

Saskatchewan Women's Experiences of Ovarian Cancer: Summary of Qualitative Findings

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Between late January and May 2011, sixteen women from Saskatchewan participated in face-to-face interviews to learn more about their experiences of ovarian cancer and illness-related issues. Following the initial interview, thirteen women participated in follow-up interviews via e-mail every two weeks for up to twelve weeks in order to capture the impact of ovarian cancer on their everyday lives. E-mail interviews were concluded in August 2011. Participants included women between the ages of 37 and 68 years, who resided in urban and rural areas of the Province, and varied with respect to relationship status and family composition. Although each woman's experience of ovarian cancer differed, many similarities emerged in the interviews that highlight common experiences and prominent concerns. A small number of direct quotations from participants have been included to illustrate aspects of each theme, however any personal information has been removed to protect the privacy of participants.

Unclear Path to Diagnosis: Symptoms and Obtaining a Diagnosis

Many participants experienced some sort of sign or symptom that led them to realize a health problem may exist, however these signs and symptoms were often downplayed by women as being related to their busy schedules, stress, or aging. Nonetheless, these participants also recognized that their symptoms were out-of-the-ordinary and required medical attention. Signs and symptoms included: pain, gastrointestinal issues, bleeding, and bloating.

Given the lack of simple and reliable screening or diagnostic tools for ovarian cancer, it is no surprise that many participants had an unclear path to diagnosis. Typically, obtaining a diagnosis began with seeking medical advice for unusual symptoms, and often required more than one medical appointment or a visit to the emergency room. However, some diagnoses were obtained quickly or by chance after medical tests were carried out for other purposes. For those participants whose diagnosis took several appointments, initial consultations with doctors regarding symptoms yielded diagnoses of minor conditions and a physical examination was often not conducted. As a result, these participants' diagnoses were delayed for months or even years, and required great persistence on the women's part.

"I started having symptoms of, just cramping, bloating, different kind of gas pains, just feeling off. And I went to my doctor about four different times before February, and nothing was really done. They just kept telling me 'You're tired, you're overworked, you're stressed. You have

irritable bowel, maybe a bladder infection', but never really did any tests until the beginning of February." (P10)

Delays in diagnosis had a lasting influence on how these participants experienced ovarian cancer and their ability to cope; feeling as if doctors had not taken their concerns seriously contributed to feeling de-valued, whereas knowing that their diagnosis could have come sooner raised many questions regarding their prognosis. The stage at which ovarian cancer was diagnosed was also influential on women's experiences, as participants acknowledged that outcomes were often better for those diagnosed with early stage ovarian cancer.

Changes in Health Status and Body

It was often a complete shock for participants to find out they had a life-threatening illness, especially when they experienced minimal signs of illness or subtle or vague symptoms thought to be indicative of a minor condition. Even those who struggled for months or years with symptoms often thought of themselves as 'healthy' otherwise. As a result, the diagnosis of a life-threatening illness brought about a shift in health status. Furthermore, diagnosis initiated a process of adjusting to being 'sick', which involved seeking health care services, relying on others for care and support, and altering everyday activities. Many women went from being busy partners, mothers, employees, and/or friends to spending a good deal of their time: at medical appointments, resting, focusing on their health, and trying to manage physical and psychosocial issues related to illness. This shift in health status affected many participants' sense of identity, as they found themselves in new territory both in terms of their health and everyday activities.

"Change in life in going from a healthy person, rarely needing a doctor; to massive medical interventions and appointments and tests and blood work. It's a whole different lifestyle, time consuming, stressful, tiring." (P6)

Ovarian cancer also had a tremendous impact on participants' bodies, many of whom reported changes in appearance and function as a result of surgery and treatment. For some, their changed appearance was detrimental to their body image, and required negotiation in interactions with partners or others. However, changes in physical appearance were something that many felt that they could adjust to, and were often less concerning to participants than changes in bodily function. Differences in what participants could and could not do were a prominent concern, as limitations in function disrupted their everyday roles and leisure activities. However, some participants were able to adapt to limitations or re-gain function following their recovery from surgery and treatment. Those participants who experienced changes in bowel function due to surgery and treatment faced challenges with adjusting to this new situation because it could affect diet, daily and leisure activities, and/or intimate relationships.

