The lived experience of women impacted by cervical cancer

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Abstract—Background: One of the deadliest forms of cancer for women in the world, cervical cancer can be easily avoided. The emotional trauma of cervical cancer's diagnosis and treatment leads to psychosexual aftereffects that have an impact on quality of life (QoL). As the number of cervical cancer survivors has increased, quality of life has grown in importance as a factor in social, psychological, and physical survival as well as a key element of health. Aim(s): This research aims to explore the experience of women diagnosed with cervical cancer in terms of its impact on physical, psychological and social health aspects. Methods: Cervical cancer survivors were targeted. Eleven women who experienced changes in their physical, psychological and social health in oncology hospitals in Baghdad city had participated in a semi-structured interview to further understand their experience. Qualitative data is analyzed using Giorgi’s approach. Results: Participants reported a significant impact of cancer and its management line on their physical, psychological and social health. Conclusions: The psychosocial health needs of cervical cancer survivors are often left behind. Also, the experience that women live with cervical cancer is a harsh life experience in terms of its direct impact on the physical, psychological and social health aspects. Healthcare teams should consider integrating communication and physical health tools in their practices in order to better meet the patient's physical, psychological and social health needs.

Keywords—cancer, cervical cancer, women health, QoL, HRQoL
Introduction

Cancer is an uncontrolled proliferation of body cells that encourages the growth of healthy cells and causes issues in the organs where it develops (American Cancer Society, 2017). People who have cancer may experience anxiety, panic, perceived or actual social shame, and a reduction in their quality of life (QoL) (Sabulei, et al., 2019). It could be any type of tumor or abnormal growth that develops in any area of the body as a result of aberrant cells. Numerous malignancies, including those of the prostate, lung, liver, and many others, can affect different bodily areas. It is an abnormal growth or tumor of the cervix that is medically diagnosed as cervical cancer (Collins, Lowy, Hodes, Grady, Gibbon, Fauci et al., 2017). The most prevalent gynecological cancer in the past 20 years has been cervicovaginal carcinoma (Bruni et al., 2015). Globally, cervical cancer affects women more frequently than any other malignancy, with an estimated 527,624 new cases being identified each year and 265,672 deaths (Bruni et al., 2017). Moreover, the leading cause of death for women in low- and middle-income nations is now cervical cancer (Arbyn et al., 2011; Denny, 2012). Early sexual activity with several partners and poor genital cleanliness are a couple of the risk factors for cervical cancer. These ailments, which are relatively common in many low- and middle-income countries, serve as a channel for the Human Papillomavirus (HPV), the primary risk factor for cervical cancer (Kangmennaang, Thogarapalli, Mkandawire, & Luginaah, 2015). Thus, that partially explains why cervical cancer is so common in certain nations. The assessment of patients’ reactions to any type of cancer and its recommended course of treatment is said to depend critically on their quality of life.

The notion of women’s quality of life has been developed, and the women felt that each person’s physical, psychological, social, and spiritual well-being was greatly impacted (Li, Chen, Chang, Chou, & Chen, 2015). Researchers also see the quality of life as a dynamic and intricate idea that is relevant to nursing care for cancer patients. According to anecdotal evidence, quality of life (QoL) is the norm of health, comfort, and enjoyment that a person or community experiences. The majority of the criteria that influence and predict QoL among cancer patients, especially those who are currently battling cervical cancer, are based on the multidimensional nature of QoL (Pfaendler, et al., 2015). Additionally, it is asserted that these elements may affect how long a woman is ill and receiving treatment for cervical cancer, which may affect how she feels physically, emotionally, and socially or how her life patterns as a whole (Machuki, 2015). Numerous cancers, together with the side effects of their various treatments, exacerbate physical symptoms and, undoubtedly, psychological discomfort, which has a detrimental impact on the patient’s quality of life (QoL). Health practitioners frequently focus on curative treatments for cervical cancer to prolong life, which may undervalue the consequences of treatment problems on patients’ quality of life (Li et al., 2015). Furthermore, it was discovered that cervical cancer patients experience a wide range of physical side effects from the disease and its therapy (Massad et al., 2013). For instance, some individuals experience vaginal sores, painful sex, bleeding, and urine incontinence. Furthermore, lower back and hip pain are common among cervical cancer patients this is a result of radiotherapy’s long-lasting side effects, which limit their ability to move around normally (Vistad, Cvancarova, Kristensen, & Foss, 2011). Cervical cryosurgery and chemotherapy,
which have been noted to be the main treatment modalities for cervical cancer worldwide, are another treatment that has an impact on women physiologically (Pfaendler, Wenzel, Mechanic, & Penner, 2015). Therefore, this study was designed to answer the following research question: What are the experiences of women with cervical cancer in terms of its impact on physical, psychological and social health aspects?

