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ORIGINAL ARTICLE

Psychological distress and coping strategies among women with incurable lung cancer: a qualitative study

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Abstract

Purpose Limited research has focused on women with lung cancer (LC) although they are recognized as the most vulnerable to psychological distress. This study explored in-depth the psychological distress experienced by women with incurable LC and analyzed the coping strategies with which they manage that distress.

Methods A qualitative methodology with in-depth interviews was employed for 34 women with advanced or recurrent LC. An inductive data-driven thematic analysis was applied to analyze transcripts.

Results Psychological distress was an iterative process for the women. Four themes were identified: shock regarding the diagnosis, distress regarding cancer treatment and its side effects, the facing of a recurrent or progressive disease, and persistent struggle with the life-limiting disease. Various coping strategies applied by the women to manage psychological distress were grouped into four themes: relying upon social support, focusing on positive thoughts, avoidance-based strategies, and religious faith and acceptance.

Conclusions Women with incurable LC experienced substantial iterative psychological distress throughout the illness, regardless of length of illness at time of interview. They applied multiple forms of coping. The findings enrich the limited existing literature on this understudied population and provide direction for the future development of interventions to improve their psychological well-being.

Keywords Lung cancer · Women · Psychological distress · Coping strategies · Qualitative study

Background

Lung cancer (LC) is a major cause of cancer-related deaths worldwide, with a 5-year survival rate of only about 17% [1]. Even after complete resection, 40% of patients diagnosed at early stages experience recurrent disease [2]. In many developed countries, as incidence in males decreases gradually, incidence and mortality in females continue to increase [3, 4]. Some clinical and pathological characteristics of LC differ between men and women [4]. In Western countries, cigarette smoking and aging are prominent risk factors [4, 5]; more than 90% of Taiwanese women with LC never smoke and are relatively young. Genetic mutations of important oncogenic drivers such as epidermal growth factor receptor (EGFR) are the predominant etiology for this population [6, 7] and approximately 70% have advanced-stage cancer at diagnosis [8]. The unexpected life-threatening diagnosis presents women with LC with multiple psychological sequelae.

Chemotherapy, targeted therapy, radiotherapy, or combinations thereof are recommended for patients with advanced or recurrent LC to decrease symptoms and prolong survival [9]. Thanks to the advance of molecular-targeted therapy for LC, the length of survival of selected patients has improved, particularly for women and never-smokers [10]. For patients

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without expected response to these treatments or with disease progression, however, further therapy is necessary. Maintenance therapy, moreover, is recommended in the absence of disease progression [9]. Frequent clinical appointments or hospitalizations are therefore inevitable. The burden from disease and treatments substantially affects LC patients' health perception and psychological well-being [11, 12] and causes higher psychological distress than in other cancer patients [11, 13, 14].

Numerous studies have suggested that physical and psychosocial responses to cancer in women are not the same as those in men; women experience longer impact of treatment side effects [15], lower levels of hope [16], and higher levels of anxiety and depression and wish to hasten death than men after cancer diagnosis [17]. Women with LC, however, report higher levels of psychological distress than men with LC [13, 18,] and perceive poorer health status than women with other cancers [11]. Psychological distress is associated with patients' wish to hasten death [17] and is a robust predictor of LC mortality [20].

Similarly, coping styles vary by gender [21]. Coping amounts to cognitive and behavioral efforts to manage specific stressful events after cognitive appraisal [22]. Women use more emotion-focused coping strategies and experience higher psychological distress [21]. Previous studies have reported coping styles related to psychological well-being and quality of life of cancer patients [23–25].

Women with incurable LC are the most vulnerable to disruptions in psychological well-being. Limited information on the impacts of the disease is available in the existing literature, indicating that women with LC have been understudied. This qualitative study performs an in-depth exploration of the psychological distress experienced by women with incurable LC and analyzes the coping strategies they adopt to manage the distress in their daily life.

Methods

Participants

Of 37 eligible women, 34 consented to participate. Three declined as unwilling to discuss cancer ($n = 2$) and unwilling to give of their time ($n = 1$). The eligible criteria were female, aged over 20, diagnosed with stage III b–IV non-small cell LC or recurrent disease at least 3 months prior, without other-site cancer, cognitive impairment, or psychiatric disease. The mean age of participants was 58 years (range 35–82). Most were married (58.8%), religious (85.3%), never-smokers (91.2%), and diagnosed with stage IIIb or stage IV (88.2%). At time of interview, the average months since initial diagnosis were 24.5 (range 3–58), and 19 (55.9%) received chemotherapy. Table 1 shows participants' characteristics.