Some participants discussed a changed relationship with their body due to having cancer. These changes included: having less trust in one's body following its 'betrayal' or 'failure', being more aware of one's body in general, and being appreciative that their body had endured treatment. In addition, some participants came to realize the importance of taking steps to be healthy and care for their body as a result of illness.

"My body is not so pretty anymore... There are a lot of things that I don't really like so much. I found the loss of hair so very difficult to handle, so that part of my body I'm not very happy about... And my body fails me, it's not just quite as strong. I have to take care of myself better, so I don't like that. Yeah, my body's let me down a bit." (P17)

Disruptions to Everyday Life: Impact on Roles and Relationships

An ovarian cancer diagnosis brought about significant disruptions in the everyday lives of participants and constituted a loss of 'normalcy'. As mentioned above, once diagnosed, large amounts of time were now devoted to illness-related activities (appointments, managing side effects of treatment, etc.). Participants who were previously employed outside of the home typically ceased working during the treatment period, with some not returning to work after. Participants who returned to work experienced challenges with resuming their former roles, particularly because of fatigue. Those women who were not employed or were retired experienced less significant changes in their daily routines, although illness still affected how they spent their time.

Those participants with children living at home faced a difficult situation in which they tried to minimize the disruption that illness caused to their family, while also trying to cut back on their responsibilities to ensure adequate time for recovery. Some found it difficult to step back from their former role in the household, but also struggled with getting family members to take on a greater share of the household tasks. In many ways, having others who were reliant on them was both a positive and a negative for women as they sought a sense of normalcy amidst the chaos that ovarian cancer had introduced. On the other hand, women who had adult children or did not have children tended to minimize the disruptions that illness had caused to their roles in comparison to women with young children.

"My family did the best they could. We hired a cleaning lady so that was fantastic, and we still have her which is good because I still have troubles with my energy. We had lots of help from family and friends who would bring meals in and help that way, and my husband and kids would have to pitch in a little bit more and do a little bit more. But, my kids were scared of me. It was like they didn't know how to talk to me, they didn't know what to say to me, they didn't know how to make me feel better - and that was awkward, because as a mom you always want to be able to be with your kids." (P14)

Participants also described changes in their relationships related to their ovarian cancer experience. These included relationships with partners, children, other family members, and friends. Communication difficulties were most commonly discussed, with participants describing how they had to negotiate when and what was talked about. Although it was recognized that others meant well, unwanted advice or a lack of caring was problematic and created tension in some relationships.

Women with children living at home indicated that they experienced challenges related to communicating about ovarian cancer with their children, and particularly what to tell them given the uncertainty of what the future would bring. Many participants reported being worried about the impact of their illness on family members, and felt that it was difficult to support them while trying to cope oneself.

Women with partners described a number of relationship challenges related to illness, including issues with communication, especially about the uncertainty of the future, negotiating instrumental and emotional support, and intimacy. Pre-existing problems were often exacerbated as a result of illness, and some ended partnerships. It was also difficult for some women to form new relationships given their cancer history and possible uncertainty of their future. On the other hand, some partnerships benefited positively from the experience, as a greater appreciation of time spent together emerged from the illness experience.

“You come so close to dying, then perspective and priorities completely change, and that’s what happened for me. So, that relationship didn’t last. I got out of that relationship. I found the courage and the strength.... And I got through it all because of my family and my friends.” (P18)

Disruptions to Envisioned Life Course

Several participants emphasized that having cancer at their age was very much unexpected and out of line with how they thought about being young and middle-aged women. The life-threatening nature of ovarian cancer led many to feel as if their lives could be cut short, and the side effects of treatment often contributed to feeling unlike others their age. As such, ovarian cancer did not fit with how some participants thought about their current stage in the life course.

Having ovarian cancer also prompted participants to consider that their lives might not turn out like previously expected, and thus many talked about having to re-examine their expectations and plans for their lives. This process involved recognizing that the future was uncertain and they may not have as much time to accomplish their goals as formerly believed. Some participants identified potential losses that could result from having a life-threatening illness, such as not being able to: raise children or see them grow up, fulfill employment responsibilities and goals, enjoy retirement, travel and/or spend time with family. Often, ovarian cancer led participants to become more focused on the present, rather than the future.

