasive (Stage C or D) bladder cancer commonly necessitates radical cystectomy and surgical construction of a urine storage pouch by one of several methods. These options include ileal conduit diversion, continent cutaneous urinary diversion (Kock, Florida, Indiana pouch), and orthotopic or neobladder substitution (Bernier, 2001; Costa & Kreder, 2002; Mansson & Mansson, 1999). The oldest procedure, ileal conduit diversion, is known to provide adequate emptying of urine into a section of ileum constructed to collect urine which then empties into an externally placed and maintained appliance. Use of this diversion precludes voluntary control of urinary elimination, therefore drainage is constant. Drawbacks associated with this device include incontinence, difficult catheterization, anastomosis leaks, pyelonephritis, bacteruria, erectile dysfunction, nephrolithiasis, electrolyte imbalances, and spontaneous rupture (Bernier, 2001).

Internal storage of up to 800 ml of urine is possible, with a daytime continence rate of up to 93% and a nighttime continence rate of up to 76%. However, adequate eyesight, dexterity, and motivation are essential for successful use. Drawbacks associated with this device include incontinence, difficult catheterization, anastomosis leaks, pyelonephritis, bacteruria, erectile dysfunction, nephrolithiasis, electrolyte imbalances, and spontaneous rupture (Bernier, 2001).

Sometimes the urethra can be spared, allowing the creation of a neobladder, also known as an ileal W-bladder. The neobladder is created similarly to a continent diversion except that it empties via a pelvic outlet to the urethra. Several weeks after surgery, the catheter is removed and the patient taught to empty the neobladder by relaxing the external sphincter and creating abdominal pressure. If the urethra has also been resected, a reconstructed neoourethra together with an artificial sphincter is created. This operation is the procedure of choice for a client with bladder cancer that has invaded the bladder muscle. The complications are as listed for a Kock, Florida, or Indiana pouch (Bernier, 2001).

Rationale for choice of surgical procedure. Choice of procedure is influenced by diagnosis; those without cancer or in Stages 0, A, or B involve less-radical procedures such as partial cystectomy. Reasons for urinary diversion in the absence of bladder cancer include relief of ureteral or urethral obstruction, strictures, trauma, refractory interstitial or radiation cystitis, a neurogenic bladder, or severe damage to the ureters or kidneys from chronic infection (Dixon, Wasson, & Johnson, 2001). Those with invasive bladder tumors may require either surgical procedure depending on degree of involvement of bladder tissue, muscles, and other organs affected by malignancy and degree of invasion or stage. Surgical treatment for invasive disease (Stage C or D) involves total radical cystectomy which includes removal of the bladder, urethra, and section of the lymph nodes. If there is lymph node involvement, a vaginectomy and a total hysterectomy may also be required. Radiation and combination chemotherapy are also used as adjuvant treatments or added if disease progression is later discovered (Falvo, 1999).

Surgical procedure and quality of life. Regardless of surgical procedure, psychosocial and sexual problems associated with each type of diversion may negatively affect quality of life (Mansson & Mansson, 1999; Meade-D’Alisera et al., 2001). However, the type of urinary diversion used influences the patient’s quality of life considerably. Studies indicate that continent urinary diversions provide a significantly higher quality of life than ileal conduits, and therefore, when not medically contraindicated, are used consistently (Hobisch et al., 2000; McGuire, Grimaldi, Grotas, & Russo, 2000). Those with continent diversions report improved self-confidence, rehabilitation, leisure and professional traveling, social activities, and decreased risk of inadvertent loss of urine (McGuire et al. 2000). Further, those with neobladder and re-established continence indicate they would recommend the procedure to a close friend, while only 36% would make similar recommendations for ileal conduit (Hobisch et al., 2000).

Purpose
The aim of the study was to disclose and understand the contextual meaning of living with bladder cancer.

Methodology
The research question. The research question for this phenomenologic case study was: What are the lived experiences of surgically re-established urinary continence in a woman survivor of bladder cancer?

Sample. A woman with invasive bladder cancer with surgi-
UROLOGIC NURSING / October 2003 / Volume 23 Number 5

Ethical considerations. Permission to conduct this research was granted by the institutional review board at The University of Southern Mississippi. Informed consent was obtained prior to data collection. No identifying data were collected, and the alias “Daisy” was adopted and used throughout the study.