Procedure

Institutional Review Board approvals were obtained. Purposive sampling was used to enroll participants in the outpatient departments (OPDs) of a medical center and its branch hospital. The intention was to obtain maximum variation of experiences [26] regarding psychological distress and coping strategies in terms of lengths of illness, ages, and current treatment regimens. The first author (YCL) screened medical records and selected participants before the clinics started, requested patients' participation, and provided a detailed explanation of the study's purposes after their clinical appointments. If they agreed and provided a written consent, in-depth, face-to-face interviews were conducted by YCL. The patients were interviewed once, alone in the OPD. The interviews followed an interview guide consisting of several open-ended questions. Probes and prompts were used to obtain more in-depth responses and clarify information [26].The interviewer maintained field notes to record observations and reflections. Patient enrollment continued until thematic saturation.

Data analyses

The interviews were audio-recorded and transcribed verbatim. Inductive data-driven thematic analysis was conducted [27]. The researchers first read and reread the transcripts line by line to familiarize themselves with the data and understand the initial ideas. The initial coding of the data was independently performed by two investigators (YCL and JLS) using Atlas. ti software. Analysis meetings were held to categorize codes into potential themes and subthemes which were reviewed and refined in accordance with the coded extracts and the entire data set. Disagreements were discussed until consensus was achieved. Definitions and theme names were generated. The analysis process was recursive, not linear [27].

Results

Psychological distress

Shock regarding the unexpected diagnosis

The women experienced substantial psychological crisis after the unexpected diagnosis. The diagnosis was unbelievable, shocking, unfair, and unacceptable because most of them believed that their lifestyle was healthy and all but three were never-smokers.

"…I could not stop crying…I couldn't accept the diagnosis of lung cancer because my husband and I never smoke. If the doctor had said that I had breast cancer or cervical cancer, I could have taken it, but not lung cancer."

Table 1 Participants' characteristics ($n = 34$)

Variable	*M* (SD)	Range	Number (%)
Age	58.3 (10.3)	35–82	
Marital status			
Married			20 (58.8)
Not married (single/divorced/widowed)			14 (41.2)
Religion			
Buddhism			14 (41.2)
Taoism			12 (35.3)
Christian/others			3 (8.8)
None			5 (14.7)
Smoking history			
Never			31 (91.2)
Cessation			3 (8.8)
Months since new diagnosis	24.5 (16.5)	3–58	
Cancer stage			
IIIb			3 (8.8)
IV			27 (79.4)
Recurrence			4 (11.8)
Current treatment			
Chemotherapy			19 (55.9)
Radiotherapy			1 (2.9)
Target therapy			8 (23.5)
No active treatment			6 (17.7)

The women were devastated, felt the incurable disease was the end of their world and believed that their death was imminent. A woman described her shock: "As I heard the diagnosis, I trembled all over and could only ask the doctor how long I would live. My husband and I had an emotional breakdown on the spot. I couldn't stop trembling with fear for half a month." They felt that their lives were tragic, meaningless, worthless, and hopeless. A woman cried and said, "I can't stop thinking: why me? I have had a rough time for my whole life… it's not fair, I can't see hope anymore."

The lives of the women were turned upside down because of the dreadful diagnosis. Unfortunately, the subsequent initial treatment and physical distress brought about further shock and great anguish. The women and their families experienced chaos. All but five women said that the shock persisted for at least 6 months. Psychological distress occurred daily, including uncertainty, powerlessness, helplessness, fear, anger, panic, sadness, and defeat. Six participants experienced suicidal ideation because they could not face the torture from the disease and the various treatments, particularly chemotherapy.

"Nothing has been difficult for me in my whole life, but this disease is exhausting."

"This lifestyle is so painful. I told my husband that I've become a walking dead person."

"… I don't want to suffer repeatedly from each round of chemo and don't want to ruin my husband's life. He deserves a better life…."

Distress regarding cancer treatment and its side effects

All of the women experienced significant changes and losses in their lives because of the frequent clinical appointments and the amount of time consumed by treatments. A 42-year-old woman who quit work after her diagnosis reported "…I worked very hard before and had a good position, but all I can do now is stay at home and wait for the next clinical appointment."

Participants were severely disturbed by the unanticipated treatment side effects and physical deterioration, which caused various negative emotional responses, including fear, depression, anger, and frustration and wish to hasten death. Fatigue, weakness, poor appetite, and taste disturbance were the most prevalent and distressing symptoms.

