The Lived Experience of Ovarian Cancer

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The Lived Experience of Ovarian Cancer

Abstract
It was estimated that in 2009, 21,550 women would be diagnosed with ovarian cancer and 14,600 women would die from it. There are approximately 176,007 women living with ovarian cancer in the US. While there is extant quantitative literature surrounding quality of life of women with ovarian cancer, there are significantly less qualitative studies. The purpose of this study was to explore the lived experience of how women with ovarian cancer perceived their quality of life. I Five women were interviewed. Interviews were tape recorded and transcribed, then I read for overall impression and general themes. Three major themes were identified in the data: feelings of loss, impact on family, and life has changed. The findings were consistent with that of other qualitative studies and provide insight for health care providers caring for these women. Women who are battling ovarian cancer need emotional as well as physical support from their health care providers. Providers need to be aware of the implications that a diagnosis of ovarian cancer has on a patient and her family.

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Abstract

It was estimated that in 2009, 21,550 women would be diagnosed with ovarian cancer and 14,600 women would die from it. There are approximately 176,007 women living with ovarian cancer in the US. While there is extant quantitative literature surrounding quality of life of women with ovarian cancer, there are significantly less qualitative studies. The purpose of this study was to explore the lived experience of how women with ovarian cancer perceived their quality of life. Five women were interviewed. Interviews were tape recorded and transcribed, then read for overall impression and general themes. Three major themes were identified in the data: feelings of loss, impact on family, and life has changed. The findings were consistent with that of other qualitative studies and provide insight for health care providers caring for these women. Women who are battling ovarian cancer need emotional as well as physical support from their health care providers. Providers need to be aware of the implications that a diagnosis of ovarian cancer has on a patient and her family.
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Chapter One - Introduction

The Ovarian Cancer National Alliance estimated that in 2009, 21,550 women would be diagnosed with ovarian cancer, and 14,600 women would die as a result (Ovarian Cancer National Alliance, 2009). There are approximately 176,007 women living in the United States who presently have or have had a history of ovarian cancer (Ovarian Cancer National Alliance, 2009). Ovarian cancer is the fifth-leading cause of cancer-related deaths, and the ninth most common cancer for women in the United States. Mortality rates are slightly higher for Caucasian women than minority women. The mean age at diagnosis is 63 years, and the mean age at death is 71 years. It has been suggested that 70-90 percent of all women diagnosed with ovarian cancer will have a recurrence. The overall five year survival rate is 45 percent. One out of every 95 women will die from ovarian cancer (Ovarian Cancer National Alliance, 2009).

Treatment for ovarian cancer involves surgery to remove all visible tumors, ovaries, fallopian tubes, uterus, and sometimes the omentum, if there is metastatic involvement. After surgery, women are started on chemotherapy. Most commonly, patients receive six cycles of Taxol and Carboplatin or Cisplatin (Ovarian Cancer National Alliance, 2009). Receiving chemotherapy has a huge impact on patients’ quality of life (QOL). Also, with the chance of recurrence being high, QOL can be affected throughout the course of the disease. Quality of life can be defined as someone’s personal satisfaction, or dissatisfaction, with the cultural or intellectual conditions under which they live. Patients often times have to go through multiple rounds of chemotherapy due to recurrence, which also has an effect on quality of life.
Statement of the problem

While there is extant quantitative literature surrounding quality of life (QOL) of women with ovarian cancer, there are significantly less qualitative studies. The knowledge gained from this project will help providers provide better care to similar patients in the future. Knowing how the disease is affecting the patient emotionally, as well as physically, is imperative for optimal care. Currently, there is insufficient available evidence related to how this disease has affected quality of life in this among women with ovarian cancer. The aim of this research was to investigate this phenomenon.

Purpose of the study

The purpose of this study was to explore the lived experience of how women with ovarian cancer perceived their quality of life. Ovarian cancer can be a long battle, often resulting in recurrence and complications such as bowel obstructions. Many women with ovarian cancer suffer from recurrent bowel obstructions due to the location of their disease. This discomfort associated with these recurrences largely affects QOL. The number of women with ovarian cancer is increasing. Patients need to be supported physically and emotionally. Many patients will endure primary surgery and months of chemotherapy, only to have recurrence months or years later. This can cause a great impact on the quality of life for these women and their families. The researcher identified a need for this study while working with these patients over a number of years. Patients are taken care of by the same group of providers who see patients starting at the time of diagnosis until the end of their lives.
It is important for these patients to feel that their providers understand what they are going through and that they are sensitive to their needs. Findings from this study will serve to increase care provider knowledge related to both the emotional and physical needs of women with ovarian cancer. Addressing both of these needs at office visits as well as during hospital admissions may be expected to result in better patient outcomes. The research question for this study was “What is the lived experience of women who have ovarian cancer and how has this disease affected their quality of life?”