Methods Study Design, Sample and Setting

Setting

A sample of 11 women who have cervical cancers at the oncology centers & teaching hospitals were interviewed. The oncology consultation clinic at Yarmouk teaching hospital, and the center for early detection of cervical cancer at Al Alawia Maternity Teaching Hospital, and— the Medical City directorate/ Oncology Teaching Hospital, were chosen because they are specialized centers for cancer patients treatment. Interviewing eleven women was enough to reach the saturation point. It is the point in data collection and analysis when new incoming data produces little or no new information to address the research question (Guest, Namey, & Chen, 2020).

Data Collection Process

Semi-structured interviews were conducted with all who agreed to participate in the study. The main advantage of a semi-structured interview is that the researcher can attend to the experiences of the individual, (Galetta, 2013). Also, face-to-face interviews provide the opportunity to assess the validity of participants' responses by noting nonverbal cues, which is useful when discussing sensitive topics (Louise Barriball and while, 1994; Dabble, & Cathain, 2015; Lamont, et al, 2016). A 12-item semi-structured interview guide was developed to investigate the impact of cervical cancer on aspects of physical, psychological, social, and spiritual life quality choosing the right type of interview is critical in qualitative research (Neergaard & Leitch, 2015; Nicholls, 2009).

Study design

The phenomenological research design was selected to steer the qualitative section of the study. This approach is popularly used to study the lived experience, to gain a deeper understanding of how human beings think, and expand a researcher's knowledge about a phenomenon. (Vagle, 2018).

Ethical Consideration

First, the research ethics committee at the University of Baghdad, College of Nursing had reviewed and approved the study protocol, reflecting that the intended study research procedures are congruent with the Declaration of Helsinki Ethical Principles for Medical Research involving human subjects. After obtaining the official approval from the departments of oncology centers in the City of Baghdad, an oral consent was taken from women with cervical cancer after
informing them that the information will be treated confidentially and used for scientific research purposes only.

The participants were told that they could refuse to answer any question or that they could withdraw from the study at any time during the interview or if the questions were embarrassing or if they were unable to complete the interview due to their poor health. The confidentiality of the participants was protected and their privacy was secured. Numerical numbers were given to each participant, not names, to maintain complete confidentiality of the participant. All personal details that could be used to identify specific individuals have been removed from the data. All recorded audio interviews were stored in a password-protected computer, allowing access only to the researcher.

Result

Giorgi’s phenomenological method guided the data analysis. With this method, the researcher identified significant words, phrases, sentences, and paragraphs for extraction from each transcription (Giorgi 1985; Flood, 2010). Then the extracted data grouped into high-level conceptual modules or topics, which include ideas and feelings of patients with cervical cancer. The basis of objective extraction is conceptual threads common to the eleven interviews conducted, through which the researchers identifies the essence of the experiences of patients with cervical cancer to a degree which enables to draw conclusions and recommendations. Themes emerged from the analysis of the participants’ interviews touched on the core experiences of patients with cervical cancer. The first group focused on the themes of the impact of cancer on the physical aspect of a woman’s life, while the second group focused on the themes of the impact of cancer on the psychological aspect of a woman’s life. Of equal importance, the third group highlighted themes of the impact of cancer on the social aspect of a woman’s life. The emerged themes were supported by data from the study participants.

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Themes of the impact of cancer on the physical aspect of a woman's life
Pain as a part of my life with cancer

In response to the following questions "Tell me about what led you to finding out you had cervical cancer, where you having any symptoms?" The feeling of pain was in some of the reviews the indicative sign that led them to seek health care providers advice to diagnose the condition. Participant 3 reflected “First of all, I have abdominal pain, back pain, very strong, ...I was thinking it might be related to irritable bowel syndrome...however it was not! Participant” 10 stated that “Abdominal and back pain were the major problems that had led me seeking health care providers advice! Thank God ...I have heard that some patients may not fell the pain until it’s too late!