"The weakness and fatigue scared me. I wondered whether my disease was getting worse."

Participants said that their poor food intake worried them and their family caregivers because of the concern that nutritional deficiency would cause further physical deterioration and treatment suspension.

Additionally, neuropathy caused by chemotherapy affected their mobility and functions. It was bothersome and significantly affected their emotions.

"Chemo caused severe numbness in my feet, making it very difficult to walk. These kinds of things made me depressed."

"I'm so frustrated by the numbness. One day I was very mad and hit my right hand because I could not do very simple things."

Cutaneous side effects, including dermatitis, acne, and dry and itchy skin, caused by targeted therapy were among the distressing symptoms. Unlike the periodic chemotherapy side effects, the cutaneous side effects distressed some women daily for the entire day and caused disruption of body image and further social constraints.

"I got horrible skin rashes on my face. It was really scary, and I didn't want to leave my house."

"I have terrible hair loss and skin itching. I cannot go out without a wig and cannot sleep. I am really upset."

Facing a recurrent or progressive disease

All of the women reported extreme fear of disease recurrence or progression. Most experienced severe anxiety for several days before each medical appointment because they were afraid of receiving "bad news" from the physician. They typically experienced disease progression multiple times and were required to change treatment regimens. This evoked the threat of death because the effectiveness of the next treatment was uncertain.

"My doctors informed me of all the treatment options, and I needed to make a decision…. I was so scared of making a wrong decision, which could kill me."

They feared disease metastasis and worried about whether their physical condition would enable them to tolerate more anticancer agents than they were currently receiving.

"My disease is not stable and I need to switch to another treatment…. But I'm afraid that my body has been damaged by previous treatments. If my body can't tolerate it, I will have to stop the treatment, and the cancer may spread."

Women with recurrent disease experience more uncertainty, anxiety, and depression when facing recurrences than at first diagnosis because they had believed that after undergoing surgery, they would be cured.

"I am panicked and depressed. I often lie in bed all day and think, 'Why has this happened to me?' I can't sleep well or eat…. It's really stressful."

Persistent struggle with a life-limiting incurable disease

The incurable nature of the disease caused various negative emotions. Participants said that their lives were out of their control and that they resembled "a disabled and hopeless person." Eighteen women said that death was an inevitable outcome of the disease, but that the length of survival was uncertain. They frequently thought about death and worried that the dying process would be too abrupt or involve prolonged suffering. Three of them believed that people around them would perceive them as "dying."

"I can't stop thinking about death…. I can't sleep well… and it's impossible to be optimistic…."

"Everyone knows that lung cancer has the highest mortality rate among all types of cancer; I have no idea how long I can live…."

Ten women reported fearing becoming a burden to their families during the end of their lives. They felt guilty because they substantially affected the lives of their loved ones.

Coping strategies

The analyses established that participants typically applied multiple coping strategies.

Relying upon social support

All participants valued social support for their emotional regulation, including support from family, healthcare professionals, and their social network. Substantial physical and emotional support from family members was the form of support that facilitated strength and courage in the management of distress.

"I can't imagine what life would be like without my husband…. He resigned from his job to take care of me.... He's really helpful, and I appreciate him."

Women stated that comprehensive information, including a treatment plan, self-care knowledge, and a supportive attitude from healthcare professionals was imperative for them in reducing their fear, uncertainty, and anxiety and increasing their confidence.

Eleven participants said that if their physical condition could tolerate it, they would strive to maintain their social network. Social networks provided mental support, distracted them from negative thoughts, and allowed them to feel that they were as healthy as before.

Focusing on positive thoughts

Eighteen women acknowledged that it was essential to change negative thoughts and focus on positive thoughts. The five strategies described by the participants were thinking positively, maintaining hope, making positive comparisons, maintaining normalcy, and having a fighting spirit. Seven participants emphasized that maintaining positive thoughts and emotions was necessary to control the disease.

"Do not frighten yourself. Many people die because of fear, not of cancer."

"I don't think about how painful the chemo is; I always think about how my body will get better after chemo."

Eight women indicated that maintaining hope and a fighting spirit was helpful for reducing distress. "I haven't found any reason that I can't be one of the 5% of 5-year survivors."

Three participants suggested that comparing their conditions with other cancer patients' could stimulate positive thinking.

"I met a woman with breast cancer. I felt quite lucky because my situation is much better than hers. When you see so many people here (OPD) with the same disease, I realize that the disease is not as bad as I thought."

