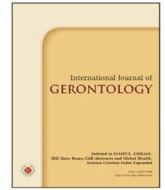




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## Original Article

# Lived Experiences in the Illness Trajectory for Elderly Patients with Ovarian Cancer in Taiwan: A Phenomenological Study

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## SUMMARY

**Background:** Elderly patients with ovarian cancer have complex emotional responses to the cancer diagnosis and treatment such as worry about performing daily routines. As cancer treatment progress, these patients need support from family, community, and health care professionals to cope with physical and psychological symptoms and impairments.

**Methods:** Giorgi's phenomenological methodology was employed to explore the essence for elderly patients' lived experiences amid the illness trajectory of ovarian cancer.

**Results:** Fifteen interviews were conducted. Four themes and 10 subthemes emerged from the verbatim transcripts: (1) hopelessness regarding loss of health: treatment side effects exceed expectations, worries about loss of energy hindering the cancer battle, and interruption of daily activities and interpersonal relationships; (2) endeavoring to fight for life: optimism and difficulty in establishing a new perspective on life, and cooperation with prescribed treatment; (3) managing uncertainty: realizing the impermanence of life and seizing the moment, self-reflection on the meaning of life, and attempting to regain physical health; and (4) learning to face early death: perceiving the upcoming end of life, and seeking peace of mind for lasting love.

**Conclusion:** The low cure rate of ovarian cancer forces elderly patients to face the possibility of death. Medical teams must provide urgent and long-term medical care and value the medical autonomy of elderly patients with ovarian cancer to offer timely professional opinions and adequate care. Medical professionals should help patients develop adjustment strategies and establish a support system by integrating social resources for the holistic well-being of the patient.

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## 1. Introduction

Ovarian cancer is one of the 10 most common cancers in women in Taiwan. In 2016, 1,349 new cases were reported, of which 52% were beyond stage III and 30% were in women older than 60 years.<sup>1</sup> Older patients with cancer are typically at risk of multimorbidity, disabilities, and polypharmacy and are vulnerable to injury.<sup>2–5</sup> Adverse treatment effects, such as the chemotherapy-induced cognitive impairment, are more severe than those in younger patients.<sup>2–6</sup> Qualitative studies have revealed various themes in the experiences of women undergoing treatment for gynecological or ovarian cancer; these themes are related to cancer diagnosis, treatment options and autonomy, side-effect severity, recurrence and uncertainty, self-advocacy, support and perceived control, quality of life (QOL), and early death.<sup>7–15</sup>

In Taiwan, lack of study has investigated the lived experiences of older survivors of ovarian cancer. The presented literature review indi-

cates that patients of ovarian cancer experience various pressures due to their treatment, which affects their bodily functions and family relationships and their ability to return to the normalcy of life before cancer. These patients experience complex psychological twists when facing a cancer diagnosis. If they remain perseverant and hopeful, these patients can change their perspective on death and find new meanings on life. This study was aimed to understand the survival experience of these patients in particular with older age and to identify the meaning structure of these experiences. The findings of this study should provide an insight of these experiences for healthcare professional to develop care strategies and support systems for these patients.

## 2. Methods and materials

### 2.1. Research design

A qualitative method was employed to explore the lived experiences of older survivors of ovarian cancer.

### 2.2. Participants

Outpatients that met the inclusion criteria were recruited: (a)

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survived ovarian cancer; (b) aged 60 years or older; (c) clear consciousness and ability to communicate in Mandarin or Taiwanese, and (d) no psychiatric disorders. Participants were invited from medical centers in Taiwan based on case history and physician's referral.

### 2.3. Data collection

The participants were interviewed in an unstructured and in-depth style at quiet and independent locations. All interviews began with few open-ended questions, which were related to the survival experience of ovarian cancer, and were recorded and transcribed verbatim.

### 2.4. Ethical considerations

Ethics approval was granted by an institutional review board (CMUH107-REC2-132). Participants were informed and agreed upon the purposes of the study with written consent forms and were promised anonymity of their identity.