Exhaustion, Energy depletion, & Collapse

In their response to the following question “Tell me about your experience with cervical cancer”, all were shocked and fatigued of this difficult experience affecting all aspects of life and the suffering they had experienced during their journey with cervical cancer. Participant 1 reflected” I got tired of everything, even simple activity of daily living...how can I move on with my life anymore?!” I always feel annoyed! In the same way, Participant 2 was saying "I was tired both physically and emotionally... moving through life with cervical cancer was even difficult because of my husband who decided to left me when he heard about my confirmed diagnosis...He left me alone with my children...sigh...may God curse him...amen!

Anorexia-related malnutrition

In response to the following questions, “How the side effects of cervical cancer treatments affected your quality of life the most &why? Many of the study participants answered that they knew about chemotherapy and they blamed the loss of appetite as a result of chemotherapy

Participant 4 stated:
During the cancer treatment phases, I started feeling tired and I started to loss my hair ...as a result, I didn't want to eat at all,...sigh... and I developed anemia...
Participant 5 stated:
“I suffer from appetite loss, and food becomes tasteless...life itself become tasteless!”

Menorrhagia

Many of the study participants had reported that unexplained vaginal bleeding was one of the major physical problems that they experienced.

Participant 2 stated:
I had a strong vaginal bleeding. I went to the hospital and did some tests. The doctor told me to see a specialized surgeon. I was scared... I had all the tests done and he said that I should seek surgeon’s advise! yes! hysterectomy... that was a turning point in my life!
Participant 4 stated:
I had a heavy unexplained vaginal bleeding, I went to the doctor and did an ultrasound and many lab examinations. Then I became anemic and didn't want to eat...Before I got there, I had pain in the area, but I thought it was infections. Then the result appeared, cervix cancer!

**Themes of the impact of cancer on the psychological aspect of a woman's life**

**Domination of Negative Feeling and Losing of hope**

In response to the following question, "when was cervical cancer first discovered and how did the news affect you & why?" Many participants in the study answered that the negative feeling was the one they had at the time of discovering and confirming the disease diagnosis as a result of the shocking news.

Participant 1 stated:
Knowing about my confirmed medical diagnosis was one of the hardest stations of my journey with cancer fight! Moving from completely normal health to radical surgery for the first time in my life...also the experience I had waiting for the results of tissue biopsy.... I went through shock...anger...denial...... I was dominated by the negative thought process that I’m going to die... but thank God I did not die...so far!

Participant 2 stated:
I was and still so tired, the world has become dark in my eyes ...life was meaningless for me! Why me?...that was a question going through my mind!

Participant 3 stated:
After a year of pain. After several reviews, they knew that it was a gynecological disease... I was so shocked that I felt that after how many days I will die and the shock was very strong it almost crippled my life.

Participant 5 stated:
At first, I didn't know more about my condition...however later on ... I did. When they inform me about the histopathology report...sigh ...It was a difficult time for me and my family too... silence... we went through shock state, and I felt weak, helpless and destined to death

Participant 7 stated:
When I did a biopsy a week later, the result came out and I was very terrified, shocked, and submissive to God’s destiny

Participant 8 stated:
When the health care providers decided that a cervix biopsy is needed, I entered the vicious cycle of intense fear, desperation, and anxiety . the results of the histopathology were positive!...silence... I was thinking that I'm going to die...it's a matter of time... and my daughters were sad and crying all the time because they told them there was no hope for me. You can imagine my situation at that time!
Participant 11 stated:
when my cervix biopsy report showed that I had cancer, I was very shocked and broken down, and my family was so shocked too by the news...we all were thinking that death is coming to me! I was not able to see the light at the end of the tunnel!

Participant 1 stated:
I felt like I was going to die and never be able to see my children growing in front of my eyes... silent tears... and I felt hopeless about everything...I literally collapsed

Participant 2 stated:
The world has become dark in my eyes and especially that I am alone and no one is with me and my husband has left me...due to my disease nature! Can you imagine?!