“I really thought I was going to live to be eighty-five years old, you know? I mean, you plan a long life when you don’t have any reason not to. I don’t feel that way anymore. There’s-honestly, I certainly could, there’s no reason why I couldn’t live to be eighty-five. But I don’t plan the same way. You don’t think about things the same way.” (P4)

Although the notion that their life course could be shorter than expected was challenging to deal with, participants also experienced this realization in positive ways. Foremost, illness prompted a shift in priorities for participants, as they gained greater perspective on what was important to them. For example, some participants described how the ovarian cancer experience opened up new opportunities for them, or was the catalyst to remove themselves from negative situations. Some women also discussed how the illness experience helped them to feel less obligated to do things that they did not want to. Therefore, illness brought about positive shifts in their everyday lives.

“When it comes to how cancer has affected my life, I think that... it's not something an observer would notice. The change is within me and has to do with attitudes, feelings and reactions... such as being less concerned with physical appearance and a gut knowledge (as opposed to intellectual knowledge) of my own mortality. I get less caught up in everyday issues because so many of them seem trivial to me... I am very aware of the value of my time (not monetary value, but the value to me) and am very apt to say no to demands on my time.” (P2)

Coping With and Finding Meaning in the Ovarian Cancer Experience

Most participants were plagued by worries about recurrence and the possibility of dying from ovarian cancer. No matter what stage the cancer was diagnosed at, participants described experiencing fears that cancer would recur following treatment; however, these worries were often elevated by knowledge of the high rates of ovarian cancer recurrence. Thus, participants lived in a state of uncertainty that had profound implications for their everyday lives. Only after many years of survival (typically five or more) did such fears appear to lessen somewhat, but nonetheless remained present.

“For the first two years, it was every 3 months, and then every 6 months for the next two years. It’s a 5 year process, and then after that I guess I haven’t seen him in a while, almost 2 years. You’ve probably heard of the CA125 blood test and there’s a lot of controversy about that, but right now I live by it. I live by my markings because it helps me get by.” (P13)

Participants who experienced recurrence knew firsthand that their worries had not been unfounded, but sought to maintain hope for the successful treatment of the cancer and their future. Those participants who had made or were making preparations for their death communicated that it was difficult but they appreciated the opportunity and felt better knowing that their families would not have to do so. Specifically, making such preparations was therapeutic and offered a sense of peace to these participants.

Despite the clear psychological toll of chronic risk of recurrence and death, many participants found some sort of meaning in the illness experience, although finding meaning was an ongoing process. As mentioned above, many participants viewed ovarian cancer as a sign to live their lives differently and seize opportunities that presented themselves. Although illness disrupted many aspects of their lives, participants sought to adjust to changes and find a new sense of 'normal' in their lives, which was often a challenging task. Some also described having a greater appreciation for their former roles within the family or at work.

For some participants, raising awareness of ovarian cancer and supporting others affected by the illness helped them to find meaning in their own experiences. Efforts to fundraise, educate women and health care providers, and support others allowed these women to feel as if their experience could make a difference for others and improve health care and support services. Such efforts also offered a sense of purpose and a way to re-gain a sense of control following experiences in which they perceived little control. In addition, many women sought to fundraise and generate awareness in honour of women they had known who had died from ovarian cancer. However, some participants also recognized that supporting others could be challenging because it reminded them of their own experience and the uncertainty that they continued to face.

“For me, supporting others gives me purpose and a way to benefit other women from what I have experienced through my surgeries, treatments and recurrences. There is not too much that I have not experienced on this journey. There are some aspects to supporting so many, in that some days, it can be very tiring and sad when someone is not doing well...” (P1)

Ongoing implications of Ovarian Cancer

All participants described some ongoing or chronic aspects of the ovarian cancer experience, with many participants identifying lasting physical effects of surgery and treatment, and psychological and social disruptions that required ongoing negotiation in everyday life. Additionally, chronicity was evident for those participants who had experienced a recurrence or were currently in treatment because ovarian cancer was viewed as requiring daily management similar to other chronic illnesses.