The research setting. Interview data were collected in a private, convenient location of the informant’s choice. A tape recorder was used, and permission to record was obtained from the informant.

Research method and design. The framework for the study was derived from hermeneutic phenomenology. In phenomenologic research, the aim is to reveal meanings of lived experience (van Manen, 1997). The method of discovering meanings and reflections of other people’s lived experiences is to borrow recollections of lived experiences to enable researchers to understand deeper meanings associated with memories of sensations and impressions (van Manen, 1997). It is through this vehicle those inner meanings were revealed from the perspective of the individual with the most insight into the experience; therefore, the nature of the phenomenon was uncovered.

Human science research efforts are considered explorations into the human life-world that is experienced in everyday situations (van Manen, 1997). Phenomenology is a way of looking at the world that apprehends uniquely experienced events. The worldview of this philosophy and methodology emphasizes the importance of individual experience as the source of all meaning and reality (Husserl, 1962). The activities of the method include: turning to the nature of the lived experience, existential experience, phenomenologic reflection, phenomenologic writing, maintaining strong orientation to the phenomenon, and balancing the research context by considering parts to whole. Use of phenomenology enabled disclosure of tacit and explicit themes and essences.

Data collection and analysis. Open-ended questions included interrogatives that focused on lived experiences of bladder cancer, urinary continence, incontinence, and temporal and contextual phenomena connected with onset and duration/treatment were posed to the informant. Constant comparative analysis of responses and journaling were used concurrently for preliminary data analysis. Validity was ascertained by strict adherence to methodologic rigor that is determined through use of five criteria including (a) descriptive vividness, (b) methodologic congruence, (c) analytical preciseness, (d) theoretical connectedness, and (e) heuristic relevance (Burns, 1989).

Findings

Transformation was the overarching theme revealed. Subthemes included: unknowing, awareness overlaid with suffering, loss of self, the insider’s view, metamorphosis, restoration, and the unfolding path.

The first theme discerned was unknowing in which all Daisy knew about her health was suddenly called into question: “I was a little alarmed at that point when my symptoms first appeared but I thought well, I don’t have an infection and I still wasn’t seeing blood in the urine. I realized that at home I had those blue things in the toilets which went out the window. No one should have anything in their toilet that makes the water colored, because you really need to...people need to look at their urine once in a while and see. I didn’t pay any attention to it but later that week I went to my physician. He took one look at my specimen and he didn’t just refer me, he personally went into his office and picked up the phone and called himself. He didn’t have the nurse call or his front office, he called. This was the only alarm I had. I stood in the doorway to his office when he called and that made me realize that this was really important, that was my red flag.”

A second theme revealed was awareness overlaid with suffering: “When I add up everything, if I had any awareness of bladder cancer symptoms, to me everything I had pointed to bladder cancer. I just wasn’t aware; I didn’t add those things up. The stress incontinence, the spaming, the urgency, the frequency, and the extreme tiredness...I look back now and it should have added up to something that alarmed me and it didn’t because I felt good otherwise. I have always been healthy, never had anything serious.”

A third theme discovered was loss of self: “It was the night before my surgery and it was very clear to me with my fear and complete clarity that I was not going to have good news. I am also a spiritual person and I also had a reassurance that I was going to be okay, but that there wasn’t going to be good news. It was worse than getting the cancer diagnosis I think. It was just like one more big thing heaped on top of another. Like being hit with one bolt of lightening and now this other bigger one is coming and there is no dodging it. I know I didn’t talk to anyone about it. It was a long week before that surgery because I was really convinced that I would never be the same and I couldn’t talk to anybody. I didn’t mention it to a soul. When the urologist told me I might have to have even more extensive surgery removing my vagina, I was devastated. I was terrified. Now I was more scared of that than the whole bladder surgery and the reconstruction. I just really felt like...can’t even put it into words. Almost like a total loss, loss of myself.”

A fourth theme identified was the insider view: “There wasn’t just one tumor. The pathology report said ‘numerous, very large tumors,’ too many to count. I had one down deep in the neck of the
bladder and that's what was holding it open. That's why I lost that sphincter control because they weren't just in the dome, they were in the neck. I had one blocking the left ureter. When he went in to do the cystoscopy, the night before is when I really started getting scared. I wasn't despondent; I was just terrified."