Significance of the study

The topic for this study was significant because important information was gathered about the participants’ attitudes, perceptions, and behaviors regarding their lives and how they have changed since their diagnosis of ovarian cancer. Nurses caring for patients with ovarian cancer need to be aware of the physical and emotional needs of their patients. Understanding these needs may lead to better patient care, resulting in better patient outcomes.

This study was based on phenomenology. The phenomenological method is “a process of learning and constructing the meaning of human experience through intensive dialogue with persons who are living the experience” (LoBiondo-Wood & Haber, 2010 p102). The goal is to understand the meaning of the experience as it is lived by the study participant. Meaning is pursued through a dialogic process. This is much more extensive than a simple interview. It requires thoughtful presence on the part of the researcher (LoBiondo-Wood & Haber, 2010). The researcher studied a dimension of day-to-day existence for women living with ovarian cancer.
Chapter Two- Literature Review

When researching QOL, an extensive literature review was performed. Multiple search engines were used. Ten articles were found using PubMed and CINAHL search engines. Several research studies investigated the relation between QOL and having a positive attitude about the disease. Many of the articles found were done quantitatively; only two qualitative studies were found.

Two quantitative research studies about quality of life in patients living with ovarian cancer and receiving chemotherapy were found. De Moore, De Moore, Basen-Engquist, and Kucella (2006) discussed the relationship between positive attitudes (higher quality of life) and better outcomes in patients with ovarian cancer during chemotherapy. They determined that situational as well as dispositional optimism were inversely associated with distress and positively associated with health-related quality of life. A greater level of dispositional optimism at the start of chemotherapy was associated with a decrease in serum CA-125 levels (De Moor, De Moor, Basen-Engquist, Kudelka, 2006). These findings were significant because these suggested that individuals with a positive attitude had lower CA-125 levels, suggesting that they had a lesser chance of recurrence. Patients who had positive attitudes during their treatment did better overall. This finding is important for practice. Being able to help patients achieve better QOL by addressing their emotional and physical needs should result in better patient optimism, and therefore, better treatment outcomes.
Fujwara and Coleman (2003) studied quality of life during neoadjuvant chemotherapy. The conventional treatment for ovarian cancer is cytoreductive surgery, followed by chemotherapy. The researchers examined neoadjuvant chemotherapy and cytoreductive surgery after three or six cycles of chemotherapy for efficacy of treatment. They studied 17 women who were treated non-conventionally. Non-conventional treatment was chemotherapy prior to surgery (neoadjuvant). Disease was confirmed with CT and patients were given Taxol/Carboplatin. After three or six cycles (depending on patient outcome), cytoreductive surgery was performed. Quality of life over time was examined using the European Organization for Research and Treatment of Cancer QLQ-C30. This research tool was designed specifically for patients with ovarian cancer to quantitatively assess quality of life. These results were compared with a previous study by the same authors involving women treated conventionally. Overall QOL improved after chemotherapy, and this improvement continued for up to 12 months. Scores on functional scales of the tool showed improvement over time, with the exception of role functioning and cognitive functioning at three months post chemotherapy. Patients treated with neoadjuvant chemotherapy seemed to score better on the QLQ-C30 than conventionally treated patients, but the differences were not statistically significant (Fujwara & Coleman, 2003).

Fox and Lyons (2007) also researched quality of life in ovarian cancer survivors. These researchers stated that only 19% of all ovarian cancers were found at an early stage, therefore women often have a prolonged course of treatment. They thought that QOL was understudied in these women, and wanted to "describe a
symptom cluster and its relationship to QOL in women with ovarian cancer who were recruited from an ovarian cancer support group” (Fox and Lyon, 2007, p. 354). Most of these patients had stage III cancer; 97% had undergone treatment prior to the study. The investigators looked at fatigue and depression for their symptom cluster. This symptom cluster explained 41% of the variance in QOL. This finding demonstrated that fatigue and depression were real problems for ovarian cancer patients. These two symptoms can have large effects on quality of life. Patients who are depressed usually do not feel up to joining in social activities or spending time with their family and friends, and being fatigued also decreases one’s ability to interact socially. Having these limitations can drastically change one’s quality of life.

Results of a study by Nicholson (2002) showed which self-care activities had effects on quality of life in ovarian cancer patients. She surveyed 150 patients, and received 96 responses. It was determined through the surveys, that self-care activities, such as activities of daily living and the ability to care for self, were predictors of QOL. Age also was a predictor, while marital status, income, and cancer stage were not. Self-care activities accounted for 19.7% of the variance in QOL (Nicholson, 2002). She found that patients who were unable to care for themselves in the way they previously could felt that their quality of life was worse. Patients who still were able to care for themselves, but unable to perform other activities, felt that they had a better QOL.