Maintaining normal daily lives and work was crucial and meaningful for most participants.

"I try to do my work. It makes me feel my life is meaningful…if I just stay at home, I feel I'm a very ill person."

Avoidance-based strategies

Avoiding stimulators of distress was one of the means by which the participants prevented psychological distress. They felt that it temporarily released them from the stress of cancer.

"I just try not to think about my illness. I tell myself I am okay, and my disease is gone."

Discussing cancer with others was overwhelming for some women. Two women said, "I'm afraid that I'll go to pieces if I talk about cancer with others…." Concern and suggestions from others stimulated negative emotions. Approaches to avoid these included concealing their cancer, avoiding social contact, and distancing themselves from their social network.

"I refuse to see any of my old friends because I don't want them to gossip about me and I don't want to repeatedly answer their questions about cancer. This makes me sad."

Religious faith and acceptance

Seven participants said that religious faith was an essential support in confronting the demands of the disease. Those who reported that they were calm and had no fear tended to be religious.

"Maybe it's owing to my religious belief. I come to accept it and become free from troubles…Buddhism taught me that quality of life is much more important than the length of life."

Although several participants reported non-acceptance of the fact that they had advanced LC and were still experiencing substantial distress, 15 women stated that they gradually accepted the fact. They expressed the view that the length of time from shock to acceptance was typically several months or years, but five participants indicated that they did not require that much time to accept their condition.

"I've never asked, 'Why me?' Why should it be anyone else? Yes, I have cancer, so I face it and treat it."

Three participants indicated that, after the shock, they viewed the disease gratefully because it helped them to adopt a healthier lifestyle.

"No, I am not terrified; I definitely know why I got lung cancer. I've worked too hard and didn't take good care of myself. So, I need to slow down, receive treatment, and enjoy the rest of my life."

Discussion

This is the first study to provide in-depth analysis of the psychological distress and coping strategies of women with incurable LC. The findings revealed that substantial psychological distress existed throughout the illness trajectory, regardless of length of illness at time of interview. "Living with an unexpected and incurable disease" acted as a focal stimulus. The threat of death invoked an iterative process of psychological distress.

Previous study [28] revealed that the stage at diagnosis was an important factor influencing cancer patients' adjustment. In contrast to women diagnosed with early breast cancer, who were shocked and scared by the diagnosis but were grateful it was a treatable cancer [28], our participants experienced tremendous existential crises after their diagnosis. The word "incurable" anguished them, especially because most of them were never-smokers. Some thought of committing suicide because of fear of suffering. Previous studies have reported that women with advanced cancer had a stronger wish to hasten death than did men [17] and viewed cancer diagnosis as a death sentence [29]. Treatment initiation, furthermore, acted as a stimulator of a second shock for participants and induced more distress, such as fears and uncertainty. Similar findings were revealed by Baker et al. [30], who concluded that cancer patients newly engaged in treatment accepted the need for an emotional support service. Timely supportive interventions should therefore be provided from the beginning of the illness to help patients to cope with the crisis.

Treatment-related symptoms, such as fatigue and neuropathy, disrupted the participants' mobility and functions, significantly contributing to their psychological distress. This highlights the fact that the maintenance of function and mobility is meaningful for patients because it symbolizes a control over the threatening situation. Lazaurs and Folkman [22] assert that a sense of control can be used as a coping strategy when a person encounters a threat. This further explains why the maintenance of normalcy was one of the most frequently applied coping strategies of the participants and other patients with advanced cancer [31, 32].

It is worth noting that women with LC are vulnerable to disruption of body image. The findings revealed that severe and continuing cutaneous toxicity from target therapy can negatively affect participants in psychosocial terms. It has been reported, moreover, that cutaneous toxicity was a major side effect leading to LC patients withdrawing from EGFR-TKI treatment [33]. Healthcare professionals should continuously assess and understand the distress symptoms of LC patients and provide adequate interventions to relieve them. The provision of coping strategies to elevate patients' sense of control and body image is also recommended.

The poor prognostic nature of advanced LC typically resulted in participants experiencing multiple disease progressions. In contrast to disease-free, early-stage LC women reporting similar emotional status to the general population [34], women in the current study expressed psychological distress similar to those found in previous studies of women with metastatic breast cancer [35]. Intrusive thought acts as a continuous signal of impending death for the participants. Previous studies have shown that women with advanced cancer experienced high risk of fear of recurrence/progression and death [32, 35], which have been associated with high levels of psychological distress and low quality of life [36]. More efforts should be devoted to helping women with incurable LC to manage fear of disease progression and related distress.