### 2.5. Data analysis

Interview transcripts were analyzed using Giorgi's phenomenological steps: (a) reading: obtaining a global sense from the texts; (b) classification: focusing on a specific phenomenon (primary meaning unit); (c) organization of the raw texts using terms: combining "meaning units" into threads of thoughts (submeaning units) with reflection and imaginative variation; (d) structural description of phenomena: describing individual experience to obtain a specific description of a situated structure by integrating meaning units; and (e) synthesis: merging individual structural descriptions into a general description of the situated structure.<sup>16,17</sup>

### 2.6. Rigor

The rigor of the present study was ascertained through peer debriefing to determine its credibility, dependability, and confirmability.<sup>18</sup>

## 3. Results

Fifteen interviews were completed between April and July 2019. The demographics of the participants was characterized by: age between 60 and 75 years old; educational level from elementary school to graduate degree; diagnosis period from 3 months to 10.5 years; and, 8 cases of recurrence. Four themes and 10 subthemes emerged.

### 3.1. Hopelessness regarding loss of health

The participants lacked hope regarding their health and future control. Three subthemes were identified.

#### 3.1.1. Treatment side effects exceed expectations

Aging, frailty, and co-morbidity affected participants' tolerance to cancer treatment. **Case B:** "After chemotherapy, I felt weak and looked haggard." **Case E:** "My reaction to chemotherapy was severe. After second session, I stopped chemotherapy. My family could not bear me weakening." **Case D:** "Because I am older, doctors lowered chemotherapy dosage."

#### 3.1.2. Worries about loss of energy hindering the cancer battle

The participants described how they lost the energy and wor-

ried ability to perform self-care due to treatment side effects. **Case A:** "I was scared that I lost so much weight after the first chemotherapy session." **Case E:** "With chemotherapy, I was always tired and could not carry anything heavy."

#### 3.1.3. Interruption of daily activities and interpersonal relationships

The participants gradually retreated from social interaction, which affected their normal activities and relationships. **Case F:** "I stopped socializing as much." As such, the participants had to change their plans. **Case G:** "When I finally achieved what I wanted, I fell ill. I have to get over it..." **Case H:** "I planned to attend university for senior citizens, but I had to put it on hold." The participants also mentioned their efforts to avoid being labeled by their cancer. **Case B:** "Having cancer isn't great. To stop people gossiping about me, the less they know the better."

### 3.2. Endeavoring to fight for life

The participants had to overcome physical, psychological, social, and economical challenges when faced with the cancer diagnosis. This was explicated by two subthemes.

#### 3.2.1. Optimism and difficulty in establishing a new perspective on life

Initially, the participants were optimistic about recovery. **Case N:** "I received treatment, chemotherapy, and follow-ups according to the doctor's suggestions." **Case J:** "My physical condition and immune system were alright. I took chemotherapy by myself." Nevertheless, the participants prioritized personal responsibility over sadness. **Case I:** "I didn't want my family to be under the shadow of my illness. I practiced Tai-chi, bought groceries, cooked, and did chores as usual."

#### 3.2.2. Cooperation with prescribed treatment

Cancer treatment is challenging and difficult, especially when cancer recurs. **Case K:** "I was pessimistic and thought that the cancer would recur." **Case G:** "Whenever someone mentioned recurrence, I worried about it." However, the participants were confident and cooperative with the prescribed treatment. **Case L:** "I made follow-up visits because the doctor told me to." **Case J:** "I shared my treatment result, and the doctors congratulated me for recovering well."

### 3.3. Managing uncertainty

To cope with uncertainty, the participants acknowledged the likelihood of recurrence and learnt to live in the moment. They learnt to manage the uncertainty by finding new meaning in life through self-reflection and by the examples of fellow survivors. This theme was constituted by three subthemes.

#### 3.3.1. Realizing the impermanence of life and seizing the moment

The participants would cherish and live every moment to enrich their lives. **Case H:** "I now know to seize the moment, and every moment should be cherished for a happy life." The participants felt satisfaction and sought new meaning in life. One participant (**Case E**) rejected chemotherapy after surgery, explaining: "I'm satisfied with my life. Now I continue my volunteer and pray in temples."

#### 3.3.2. Self-reflection on the meaning of life

The participants reflected on their life and realized the values of

family for companionship, security, and caring. **Case J:** "Being sick made me care more for others and respect life more. I feel so much warmth from other people." The participants received emotional support and consolation regarding their illness. **Case D:** "I 'steal' time from God every day. Whenever my health permits, I do something I like to live a colorful and meaningful life."