Ferrell, Cullinane, Ervin, Melancon, Urman, and Juarez (2005) examined women’s views on their QOL, surveying 1,383 women with ovarian cancer. A research tool, the QOL-OV28, designed to look at quality of life in ovarian cancer
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patients was used. Women were asked to complete the QOL-OV28 and a short demographic questionnaire. The scores from the QOL-OV28 were compared over six independent variables, including disease status, age at diagnosis, stage at diagnosis, marital status, household income, and use of alternative therapy. There were significant QOL concerns with physical, psychosocial, social and spiritual well being (Ferrell et al., 2005). They determined that ovarian cancer patients experienced QOL concerns that required emotional and physical support. Nurses need to be aware of these concerns and treat them appropriately.

In a further examination into QOL among ovarian cancer patients, McCorkle, Pasacreta, and Tang (2005) looked at psychological issues in women with ovarian cancer. They found that because these women were often diagnosed at such late stages, the medical and surgical interventions were sometimes overwhelming and caused psychological trauma. They stated that a diagnosis of ovarian cancer resulted in a high level of anxiety, uncertainty, and depression when diagnosed at a later stage. Women were treated aggressively with medical and surgical interventions regardless of the stage of their disease (McCorkle, Pasacreta, & Tang, 2005). It is important that caregivers are able to support their patient through this process, and help them with any quality of life issues they may have. They concluded that health care providers need to be aware of the increased risk for a decrease in QOL in women with ovarian cancer.

Ekwall and colleagues interviewed 12 women in Sweden who had ovarian cancer 5-10 months after learning of a recurrence (Ekwall, Ternestedt, and Sorbe, 2007). The participants discussed “living in limbo” as one of the main themes. These
women were fighting to stay alive, and at the same time preparing themselves for death. It was stated that while women often know they have a high risk of recurrence, they were shocked at the time of recurrence. Having experienced the initial treatment and knowing what was involved made the anticipation of recurrence even more frightening. Women had to undergo chemotherapy and relive the side effects all over again. Each woman was interviewed about the experience of being informed of a recurrence. Researchers found that when learning of recurrence, women were exposed to a greater death threat than that at initial diagnosis. Women seemed to be more convinced they would beat ovarian cancer during treatment for the primary diagnosis than during treatment for the recurrence. Women were more upset when the only evidence of recurrence was an elevated Cancer-Antigen 125 or malignant ascites. Without definitive determination of where the tumor(s) were, it was more difficult to believe the news of recurrence. It was easier to understand the disease when there was an experience of symptoms, or when the woman felt ill. The news of recurrence was sometimes thought of as a failure. The women beat cancer, and were survivors, and then “failed” when recurrence occurred. Women felt disappointed because they had not succeeded at staying healthy. In taking care of these women, it is important to support their strength and will to live, and to help them achieve the highest level of well-being (Ekwall, Pasacreta, & Tang, 2003).

Von Gruenigen and colleagues (2010) conducted a quantitative study of QOL domains and clinical factors in women with ovarian cancer. Their primary objective was to compare data obtained from ovarian cancer patients with normative data to assess the degree to which QOL differs from the norm. They looked at demographic
variables to determine if there were correlations between physical/functional and social/emotional scores during chemotherapy. Patients with Stage III or IV who underwent chemotherapy with Taxol and Cisplatin completed the Functional Assessment of Cancer Therapy – Ovarian. Four domains of physical, functional, social, and emotional well being were assessed via this instrument. The results suggested that women with ovarian cancer had scores similar to adult women in the US without ovarian cancer. They had lower scores in physical, emotional, and functional well being, and higher scores in social well being. This suggested that ovarian cancer patients have decreased quality of life in functional, physical, and emotional domains, but may compensate with an increase in social support. They concluded that assessment of treatment outcomes should take into account the effect of these independent variables (von Gruenigen et al, 2010).

Kornblith and colleagues (2010) examined the long term adjustment for patients with advanced-stage ovarian cancer. They surveyed 42 survivors diagnosed with advanced-stage disease with no evidence of recurrence and a mean of 6.1 years since diagnosis. They found that 64% of the survivors’ mental health was at or above then normal medical outpatients. No patients reported post-traumatic stress disorder at a diagnosable level. The majority of the survivors reported a positive impact of cancer on their lives and excellent social support. There was, however, a subset of survivors that needed more help than was received regarding emotional problems (Kornblith, Mirabeau-Beale, Lee, Goodman, Penson & Matulonis, 2010). This showed that patients are in greater need than providers understand regarding emotional stress.
In summary, the studies reviewed demonstrated that patients experienced a drastic change in their quality of life after being diagnosed with ovarian cancer. Many studies suggested that patients felt they had a worsening QOL, and even more so with recurrent disease. Patients who experienced recurrent disease felt as though they had failed. Fatigue and depression were two significant factors that were affected when looking at QOL. It is important that health care providers be aware of this and ask their patients how they are coping with these changes. Not all patients feel comfortable talking about depression and it is important to discuss this with patients. If depression is treated early, QOL may be better for these women. This may also help increase their ability to take care of themselves, which will in turn increase their perceived quality of life. Health care providers also need to be aware that patients experience significant changes in their physical, psychosocial, and spiritual well being. Asking patients about this opens the door to conversation that may not otherwise occur, and could be influence QOL. Some people admitted to being ashamed when talking about depression. Socially, it is a topic that sometimes is avoided. A patient may feel depressed and not feel comfortable talking to their family or friends about feelings of depression. If not asked by their provider, they may never bring it up. Patients also may think it will pass with time, but need to know that this is a condition that can be treated. It is important for patients to know that it is acceptable to discuss feelings of depression with their health care provider.