Participant 9 stated:
...they would take out the uterus and this is part of my body and I felt that something was missing.

Participant 11 stated:
I was afraid so much because cancer is a synonym of inevitable death, I started to count down my days in this world!

**Challenging coping**

In response to the following question,” How has your illness and treatment affected your psychological state & why? “Many of the participants in the study answered that the psychological state they were going through was very bad, as most of them were disturbed by the simplest things, and all this was due to several reasons, including treatment, the quality of life they live in light of this disease.

Participant 3 stated:
I was always upset, especially after sunset... it gets worse for me, I was very depressed, I wanted to be alone, and I can't stand the noises of any child...that was a hard time for me!

Participant 6 stated:
I did not like to see anyone and felt suffocated, and psychologically tired and depleted

Participant 8 stated:
I was experiencing a mood swing ...in other words a sudden or intense change in emotional state form happiness when seeing others who were successful in fighting cancer, and extremely depressed when seeing those who lost their battle with this intractable disease
**Faith Based Resilience**

Despite the obvious catastrophic effects of cervical cancer on subject’s life quality, some testified that their resilience level had increased due to faith in almighty God. They viewed that this experiences is a divine test that they must pass with faith-based courage.

Participant 4 stated....
My psychological condition was affected and I was in a bad situation, but my family and my husband helped me, thank God. I never thought like that before. I say thank God. Physically, psychologically and spiritually, I was affected by it, especially at first...but now I can say, thank God.

Participant 5 stated:
At the beginning of my condition, I got very tired, then thank God I got used to it. before I didn’t want to go to the hospital. But I got used to it.

Participant 7 stated:
This is what I consider a test from my Lord of the worlds. Something God wants to test with me...and every little thing comes out, praise be to God.
Every time my mental state gets tired, I ask God’s forgiveness and thank God for everything.

Participant 8 stated:
I have already tired and what comes from God is welcome, praise be to God.

**Themes of the impact of cancer on the social aspect of a woman's life**

**Disharmony and Social Isolation**

In response to the following question,” How has your illness and treatment affected your relationship with people including your immediate family &social circle? Most of the participants in the study answered that their social status was negatively affected,

Participant 1 stated:
I was trying not to meet people. Because every one of them tells me how much I have changed and become weak, and that makes me upset!

Participant 3 stated:
My family, praise be to God, did not leave me alone, but I am disturbed by the chaos and I want calmness. I do not want to go out, but I like meeting people. A difficult equation!

Participant 5 stated:
Of course, it wasn't the same as before having this...sigh... I used to go to the market for shopping, now I get tired a lot when I go out. I want to stay at home, they try to make me go out but I can't go out...life is never the same for me!
Participant 7 stated:
I took a leave of absence from work, and I do not like to say that I have this disease, even for my relatives, but my immediate family members and those close to me know.

Participant 8 stated:
I started wishing death so that I would not move through when I experienced during the management phases

Participant 9 stated:
My social relationships have become fewer and fewer when compared to my life before the diagnosis with this disease, It was limited to only my family and those who are very close to me.

**Losing Intimacy**

In response to the following question, “How has your illness and treatment affected your fertility & why? Most of the participants in the study answered that the marital relationship and fertilization were affected by the disease and treatment, as it has a direct effect, especially sexual life

Participant 2 stated:
... As a direct result of my diagnosis with cervix cancer, having a baby was not a possible option for us as a couple... he decided to move through separation. Divorce ... sigh... I mean, there were problems between him and me!

Participant 3 stated:
I'm aware that I'm not young anymore... this disease devastated me. Of course, fertility is gone forever!

Participant 5 stated:
Hysterectomy was done to save my physical life. However, it destroyed my marital life!

Participant 7 stated:
My marital life was definitely affected, especially by when taking the treatment, because I was so tired and not able to engage with any sexual activities!

