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Adjustment to “new normal” after cancer among non–small cell lung cancer survivors: A qualitative study

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Abstract

Objectives. Cancer is a life-changing experience, and side effects from treatment can make it difficult for survivors to return to their pre-cancer “normal life.” We explored the “new normal” and barriers to achieving it among lung cancer survivors who underwent surgery.

Methods. Semi-structured interviews were conducted with 32 recurrence-free non–small cell lung cancer survivors. We asked survivors how life had changed; how they defined the “new normal”; barriers that prevent them from achieving a “normal” life; and unmet needs or support for normalcy. Thematic analysis was performed.

Results. Defining “new normal” subjectively depends on an individual’s expectation of recovery: (1) being able to do what they want without pain or discomfort; (2) being able to do activities they could accomplish before their surgery; and (3) being able to work, earn money, and support their family. We found that (1) persistent symptoms, (2) fear of cancer recurrence, (3) high expectations in recovery, and (4) psychosocial stress and guilty feelings were barriers to achieving a “new normal.” The needs and support for normalcy were information on expected trajectories, postoperative management, and support from family and society.

Significance of results. Survivors defined the “new normal” differently, depending on their expectations for recovery. Informing survivors about the “new normal” so they could expect possible changes and set realistic goals for their life after cancer. Health professionals need to communicate with survivors about expectations for “normality” from the beginning of treatment, and it should be included in comprehensive survivorship care.

Introduction

Lung cancer is the most common cancer worldwide. Earlier detection and advancements in treatments have led to improvements in survival and an increased number of lung cancer survivors (Kang *et al.* 2023; Shin *et al.* 2019). According to the Korea Central Cancer Registry, the 5-year relative survival rate has reached 69.1% in males and 87.6% in females with localized SEER summary stage (Kang *et al.* 2023). Survivors who complete their cancer treatment may want to return to “normal life” as soon as possible and often struggle to reach that goal. However, cancer is a life-changing experience, and debilitating side effects from both cancer and its treatment may make it difficult to return to a pre-cancer “normal” life. As a result, survivors need to adapt to life after cancer (Blows *et al.* 2012; Little *et al.* 1998; Trusson *et al.* 2016).

“Normality” means different things to different survivors (Henshall *et al.* 2017). It can be important in terms of survivors’ expectations for their recovery, planning for future life, and communication among survivors, their families, and healthcare professionals. However, few qualitative studies on this topic have been published, and most focused on cancer in general

or breast cancer (Trusson *et al.* 2016). For example, a previous study involving a focus group of 18 people in England who completed their treatment for various types of cancer found that the words “being normal” or “normality” were problematic for some cancer survivors because they failed to recognize their individual experiences (Appleton and Flynn 2014). Instead, some preferred the term “new normal,” which reflects changes in life after a diagnosis of cancer, and this term has come to denote redefined identities (Appleton and Flynn 2014). This term was also associated with a recovery of physical status and a return to daily routines and social roles (Appleton and Flynn 2014). Lung cancer survivors may experience more difficulties with a new normal as they have more physical and psychosocial burdens due to cancer.

To our knowledge, no research on how “normality” or “new normal” is experienced and perceived by survivors of lung cancer has been conducted. We, therefore, conducted a qualitative study of how lung cancer survivors perceive the “new normal” and adjust to life after cancer.

Methods

Study participants

Study participants were recruited from a thoracic surgery oncology outpatient clinic at a tertiary cancer center in Seoul, South Korea, from July 24 to September 10, 2019. Recurrence-free survivors who had undergone lung cancer surgery with curative intent at least a month prior to enrollment were eligible to participate. Trained researchers recruited survivors through telephone calls and scheduled interviews for the day of the outpatient visit. Survivors were sampled according to age, sex, and time since treatment. Informed consent was collected before each interview.

Data collection

The purpose of the study was explained by the researchers before the interview, and confidentiality of personal information was assured. Interviews were made by 2 interviewers (1 primary and 1 assistant), when possible (25 of 32 interviews). Primary interviewers were trained researchers with a background in behavioral science (J. Cho), oncology nursing (G. Lee), and sports medicine (S. Kong). Although no time limit was set, interviews were conducted within a single session lasting 60–90 min. To encourage participants to share their experiences freely, accompanying family caregivers were asked to wait in a separate room during the interview.

In-depth interviews with survivors were conducted in accordance with semi-structured interview guidelines. We asked survivors (1) how their life had changed physically, mentally, and socially after the onset of cancer and how they recovered from the changes; (2) how they perceived or defined the “new normal”; (3) for a description of the barriers that prevent them from achieving a “normal” life; and (4) to list the unmet needs or support survivors would need for normalcy.