Lazarus and Folkman [22] suggest that emotion-focused forms of coping, including positive comparison, distancing, and the wresting of positive values from negative events are often applied to manage emotions when people judge that nothing can be done to alter the threat. Our participants tended to apply multiple forms of this coping strategy, such as focusing on positive thoughts. This again reflected the fact that the incurable nature of advanced LC was their principal concern. Previous studies have shown that women with advanced cancer applied denial or avoidance to cope with their disease [32, 37]. Increasing denial or escape-avoidance coping has been associated with a high level of emotional distress [23, 37]. Denial did not emerge from the current data but avoidance-based coping temporarily diminished negative thoughts for some participants. Lazarus and Folkman [22] assert that, "a (coping) strategy can have a given function such as avoidance; however, it cannot result in avoidance." A previous study [31] reported that LC patients who applied a denial-like coping strategy could accept reality. These findings illustrate that our participants found that focusing on positive thoughts could substantially reduce threats by changing the manner in which they viewed their current situations. It did not, however, alter their cognition about the fact that the disease was incurable [22]. Avoidance does not necessarily equate to unacceptance [38], but health professionals should monitor patients' distress as they apply this type of coping.

In line with the findings of previous studies [28, 31], relying on support from family and social network was a crucial strategy. Unsupported concerns and unwanted suggestions from others nevertheless elicited psychological distress for some patients and resulted in further distancing them from their social network. Similar findings emerged in previous studies focusing on women with breast cancer or ovarian cancer [32, 37], suggesting there is a group of women confronting difficulty about disclosure of their cancer to others. This may also reflect a cancer stigma affecting some patients and can lead to persistent distress and social constraint [29, 37].

Consistent with previous studies [39, 40], those favoring religious or acceptance coping strategies tended to be

Table 2 Potential clinical implications concerning the management of psychological distress among women with incurable LC

Psychological distress	Clinical implications
Shock regarding the diagnosis	Need for • Timely supportive intervention • Cancer treatment education • Self-management skill training • Continual psychological consultations
Distress regarding cancer treatment and its side effects	Need for • Continual symptom assessment and monitoring • Management of symptoms affecting patients' mobility, function, and body image • Self-management skill training to reduce patients' physical distress
Facing a recurrent or progressive disease	Need for • Coping strategy training to facilitate coping with fear of disease recurrence/progression and sense of control
Persistent struggle with a life-limiting incurable disease	Need for • Assessment of avoidance-based coping applied by patients and the consequences thereof • Coping strategy training to enhance patients' sense of control • Continual psychological consultations focusing on existential issues

peaceful and had less fear and suffering. This finding supports the proposition that religious faith can help patients with advanced disease, making life meaningful in this difficult situation [41].

Conclusion

Women with incurable LC experienced iterative psychological distress throughout their illness, triggered by the shock of an unexpected mortal diagnosis, continual cancer treatments and their side effects, and disease recurrence or progression. They persistently struggled with the life-limiting disease. They employed various types of coping strategies, including reliance on social support, focusing on positive thoughts, avoidance-based strategies, religious faith, and acceptance.

The findings enrich the limited existing literature on this population and identify several potential clinical implications, as listed in Table 2. On the basis of the literature [42, 43], timely supportive intervention after diagnosis, followed by cancer treatment education, self-management skills in physical distress training, and continual psychological consultations may be helpful for this population. In addition, coping strategy training is imperative, to increase patients' ability to cope with fear of disease progression and enhance their sense of control. Avoidance-based coping and the consequences of the avoidance need to be assessed [44]. We recommend that healthcare professionals continually monitor and manage those symptoms that affect patients' mobility, function, and body image. Both early identification of patients with difficulties in communicating about their disease and tailored communication skills training would be beneficial in preventing further social constraint.

Limitations

First, although our participants had varying lengths of illness and the use of prompts enabled the complete exploration of their experiences, the study was limited by its cross-sectional design and single interview. Second, because a homogenous sample of women was recruited from one medical center and its branch in Taiwan, the findings may not be applicable to patients in other cultures. Generalization, however, is not the objective of qualitative studies. Additional themes could emerge from patients from other regions or cultures. Lastly, the study's aim to gain an in-depth understanding of women's experiences precludes speculation on any differences between women's psychological distress and associated coping and those of men.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflicts of interest.

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