The gap in the literature identified from this review was that only two qualitative studies were found that were carried out in the United States. In the present study, the researcher wanted to capture the essence of the experience of living
with ovarian cancer and qualitative research provided a window into the lives of these women. Interpreting the stories that women with ovarian cancer tell can provide insight and understanding into the meaning and significance of how their QOL is affected.
Chapter Three - Methods

Introduction

This was a qualitative inquiry based on the underpinnings of hermeneutic phenomenology. Phenomenology is defined as “the study of structures of consciousness as experienced from the first-person point of view” (Smith, 2009, p.1). Hermeneutic phenomenology uses narrative texts to explain a phenomenon. It can be defined as “the art of understanding and the theory of interpretation” (Smith, 2009, p.1). All women share the same disease; however they may interpret it differently. It is important to understand whether women with the same disease feel similarly or differently about it. Knowing more information about how patients feel both physically and emotionally is important when caring for them. It is helpful for all health care providers to better understand how patients’ feel so that they can support them and understand both their physical and emotional needs.

Patients may not feel comfortable talking to their provider about depression, sexual dysfunction, fatigue, or other side effects. If providers ask them how they are coping with the changes in their lives, quality of life may be improved. Knowing how a patient is feeling emotionally is as important as performing a physical exam.

Sample/Participants and Setting

A convenience sampling technique was used. Participants were recruited from the census on the Women’s Surgery unit at the hospital where the researcher functions as the gynecologic oncology clinical coordinator. Inclusion criteria were women who had been diagnosed with ovarian cancer for at least six months and who
spoke English. Exclusion criteria included women who had ovarian cancer for less than six months and women who were choosing palliative care. Six women met the inclusion criteria and were asked to participate; five women accepted. The woman who declined became suddenly ill and chose palliative care. The patient and researcher both agreed that it was most important for her to spend her time with her family instead of participating in a study. Once a participant agreed to take part in the study, study procedures were explained. Following this explanation and after the researcher responded to questions or concerns, the participant was asked to sign an informed consent (Appendix A). They also were given a letter explaining the study (Appendix B). Women were informed that their choice to participate in the study would not influence their care while in the hospital and a time for the interview was arranged.

Participants were interviewed in a place convenient to them. Some were interviewed while in the hospital in a private room on an inpatient unit, while others were interviewed in their home or in the community at a place of their choice.

Participants were asked a broad opening question, “Tell me what your life has been like since your diagnosis of ovarian cancer.” If the participant did not feel comfortable speaking without being asked specific questions, she was prompted using questions found in Appendix C. A debriefing was given to the participant at the conclusion of the interview (Appendix D). Each interview lasted between 25 and 60 minutes. The interviews were recorded and transcribed verbatim. Interviews continued until data saturation was reached. The total number of women interviewed was five. Five interviews took place.
Data Analysis

Each interview was read after it was transcribed for overall impression and general themes. After all of the interviews had been read for overall understanding, the researcher, as well as a doctorally prepared women’s health nurse practitioner, analyzed the interviews for common themes, and then met to discuss their overall impressions, to discuss any differences, and then agreed on the common themes. These themes then were shown to one of the participants to check and see if the essence of her experience was captured. Suggestions for changes to the themes were made as necessary.

Ethical Considerations

The researcher followed the Institutional Review Board (IRB) process for informed consent as well as for minimizing the risks to the participants. The IRB at St. John Fisher College approved the study (Appendix A). All patient-related information was de-identified by using a computer generated code number assigned at the time of the interview to assure that no individual subject could be identified. Data were entered into computer files using the code number. Only the investigator and faculty advisor had access to the study files and data. Data were maintained in a location separate from the master code number ID list. The computer files containing data were password protected and will be kept for a period of three years. The investigator was thoroughly trained in issues of confidentiality, and had successfully completed the mandated St. John Fisher College IRB training concerning the ethical treatment of research subjects.
The trustworthiness of the data was ensured. Transferability and dependability were demonstrated in that themes were consistent with other research studies. Confirmability was achieved by having the researcher and doctorally prepared nursing researcher agree on themes. Credibility was confirmed when themes were taken back to one of the participants and she agreed on their meaning.
Chapter Four - Results

Introduction

All of the women who were interviewed were Caucasian, and ranged in age from 50 years through 75 years. All women spoke English as their primary language. None of the women were currently working. All except one were married. All lived in their own homes. Three women were interviewed while admitted to the hospital, one woman was interviewed while receiving chemotherapy as an outpatient, and one woman was interviewed in her own home. One of the women called after her initial interview and requested to be interviewed again. She wanted to give more information than she had initially given. She was re-interviewed at Starbucks per her request.