### 3.3.3. Attempting to regain physical health

The participants paid attention to the nutrition and culinary details of their diet in an attempt to regain physical health. **Case A:** "I paid attention to what I ate, like eating enough protein and fiber, which is transformed into positive energy." **Case L:** "I focused on staying alive and taking care of my body. I stopped eating processed food." The participants carefully selected exercise to improve their treatment and recovery outcomes. **Case H:** "I practiced qigong every day. The doctor said I recovered well." **Case M:** "I did exercise and things that made me sweat, like bathing, hot springs, and hyperthermia therapy."

### 3.4. Learning to face early death

The participants understood that they had late stage cancer still they underwent the treatment but gradually accepted that they might die early. This was explicated by two subthemes.

#### 3.4.1. Perceiving the upcoming end of life

In addition to pain, disability, and change in appearance, the participants worried about the effectiveness of cancer treatment. **Case H:** "I didn't want to know the statistics. They would just increase my anxiety and fear." **Case B:** "I heard that treatment is ineffective...Every time I think about the fact that I might die...I really hope to live to my 80 s like my neighbor." **Case O,** who was undergoing symptom treatment only, stated, "It sounded like a death sentence...I'll try to live my remaining days to the fullest. I want more time with my grandchildren."

The participants perceived their upcoming death. **Case G:** "I went to the funeral of a friend I met in hospital. I was a little scared. I hope I go without pain and intubation...I'll continue to care for other patients." **Case F:** "The cancer has metastasized. No medication is available...The doctor told me to be comfortable and happy in my remaining days."

#### 3.4.2. Seeking peace of mind for lasting love

The participants discussed their wishes and affairs with their family. **Case C:** "I told them not to worry. I'll fight and be positive. I also told them my ideas for all my affairs and the funeral arrangements." **Case E:** "Once my children came back from tomb sweeping festival, I told them that when the time comes, I don't want to be resuscitated. I'll leave them with fond memories in a simple, traditional funeral."

The participants leaned on religious faith toward a peaceful death. **Case H:** "My faith helps me relax and be free. I feel no pressure." **Case I:** "When I panicked and despaired during chemotherapy, I recited scriptures and prayed repeatedly. It helped me calm down and make the correct decision." **Case L:** "I found that scripture messages hold positive energy dealing with discomfort and distress."

## 4. Discussion

Despite advancements in medical treatments, the mortality rate of ovarian cancer has not decreased notably in the past decade, although it has decreased more for young women than older wo-

men.<sup>5</sup> Cancer affects patients' physical health as well as their mental health which is often overlooked by clinical evaluations.<sup>2-4</sup> Studies on older patients with cancer are rare; hence, early prediction of side effects and toxic reactions is difficult. The present study investigated the lived experience of older patients going through the illness trajectory of ovarian cancer and determined the meaning structure for these experiences: hopelessness regarding loss of health, endeavoring to fight for life, managing uncertainty, and learning to face early death.

### 4.1. Hopelessness regarding loss of health

Before diagnoses of cancer, the majority of the participants were reasonably healthy and independent; only few had chronic illness. To the participants, diagnoses of ovarian cancer inflicted negative impacts induced a sense of loss and limited future; and, the side effects of chemotherapy exceeded the expectation with heavy burdens, such as fatigue and loss of independence, which interrupted their daily activities and interpersonal relationship. These findings were comparable to previous studies.<sup>11,15</sup>

Scholars have proposed to adjust cancer treatment for elderly patients; for example, lowering the frequency or the dosage of carboplatin and paclitaxel but continual monitoring of organ function so as to mitigate toxic reaction and co-morbidity and keep treatment schedule uninterrupted as well as to improve QOL.<sup>2-6</sup>

Studies have suggested that patients' intentions to be actively involved with medical decision-making are influenced by their attitude and knowledge associated with their cancer.<sup>11,19,20</sup> The participants' involvements in the medical decision-making of their treatments for ovarian cancer were passive. Consequently, the participants concerned about their physical weakness and hinted to discontinue chemotherapy.