A fifth theme revealed was metamorphosis:

"I was going to have to face this. Right then the decision was made. I did have a few times when I wondered if this was really worth it. Not that I wanted to die, but I wondered if all of this was going to be worth it: Maybe I had this cancer and I was meant to die. Maybe we all, from the day we are born, begin to die and so death just comes quicker and earlier than to others. That's okay with me. I am not afraid of death or dying, but I am afraid of the process. But I wondered if I was going to go through all of this, and die anyway, then what's the point. The gyne-oncologist didn't make it seem so bleak. He was still upbeat about it. "It's okay, I know it sounds terrible but you can live this way. I have got other patients..."

The sixth theme identified was restoration:

"At that point nobody had really told me I was okay and I wasn't coherent enough to even remember what happened. But I had been terrified and now she is saying that everything went all right and I am okay. You are in St. Joseph's hospital and still in ICU. Is there anything I can do to make you feel better right now? Anything at all?" And I remember saying to her that I could sure use a hot bath. That's what sounded good to me, not a drink of water, but a bath and I don't even take baths, I take showers. Why that, who knows. I had that yucky feeling and a bath sounded good."

"And she says 'well I will see what I can do.' And this is an RN, this isn't just an aide or somebody, she had a million patients to take care of. I remember saying to her, 'You don't need to spend all this time with me.' And she said, 'Oh yes I do and I am glad to do it.' She brought a big pan of hot water and she washed my face and my neck and I remember how good it felt. The roughness of the washcloth, the hot water, and the feeling of getting clean. Of being a person...at that point I looked like a carburetor."

The final theme discovered was the unfolding path:

"The doctor felt very confident that he had gotten it all. He said it was completely contained within the bladder and hadn't spread to the nodes. No evidence of cancer anywhere else. The vagina was clear so all they had to do was take the top off. He was excited. He was more than just pleased, it was as if I had made his day or his year."

"At that point, I became a cancer survivor. I felt like I had survived and beat it. It wasn't until later, the more I learned about this kind of cancer, that I realized it has a high recurrence rate. I don't regret having the pouch, the length of surgery is doubled and recovery is longer. But with the ileal conduit I wouldn't be able to wear the clothes that I have on right now. Not having anybody at all [to talk to] was really hard. No one else has been through this, I don't know another soul until I found that Web site and that support group. "I had never even known anyone who had this surgery."

"You know I can talk about it, I don't mind showing anyone. Vic and I laugh about it, but most people don't know. One of the hardest parts of recovery is training the new bladder."

Existential investigation findings. In order to understand the phenomenon of bladder cancer, an existential investigation was undertaken. A review of the literature revealed several works that elucidated the contextual and experiential nature of bladder cancer and sequelae. "You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, 'I lived through this horror. I can take the next thing that comes along'...You must do the thing you think you cannot do” (Bartlet, 1992, p. 654).

Implications for Nursing

The role of nurses in providing effective patient care is dependent on their knowledge and skill and their understanding of the disease process and its effect on the whole patient and family. Whether you consider Virginia Henderson’s view that nursing is providing care until patients can care for themselves, the definition of the American Nurses Association (1980) which says that nursing is the “diagnosis and treatment of human responses to illness,” or the 1994 definition by Meleis and Tran-genstein which states that nursing is about “the process and experiences of human beings undergoing transition,” you must recognize the need for nurses to be able to recognize the patient’s needs in order to plan effective care for each patient (Meleis, 1997, pp. 117-118). Qualitative research methods give valuable insights into the experience of illness from the patient’s perspective and provide information that can be used to plan effective care strategies. This information allows nurses to anticipate the needs of their patients and make effective use of existing resources to assist patients in their transition back to health. By listening to patients’ voices and their stories, it becomes possible to see the experience as patients live it rather than as we conceptualize or theorize about it. Only in this way can we begin the process of uncovering and apprehend a deeper understanding of the experience and effectively meet individual patient’s needs.

Conclusion

To support women’s efforts to adapt successfully after surgical revision, better understanding of this complex phenomenon is essential. Findings of this study revealed explicit, individual perspectives into the complex and interconnected experiential phenomena. Contextual
meaning-making of lived experiences was realized, enabling clear understanding of the informant’s unique perspectives of bladder cancer and re-established urinary continence. It is the goal of this research to promote and enable effective nursing care.

References