Major themes and patterns

Three major themes were identified in the data. They were feelings of loss, impact on family, and life has changed. These themes were all interwoven, but will be discussed separately. The following analysis is one way to interpret the data as there is not only one literal way to understand a phenomenon.

Theme one: feelings of loss

The first theme, feelings of loss, encompassed many different losses experienced by the participants. The women described a loss of power, independence, friendships, and womanhood. All women who were interviewed felt powerless. One participant said:

...the diagnosis was the end of life the way it was and life will never be the same. There is absolutely nothing I can do to control it
and of course I feel powerless to do anything, that’s how everybody feels when you don’t have any power. It’s an incredible sense of loss.

All of the women interviewed had prided themselves on being independent, strong women. Being unable to take care of themselves or have any sort of control over their lives left them feeling as though they were powerless. They had no control over what happened to them. All said that this was one of the hardest parts of the whole disease process. They had no control over their disease. They were forced to schedule their lives around their chemo schedules, and were unable to plan events as they previously could because they did not know how they would feel. They felt that the disease had taken control of their lives.

All of the participants stated that they were successful, independent women. Each one of them experienced a loss of independence at some point after their diagnosis. One woman said, “I was very active. I mean I held down two jobs, taught for MCC, and worked a full time job. Now I do nothing. The biggest highlight of my day is going on Facebook and saying hi to my friends and playing my farm.”

Another said:

My husband … hooks me up to my TPN at 7 at night and takes me off around 7 in the morning. He changes my sponge, the drain sponge around my G Tube, he gives me my medications. He was emptying my ostomy. Sometimes it takes like an hour just to get me ready for the day and he has to take me to the bathroom at night because I’ve got the bag and I’m all hooked up to the TPN and that’s in a case, it’s not
hooked up to a pole, it’s in a case but it’s heavy. I don’t like people doing things for me, I’m a very strong, normally a strong person.

Many of the women felt a loss of friendship, mostly because they did not want to burden their friends with their medical problems. One woman said: I don’t want to see people. This is a time of weakness for me and as a teacher and having these friends, I was considered a strong person. So I don’t want them to see me in my time of weakness and it’s hard to explain that to them. I just tell them I don’t feel well and I know I don’t look great…I don’t look good.

She went on to say “I don’t go out and get the mail or anything like that. I didn’t want to go out with the walker down the driveway. I didn’t want the neighbors seeing me using a walker.”

When discussing the loss of womanhood, most women said that they had to rely on their husband for duties that they previously performed around the house. They were no longer able to do the grocery shopping, the cleaning, or the cooking. They felt that this was their job, being the woman, and they were unable to do this anymore. One woman said “My whole life has changed…I would just like to be able to do my dishes and make dinner for my husband, but I don’t have the energy to even do that anymore.” None of the women spoke of their sexual identity or its role in their relationships.

These women stated that they felt like they lost independence once they were diagnosed. They felt as though they no longer could act in the same capacity that they previously could. They felt as though they lost touch with friends because they did
not want people to feel sorry for them or pity them. They felt an incredible sense of loss when they had to discontinue normal lifestyle activities.

**Theme two: impact on family**

Another common theme was the huge impact that this disease had on the families of these women. They all worried about the impact their disease had on their husbands, children, and friends. One woman said:

> My husband, we’ve been married 50 years and he goes through my ups and down daily. I mean he experiences what I experience vicariously and he feels powerless because he can’t do anything to help me and he knows he can lose me at any time.

She went on to say:

> I hate that it’s impacted my husband, my family. I have a son and a daughter. My children worry about me and they worry about their dad. They worry about him emotionally and physically. They had a vacation planned and when I went into the hospital 2 months ago my son said I can’t be that far away, I can’t get back fast enough if you and dad need me.

> When talking about her sister, she said “she got so upset at my diagnosis that she’s been on antidepressants ever since...She worries about me and ever since I got diagnosed I have to call her every day.” Another discussed her daughter’s wedding the previous summer and how she was not able to help her plan any of it because she was so sick all the time. She had to go to her dress fitting on a pass from the hospital, and she could barely make it through the wedding day she was so exhausted. She felt
helpless that she was unable to do the things she wished for her daughter’s wedding. She knew she had no choice, she was not able to help out and so she delegated tasks. She also talked about her grandchildren:

My son stayed for a week after the wedding and I didn’t even go to see him off at the airport. I was too tired, too sick and in fact, that morning, they left about noon and I wasn’t even out of bed. They came up and said goodbye to me in the bedroom because I was just too tired to get up and change my clothes and say goodbye to them and these are my grandchildren. I thought being a grandmother would be a lot more fun. But when you’re not feeling well...