Although long-term survivors were less likely to perceive their own illness as chronic, participants' experiences highlighted many ongoing issues and lasting implications related to ovarian cancer from diagnosis through treatment and into survivorship. Some examples include: changed appearance and bodily function, stomach and bowel issues, nerve damage, pain, fatigue, menopausal symptoms, fear of recurrence and dying, anxiety and depression, uncertainty about the future, changed relationships with others, concern for family members, feeling different than others their age, and difficulty fulfilling past roles. Shifts in priorities and outlook on life are also evidence of the lasting effect of ovarian cancer on participants' lives. Therefore, no matter where

each woman was in the ovarian cancer experience, lasting implications of this illness were evident and continued to shape the way that they lived their lives.

“Well, my doctor told me right from the beginning, she said ‘We can’t cure this, but we can do treatments with remission, and you know this is your life now.’ You have to just kind of make peace with the fact that, you know, it’s probably not going to go away.” (P19)

Areas for Improvement in Health Care and Support in Saskatchewan

Although participants acknowledged that methods for the early detection of ovarian cancer were lacking in general, many indicated that specific improvements could be made in health care services in Saskatchewan to avoid delays in diagnosis. For example, some discussed the need for improved awareness of ovarian cancer and potential symptoms in women and health care providers, as well as greater diligence in reporting and investigating women’s concerns. It was advocated that all women reporting symptoms associated with ovarian cancer to their health care providers be given a physical examination, including the ovaries, a CA-125 blood test, and an ultrasound in order to determine if ovarian cancer was a possibility. However, it was reported that many health care providers are hesitant to perform these three tests because of the time and cost involved, as well as because of questions about the reliability of the CA-125.

It was also suggested that improvements could be made in the care and treatment of women with ovarian cancer in Saskatchewan. Shorter wait times for surgery and greater access to different types of treatment and scanning technologies (e.g., IP chemotherapy, PET scan) were areas in which improvements were suggested, in addition to access to clinical trials within the Province. Some participants also reported issues with appointment scheduling and communication with cancer centres, which was particularly problematic for rural residents. It was advocated that a specialized gynaecologic oncology unit be established within the Province’s cancer centres in order to ensure the coordination of information and services for patients. Such a unit would also improve communication among health care providers involved in gynaecologic cancer diagnosis and treatment. Many participants emphasized the value of having gynaecologic oncologists in the Province for women who are suspected to have gynaecologic cancer because of their expertise in the area, as their specialized knowledge was crucial to the well-being of this population. Some participants indicated concern with surgeries being performed by gynaecologists as they could be of an inferior standard and require patients to have further surgery in the future. This issue was thought to be related to the way funds are distributed for health care services.

“Our government, even though it is well off now, still is trying to design a system that is cheap, superficial and centralized in one city. This is really old thinking and doesn’t take into account the savings made in wellness. There is a huge budget for chemo drugs, but nothing for proper surgical/medical units for gynaecologic cancer care.” (P6)

Many participants described the invaluable support that they received from gynaecologic oncologists, social workers and family doctors; however, some participants indicated a need for improved support at transition points and outside of follow-up appointments (e.g., post-treatment, as follow-up appointments shifted from 3-6 months, at the end of 5 years of follow-up). Such support could include greater guidance regarding the next steps in the illness and recovery process, and information about where to seek non-medical care and support services. The need for improved support services was particularly evident in some women's descriptions of feeling 'left on their own' to manage concerns, as they did not necessarily want to contact their already-busy gynaecologic oncologists about every concern. It was also suggested that it would be valuable to have assistance with accessing services aimed at assisting recovery (psychological counselling, physiotherapy, massage therapy, acupuncture, nutrition and exercise consulting, pain and fatigue management, etc.)

Concerns about health care and support for those with advanced ovarian cancer was also a concern. Specifically, some participants reported that there was insufficient information regarding issues related to advanced ovarian cancer and the health care and support services available to those whose disease had progressed.

Suggestions for the improvement in health care and support services in Saskatchewan highlight the need to recognize that women at various points in the illness trajectory might require health care and support services to deal with the lasting physical and psychosocial issues they face, including those women who are more than five years past diagnosis.