### 4.2. Endeavoring to fight for life

The transition from a healthy person to a patient with cancer is often manifested with signs of depression due to loss of autonomy. Tenacity is beneficial that enables the patients to engage in healthy activities, adjust their lifestyle, utilize social and medical support systems, and set aside negative thoughts about symptoms, recurrence, or death.<sup>3,11,21</sup> The participants, like most Chinese women, shared similar experiences and had optimistic and resilient attitudes toward obstacles such as the side effects of cancer treatment. The participants of this study were cooperative with prescribed treatments and attained follow-ups to fight cancer as found elsewhere.<sup>12,13</sup>

### 4.3. Managing uncertainty

Compared with older patients of ovarian cancer, young patients often have greater fear of recurrence and are more likely to have emotional disturbance and low QOL.<sup>22</sup> The participants were intended to return to normal life to live without fears or worries associated with the side effects of cancer treatment or cancer recurrence; however, they also understood that remission meant the cancer was only inactive. Furthermore, the participants deliberately ignored the statistics of cancer recurrence and entrusted doctors' treatment decisions to impede cancer progression with improved CA-125 test results.

When faced with cancer, patients with ovarian cancer must adjust their feelings and thoughts and establish specific measures for relieving the pressure they are under in order to survive. The participants mentioned that they transformed the fact of cancer

diagnosis into a positive thought and encouraged themselves to cherish and seize the moment to live a colorful life with a new attitude. Moreover, the participants encouraged themselves to adopt a different perspective to maintain their inner peace and tranquility, discovered new strength after being sick, realized the limits of life, and experienced more intimate relationships with their family members. The change in participants' roles in the family relieved their burden and alleviated stress. Their bond with family strengthened and children became strong support and motivation for recovery. These results are similar to those obtained by Guenther et al.<sup>22</sup>

The diagnosis of ovarian cancer and the high mortality rate are often shocking and frightening to the patients.<sup>22</sup> The finding that the participants sought meaning of life through self-reflection and set short-term goals to cope with the uncertainty of recurrence was comparable to one study<sup>8</sup> but in contrast to another.<sup>23</sup>

For self-advocacy, patients with ovarian cancer frequently combine personal belief and priority with opinions from family and friends or support groups when making health-related decisions.<sup>12</sup> Exercise and nutrition-balanced/organic diet are beneficial to QOL, fatigue, psychological health, muscle strength, and balance for patients with ovarian cancer.<sup>22,24</sup> Leisure activities are generally advised for elderly patients with cancer to manage symptom and to mitigate possible impairment. Similarly, the participants in this study undertook healthy lifestyles and held beliefs in the healing power of nature in an attempt to regain physical health

#### 4.4. Learning to face early death

The participants realized the deterioration in QOL thus adopted numerous means to prepare for the worst to happen, which included seeking family support, sharing experience with fellow patients in cancer support group, and turning to religious beliefs. The finding was comparable to previous findings.<sup>23</sup>

Social network was important allowed the participants to discuss early death and accept the idea of early death; similar experiences were found in other studies.<sup>25,26</sup> With children equivalent to meaning of life, the participants resumed a natural attitude toward death. As indicated in other studies, patients of ovarian cancer experience severe pain and traumatic symptoms; finding meaning of life with sustainable supports and perceived control are crucial to them.<sup>8,15</sup> Holding religious beliefs and accessing social supports helped the participants to alleviate the emotional fluctuation, mitigate mental distress, improve QOL, and seek peace of mind. These findings were in parallel with another study.<sup>27</sup>

#### 4.5. Limitations of the study

Despite it was a qualitative study in nature, one limitation had to be addressed. Since the study employed a convenient sample of older patients with ovarian cancer from one institute, therefore, selection bias should be cautioned when comparing findings with present study.

### 5. Conclusion and suggestions

The prevalence of malignant tumors in elderly is increasing as population aging rapidly. The novel development in the areas of cancer diagnosis and treatment in medicine has extended patients' life. Elderly survivors of ovarian cancer undertake difficult treatment processes with burdens on both physical and psychological levels. They have demonstrated the perseverance to fight the disease,

manage the uncertainty of recurrence, reconstruct meanings of life, and even learn to accept the possibility of early death in their journey of cancer survivorship. Therefore, clinicians must consider the aging and physical deterioration of these patients and perform comprehensive geriatric assessment in regular basis in order to mitigate the risks and adverse effects of cancer treatment.

To meet the physical, psychological, and socio-economical needs of older patients with ovarian cancer, clinicians must integrate the concepts of geriatric care and cancer care to assist the patients and their family to face changes bring by the disease and the treatments. Furthermore, clinicians must be proactive to communicate with the patients and their family regarding issues like how to improve patients' health, nutrition, and stamina during rehabilitation or where to obtain social supports and resources, and to help family members to establish tolerant and supportive attitudes for older patients with ovarian cancer.

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