**Discussion**

Discussing the results in the light of the current literature. The main question that the current study attempted to answer was: What are the experiences of women with cervical cancer in terms of its impact on physical, psychological and social health aspects? To answer question the phenomenological descriptive research method was used to explore the experiences of Cervical cancer survivors. All eleven participants shared a unique experience about life experiences with cancer. However, there are many similarities in the way participants interact with its onset. Themes emerged from the analysis of the participants' interviews touched on the core experiences of patients with cervical cancer. The first group focused on the themes of the impact of cancer on the physical aspect of a
woman's life, while the second group focused on the themes of the impact of cancer on the psychological aspect of a woman's life. Of equal importance, the third group highlighted themes of the impact of cancer on the social aspect of a woman's life. The emerged themes were supported by data from the study participants.

Women who have survived cervical cancer may feel physically well, moderately well, or poorly well. According to the study's findings, none of the individuals had good physical health. Pain, vaginal discharge, and vaginal bleeding were the most frequent physical manifestations of the low physical well-being experienced by most of the women. Other research found that cancer patients and gynecological cancer patients (Guo et al., 2004). As well as survivors of cervical cancer (Kamau et al., 2007) had poor physical health (Masika et al., 2012). The study also showed that all of the women had cervical cancer that was far along in its development. They may not be in good physical health because of their advanced nature or the treatment they got. This confirms once more the conclusions of prior studies that indicated that people with advanced disease had poor physical wellbeing. (Nkyekyer, 2000; Vaz et al., 2007) and the treatment received (Bjelic-Radisic et al., 2012).

Pain as a part of my life with cancer

One significant physical problem that women with advanced cervical cancer endure is pain, according to a number of studies (Maree et al., 2013; Reis et al., 2010; Wainer et al., 2012). According to Levy, Chwistek, and Mehta (2008) and Portenoy (2011), lesions, direct tissue injury, and bone metastases can all cause cancer-related discomfort (Thanapprapasr et al., 2010). These writers noted differences in the pain associated with cervical cancer. For instance, Wainer et al. (2012) interviewed 25 participants in their study. Australian women who have gynecological cancer. According to the research, the women's early complaints were discomfort in the bladder, lower abdomen, colon, legs, chest, and during unpleasant sexual activity. Other studies (Maree, Langley, & Nqubezelo, 2014; WHO, 2006) have recognized stomach pain, severe leg, and back pain as indicators of late cervical cancer, whereas severe back pain is thought to be one of the presentations of very late invasive cervical cancer (WHO, 2006).

Exhaustion, Energy depletion, & Collapse

More physical symptom discomfort than bodily distress appears to have a lower level of relationship with cancer-related fatigue. The correlation between exhaustion and depression and anxiety has been confirmed by a comprehensive review by Brown and Kroenke (2009) (n = 12,103). In line with other earlier investigations, the review supported the notion that cancer-related fatigue has a psychological component (Donovan & Ward 2005; Jacobsen et al. 2007).

Anorexia-related malnutrition

Advanced cancer stages have an impact on the food patterns of cancer patients (Bell, Lee, & Ristovski-Slijerpevic, 2009; Hopkinson, Wright, & Corner, 2006). Another team of researchers discovered that nutritional issues, such as anorexia
and dysphagia, impede cancer patients from eating enough (Kubrak et al., 2010). Loss of appetite is a symptom of advanced disease in cancer patients as well as a side effect of hazardous cancer treatments (Poole & Froggatt, 2002). Studies on women who have survived cervical cancer have revealed that losing their appetite severely impacts their quality of life (Krikeli et al., 2011; Zeng et al., 2011).

**Menorrhagia**

Women with cervical cancer endure unpleasant vaginal discharge and bleeding, in addition to other vaginal abnormalities such as dryness and atrophy (Bukovic et al., 2008; Cleary & Hegarty, 2011; Lammerink, de Bock, Pras, Reyners, & Mourits, 2012). According to certain similar studies (Herzog & Wright, 2007; Maree et al., 2013; Stead, Fallowfield, Selby & Brown, 2007), vaginal changes are also experienced by women with cervical cancer. For cervical cancer survivors, vaginal bleeding and unpleasant discharges are common physical issues (Maree, 2013; VanSchakwyk et al., 2008; Wainer et al., 2012). In investigations related to this one, other study teams (Ago et al., 2013; Eze et al., 2013; Langley & Mary, 2012) also noted that vaginal bleeding and/or offensive.