All of the women discussed how the most important thing was their family and how they most enjoyed spending quality time with them. They felt that as long as they had their families, they had enough. When asked about the thing most valuable in her life, one woman said, “I think my family, and I would have to say yes, I do enjoy them.” Another said:

The fact that I’m still alive is the most enjoyable thing, believe me. I still enjoy my grandchildren, my children. I enjoy pretty much the way our life is but the greatest thing now is seven and a half years later I am very thankful and I’m grateful for it. Grateful for every day.

All of these women spoke about how this disease had not only affected them, but affected their families. All were more concerned about their families’ well being than their own. They worried that their family could not lead normal lives because of
their disease. They disliked having this impact on their families. One did discuss how she felt about how her husband would be after she had passed away. He had already taken over all responsibilities of the housework and the bills. She felt that he would be ok with these tasks after she was gone. She did not talk about how he would be emotionally.

**Theme three: life has changed**

The last theme was the change in daily life for these women. Life, as they knew it, was no longer the same. They had to change the way they lived. One woman spoke of a “new normal.” She said, “It’s very unpredictable, so it’s ups and downs and the chemo always hanging over like a cloud. You know, I’m going to have it again and I have to, otherwise I’d be dead. There’s a new normal.” All of the women talked about how they were no longer able to make plans. They worried that they would have to break the plans if they make them. They avoided planning trips because they were worried they would not be able to travel. One said “I can’t plan to go out or anything because you don’t know how you’re going to feel.” Another said, “I had to cancel everything I had going on in the summer. I had to cancel it all.”

All of the women spoke of the worry that they experienced through this diagnosis. They worried about their families as well as themselves. They worried that they would have a recurrence and need more treatment. They also worried that eventually there would be no treatment available to them. They worried about these things every day.

One woman felt as though her life was on hold. She felt that she was not able to do anything substantial in her life until she had completed her sixth cycle of chemo.
This woman had ovarian cancer for only seven months. She felt differently than the other women. The four other women were diagnosed years ago. They felt that their lives were forever changed, and the other woman felt that her life was changed somewhat, but she would be able to return to her previous lifestyle once she finished initial treatment. This woman had never had a recurrence, whereas the other four had. She had recently been diagnosed. This is a difference in the mindset of a woman with a somewhat new diagnosis, and women with recurrent disease.

The stories of these women revealed what it is like to live with ovarian cancer and the impact it had on their quality of life. The themes reflected the feelings and lived reality of ovarian cancer survivors hospitalized for recurrence and/or treatment and provide nurses an opportunity for understanding what they may do to better care for these women.
Chapter Five - Discussion

The findings of this study were similar to other studies found in literature. Two of the ten studies reviewed were qualitative studies. Findings from the present study were similar to findings from McCorkle, Pasacreta and Tang (2005). The themes found corresponded to the themes in the present study (uncertainty, anxiety, and depression). Findings from the present study also were similar to findings by Ekwall and colleagues (2007). The common themes from Ekwal’s study were failure and worry.

It is important for health care providers to understand the considerable stress experienced by women with ovarian cancer. Having a better idea of what they were going through may influence clinicians in how they provide their care. Also, when women know that their health care providers understand their emotional trauma, QOL may be affected in a positive way.

Participants in the present study were eager to know that their results would be conveyed to the nurses who took care of them. They each felt that they would receive better care when their health care providers understand the emotional and physical stress they face day to day. Nursing practice can be influenced by knowledge and understanding of what patients feel is important and what they need from their care providers.

Women who are battling this devastating disease need emotional as well as physical support from their health care providers. It is important to understand the struggles that they faced on a daily basis. Understanding these struggles will allow for more holistic patient care, which could influence their perception of QOL. Women
who had a positive attitude and an optimistic outlook did better with their treatment. For example, one patient who was newly diagnosed felt that she just needed to complete her chemotherapy treatments and then she would be able to resume her normal life. She had a positive outlook on life because she maintained hope that she would conquer the disease. The other four women understood that they would die sooner than they would like because they had recurrent disease and a worse prognosis. Women with positive attitudes appeared to have tolerated treatment better than those who did not have the same optimistic outlook.

It is important for health care providers to understand what significant others, family members, and friends of these women go through every day. Some are taking care of their husbands, parents, children, and friends while they struggle to take care of themselves. Women fighting this disease experience emotional as well as physical disruptions in their lives. They experience ups and downs daily. They are forced to make decisions knowing that these may have a negative impact on their family as well as themselves. They are fighting to stay alive each and every day.