**Themes of the impact of cancer on the psychological aspect of a woman's life: Domination of Negative Feeling and Losing of hope**

Gynecologic cancer patients experience psychological symptoms, such as depressing feelings and hopelessness, according to Akyuz et al. (2008). Particularly, the researchers found that Hispanic women with cervical cancer experienced emotional difficulties as they entertained their fears of dying and the progression of their illness (Ashing-Giwa et al., 2006). Moodley and Mabena (2012). In their study, patients with cervical cancer also mentioned having a dread of dying. They argued that patients’ fear of passing away was directly linked to the development of their illness. Most of the subjects in Vilhauer's study from 2008 described having recurring death fears that became obsessions. When cancer spreads or when victims learn of the passing of others who had the same condition, their fear of dying grows more profound. When women see images of themselves in other sick patients, their fear of dying grows more profound (Vilhauer, 2008).

**Challenging Coping**

Cancer diagnosis and treatment place a heavy physical and mental burden on patients (Shime & Halm, 2011). Nedjat-Haiem et al. (2012) claim that study participants sought medical attention as soon as their cancer symptoms become worse. Nedjat-Haiem et al. (2012) found that all participants in their study who were diagnosed with advanced cancer initially responded to their diagnoses with shock and disbelief in terror. It was reported in several studies, such Holt et al. (2009), that participants displayed rage and denial after learning of their cancer diagnosis. The study’s subjects also stated that they had no idea they could develop cancer. According to Lynos and Shelton (2004), some cervical cancer patients felt ashamed and embarrassed by their diagnosis, while others were scared and anxious about the prognosis and course of therapy. In conclusion, the
examined literature showed that women with cervical cancer generally had poor psychological health.

**Faith Based resilience**

Resilience is the ability of a person to successfully preserve or regain their mental health in the face of severe risk or adversity. It is an interactive, dynamic construct that takes protective factors and constructive response to adversity into consideration, (Hjemdal, 2007). According to the women’s stories, this study supports their belief in the ability of faith to withstand the disease despite its severity. Self-efficacy, self-esteem, internal locus of control, optimism, mastery, social support, boldness, hope, empowerment, acceptance, determination, and personal growth are among the many factors that have been reported to be associated with or predictive of resilience in other forms of adversity, including physical illness. Other factors include social support, coping mechanisms, spirituality, cognitive assessment, and a sense of cohesion. This is understandable considering that resilience can be influenced by a variety of factors, including genetics, environment, adaptability, and prior experiences.

**Themes of the impact of cancer on the social aspect of a woman's life disharmony and social isolation**

A woman with cervical cancer may experience isolation for a variety of reasons. Some women may become isolated as a result of the disease's physical manifestations, such as unpleasant vaginal bleeding and discharges. It is supported by research from Van Schalkwyk et al. (2008) and Maree et al. (2013) that objectionable vaginal discharges and bleeding may lead to isolation. Because no one ever paid them a visit at their homes, some survivors felt alone in their town (Van Schalkwyk et al., 2008). There have been documented alterations in daily life and a sense of social isolation. More than half of the participants believed that having cervical cancer had a negative impact on their ability to socialize, the size of their social network, and their sense of loneliness. (Zeng et al., 2016).

**Losing Intimacy**

Intimate interactions between cervical cancer survivors and their partners were examined both during and after their medical treatments. The results demonstrate that the participants needed and wanted their spouses to show them compassion, support, and care as they went through cancer treatment and recovered, even though they felt that most of their partners were reluctant to do so and withdrew from them. This work contributes to the body of research on relationship quality, which is now regarded as a dyadic stressor rather than an individual phenomenon (Bodenman, 2005; Bodenmann et al., 2011). The two partners must cooperate in order to deal with the stress in a dyadic relationship: giving and receiving support from one another, working together to solve problems, and regulating emotions together (Revenson and DeLongis, 2010).
Conclusion

Cervical cancer affects all aspects of a woman’s health, including physical, psychological and social well-being. The psychosocial health needs of cervical cancer survivors are often left behind. Also, the experience that women live with cervical cancer is a harsh life experience in terms of its direct impact on the physical, psychological and social health aspects. Healthcare teams should consider integrating communication and physical health tools in their practices in order to better meet the patient’s physical, psychological and social health needs.

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