Phenomenology was appropriate for this study because all women were living with the same disease and experienced it in their own way. The researcher made conclusions based on interviews and thorough review of the transcripts.

**Limitations**

One limitation of the study was the small sample size; however, this is the nature of a qualitative study. Five women participated in the study. After five interviews, data saturation occurred. Another limitation may have been the setting where the participants were interviewed, as well as where they were recruited.
Participants were treated at a gynecologic oncology center; there are few comparable centers across the country. Some women are treated by medical oncologists who may not have the same understanding of the disease or provide the same type of treatments as gynecologic oncologists because the medical oncologist does not perform surgery. Patients treated by a gynecologic oncologist have all of their care provided by the same specialist physician. The gynecologic oncologist performs surgery, doses chemotherapy, and manages complications.

**Implications for practice**

Health care providers need to be aware of the implications that a diagnosis of ovarian cancer has on patients and their families. During office visits, providers should inquire about emotional and psychosocial issues as well as physical complaints. Providers also should check with the caregivers of these patients to see if they have any unmet needs. Nurses also must be aware that receiving a diagnosis of ovarian cancer can be frightening and overwhelming. Most patients first experienced physical change after their initial surgery. Post operatively nurses need to educate patients not only on what to expect post operatively, but also what to expect during chemotherapy. Nurses in the infusion room also should work with patients on physical or emotional issues that may arise.

Participants felt that they experienced a wide variety of emotions during their disease progression. They felt joy at the end of initial treatment because it was over. They felt failure when they suffered a recurrence. They felt worried all the time, about themselves, their families and their friends. They felt that they no longer had control over what was happening to them or whether they would live or die. All of
these feelings can be addressed by nursing while interacting with ovarian cancer patients. When armed with the knowledge that these are common problems and concerns for ovarian cancer patients, nurses can better advocate and manage their care. Results of this study are expected to be useful for nurses in this regard.

In the researcher's work as a staff nurse on a nursing unit specializing in ovarian cancer, QOL often is a topic of discussion. Time and again, nurses question why patients continue to receive chemotherapy despite their diagnosis, rigorous treatment schedules, co-morbidities, and grim prognosis. Findings from this study can begin to shed light on these questions. Findings also revealed that patients still can enjoy the things that are most important to them. Living with this disease and its complications was regarded by these participants as better than not living at all.

Findings contributed to the existing literature on QOL and living with ovarian cancer, as there were only a few published qualitative studies that examined QOL for ovarian cancer patients, with similar findings. However, findings from the present study contributed to the knowledge and understanding of the lived experience of ovarian cancer. A study of women who receive care from a medical oncologist to ascertain whether they describe the same lived experience and impact on quality QOL would provide further insight into this phenomenon. Interviewing family members of women living with ovarian cancer could assist health care providers in understanding their perspectives on how quality of life for their loved ones has changed. This also would provide insight into their needs as well.
Conclusion

This phenomenological study based on hermeneutic philosophy was conducted to answer the research question “What is the lived experience of women who have ovarian cancer and how has this disease affected their quality of life?” What is the lived experience of women who have ovarian cancer and how has this disease affected their quality of life?” Analysis of the stories told by women with ovarian cancer revealed three common themes characterized by loss, the impact on family, and that life, as they had known it, had changed. These women continued to have a positive outlook despite their reports of a negative change in their quality of life. Implications for health care professionals, including nurses, and further research were discussed based on the understanding of the participants lived experience.
References


Lived Experience of Ovarian Cancer


Appendix A

St. John Fisher College, Wegmans School of Nursing

The Lived Experience of Ovarian Cancer

Consent Form

For question about this research study, contact: Jennifer Tyll, RN, BSN, FNP-S (or faculty advisor Nancy Wilk, DNS, WHNP-BC) at the Wegmans School of Nursing at St John Fisher College, 3690 East Ave, Rochester, NY 14618.

This consent form describes a research study. It is encouraged to read this consent form carefully if you wish to participate in the study. You may ask the person responsible for this study question at any time. Your care will not change if you choose not to participate in the study. You have no obligation to participate.

Approval of study: This study has been reviewed and approved by the St. John Fisher College Institutional Review Board (IRB).

Purpose: This study is being conducted to find out about the lived experiences of patients with Ovarian Cancer.

Description of study procedures: This study will take place from June 2010 through December 2010. If you decide to participate, I will set up a time to talk with you. The interview will be audio taped and will take between 1-2 hours. The interview will occur at a time and place convenient for you. Only participants who agree to be audio taped can participate in the study. You will be asked to talk about the personal experience you have had since your diagnosis of Ovarian Cancer. You might also be asked what support groups you utilized throughout treatment, and how, if at all, this helped you. At the end of the interview I will ask you some demographical data.

Time Commitment: Your participation in this research study will take between 1-2 hours. You may also be contacted later to clarify what you said if necessary. If this occurs, it should last approximately 10 minutes.

Risks and Benefits: Discussing your disease may be emotionally upsetting to you. You may decline to answer any questions or to withdraw from the study at any time without penalty. If you need to talk about these emotions further I ask that you contact the wellness center at SJFC, a social worker, or your health care provider. There are no direct benefits you can expect to receive except to know that you are helping to educate other health care professionals with your story. You may receive a gift certificate for your participation.
Confidentiality: Your individual privacy will be maintained in all published and written data resulting from this study. Audiotapes will be kept for a period of three years in a locked cabinet in the researchers office. After this time they will be destroyed. The results of this study might be presented at meetings or in publications. Your identity will not be disclosed in those presentations.

Volunteering for the Study: Your participation is voluntary. Your refusal to participate will not compromise your care as a patient on East 5 at Highland Hospital. You have the right to refuse to answer particular questions. You have the right to withdraw your data at the end of the session or at a later time. You also have the right to withdraw from the study at any time without penalty.

Subject Statement: I have read the explanation provided to me. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study.

Your rights: As a research participant, you have the right to:

1. Have the purpose of the study, and the expected risks and benefits fully explained to you before you choose to participate.
2. Withdraw from participation at any time without penalty.
3. Refuse to answer a particular question without penalty.
4. Be informed of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to you.
5. Be informed of the results of the study.

I have read the above, received a copy of this form, and I agree to participate in the above-named study.

Print Name: __________________________
Signature: __________________________ Date: __________________________

I certify that I obtained the consent of the subject whose signature is above. I understand that I must give a signed copy of the informed consent form to the subject, and keep the original copy in my files for 3 years after the completion of the research project.

Signature of the Investigator: __________________________
Date: __________________________

Audio Tape Release Form
I give consent to be audio-taped during this study: Initials
Appendix B

Wegmans School of Nursing at St John Fisher College
The Lived Experience of Ovarian Cancer
Introduction Letter to Participants

Dear Patient,

My name is Jennifer Tyll and I am enrolled in a Master’s program at St. John Fisher College. I have been employed at Highland Hospitals since 2005. From 2005-2006 I worked as a Patient Care Technician while finishing Nursing school. Once I graduated in 2006 I transitioned into the role of Registered Nurse. In 2007 I enrolled in the Master’s of Science in Nursing program at St. John Fisher College to become a Family Nurse Practitioner. During my time spent on East 5 I have taken care of many patients with Ovarian Cancer. I have become very interested in the lived experience of those with this disease. I am conducting a research study to investigate quality of life in patients with Ovarian Cancer. I would greatly appreciate your support by telling me your story and also answering a few simple questions. I would need to spend time interviewing you either via telephone, or face to face, whichever is most convenient for you. I will audio tape the conversation. The interview will take place at a time and place that is most convenient for you. You will receive no direct benefits from completing this study other than helping to educate other providers with your story. You will receive a gift card upon completion of the study. You may experience emotional distress while discussing your story. Your responses will be confidential, and your identity will not be known to anyone other than the investigator. If you have questions regarding this research study, you can contact myself or Nancy Wilk, DNS, WHNP-BC at the Wegmans School of Nursing at St. John Fisher College.

Thank you for your time and for considering participating in my study.

Jennifer Tyll, RN, BSN, FNP-S
Jennifer_Tyll@urmc.rochester.edu
(585) 275-1616 ext 81380 (pager)
Appendix C

Wegmans School of Nursing at St. John Fisher College
The Lived Experience of Ovarian Cancer

Initial Question: Please tell me what your life has been like physically and emotionally since, and leading up to, your diagnosis of Ovarian Cancer.

Further Questions (if needed)
1. How has having Ovarian Cancer affected your daily life?

2. How, if at all, does chemotherapy affect your daily life?

3. Do you feel as though you are able to continue with normal life throughout treatment?

4. What types of activities are you able to do on a regular basis?

5. What do you feel you are unable to do?
   a. How do you feel about this?

6. What things are most valuable to your life?
   a. Are you enjoying them?
Appendix D

Wegmans School of Nursing at St. John Fisher College
The Lived Experience of Ovarian Cancer
Debriefing Statement

Thank you for participating in this qualitative study on the lived experience of Ovarian Cancer patients. Your data will be analyzed for common themes among participants. These common themes will then be shared with other health care providers to increase their knowledge on the disease progress and the impact it has on patients lives.

You may experience negative effects from talking about your experience. This discussion may be emotionally painful for you. You may feel depressed or sad after the interview. If this occurs and is bothersome to you, please contact Jennifer Tyll, RN, BSN, FNP-S, Nanc Wilk. DNS, WHNP-BC, the Wellness Center at SJFC, a social worker, or your health care provider.