Data analysis

The interviews were recorded and transcribed verbatim. Transcripts were cross-reviewed by two primary interviewers and reread by another researcher (D.W. Shin, a physician in a cancer survivorship clinic) who did not participate in the interviews. Systematic comparisons of transcripts were conducted to identify

Table 1. Summary of findings

Concept	Findings
Changes due to cancer and its treatment	<ul style="list-style-type: none"> • Changes in lifestyle due to cancer • Thinking more deeply about life and death • Re-examining life priorities
Recovery after cancer treatment	<ul style="list-style-type: none"> • Overall health status had steadily improved after surgery • Survivors' quality of life approached normal within 1 or 2 years after the surgery • They had not fully recovered to pre-surgery levels
Knowledge, attitude, and perceptions of “new normal”	<ul style="list-style-type: none"> • Unfamiliar with the phrase “new normal” • Most of them understood it would be difficult to return to a state comparable to the one they enjoyed before their diagnosis • Defining “new normal” subjectively depends on the individual's expectation of recovery <ol style="list-style-type: none"> (1) Being able to do what you want without pain or discomfort (2) Being able to do activities they had could accomplish before their surgery (3) Being able to work, earn money, and support their family. • Having different expectations for recovery and “new normal”
Barriers that prevent survivors from achieving “new normal”	<ul style="list-style-type: none"> • Persisting physical symptoms • Fear of cancer recurrence • Expecting 100% recovery to life before cancer diagnosis • Psychosocial stress and guilty feelings
Needs and support for normalcy	<ul style="list-style-type: none"> • Information on expected trajectories after treatment • Information on postoperative options such as symptom control, stress management, exercise, and nutrition • Continuing support from family and society

recurrent or common themes and assigned to categories relevant to the study's aims and purpose.

Results

Participants characteristics

A total of 32 survivors (24 men and 8 women) participated in this study. The mean age of study participants was 59.7 years (± 7.3). Seventeen participants (53.1%) completed cancer treatment less than a year ago, and the mean survival period was 21.1 months (± 18.5). With respect to the cancer stage at diagnosis, 19 participants (59.4%) were in stage I. A summary of the findings is shown in Table 1.

Changes due to cancer and its treatment

All survivors reported that their lives had changed because of cancer, although the nature of that change varied. Survivors described being diagnosed with cancer as the most troubling moment and the greatest crisis of their lives.

I was only anxiously wandering around without knowing what to do.

Survivors reported physical symptoms such as shortness of breath, coughing, operation-site pain, and fatigue during and even after treatment. They also experienced difficulty sleeping, depressive moods, loss of appetite, loss of weight, and low energy levels.

When I go up the stairs, I get short of breath. Imagine that I am standing in an enclosed room, and water is pouring into the room and rising right under my chin. It's very terrifying.

However, a significant number of survivors noted that their current health status was way better than before the cancer diagnosis, mainly because of improvement in health behaviors, such as smoking cessation, quitting drinking, and increased physical activity.

I feel like I am in a better state than before cancer as I am now proactively seeking healthy habits to stay healthy.

Participants said cancer has made them think more deeply about life and death. They said that because of cancer, they had re-examined their priorities in life. They now placed a higher value on relationships with their family and friends. They have made up their mind not to be stressed about socializing with others anymore, and they have intentionally limited their social interactions with others. Some survivors said they are no longer pursuing social success in the workplace and do not meet people for business purposes. Instead, they focused on family relationships and spent more time with their families. Some survivors reported no longer meeting others as they were afraid of being discriminated against by others because of cancer.

Cancer has changed my life in many ways. Now I feel liberated from being pressured into socializing with others, and as I put my family first, our family bonding is stronger than ever.

I do not join gatherings with alumni or friends because I don't want to be treated like a sick person.

Recovery after cancer treatment

While the perceived speed of recovery differed among survivors, most said their overall health status had steadily improved after surgery. While the first 6 months after treatment were difficult, their health improved over time. Most participants said their quality of life approached normal (comparable to pre-cancer conditions) to some extent within 1 or 2 years after the surgery.

When we asked survivors to rate the level of recovery compared to a pre-diagnosis level of 100%, some reported no difference from their pre-treatment condition and no health problems. Survivors commonly reported a 70%–90% recovery 1 year after treatment. Shortness of breath and fatigue took a little longer to disappear compared with other physical symptoms.

For the first month, I was coughing, experiencing pain and shortness of breath, but I am fine now.

After three months, I began to feel better, but now that I think about it, it was not a recovered state. But after a year, I finally got better and feel like I've recovered.

Knowledge, attitudes, and perceptions of the “new normal”

We asked survivors if they were aware of the concept of a “new normal.” Many were unfamiliar with the phrase, but most vaguely understood that it would be difficult to return to a state comparable to the one they enjoyed before their diagnosis.

I don't expect to be exactly the same as I have felt before since I am getting older. I just need to carry out my daily routine as much as I can now.

The definition of “new normal” is subjective as it depends on individuals' expectations of recovery, which can affect planning for the future. Some reported that they believed that it meant “being able to do what they want without pain or discomfort.” Some reported it means reaching a “new normal” when they were able to do activities they had could accomplish before their surgery. Others described “being normal” or achieving a “new normal” as being able to work, earn money, and support their family.

I think I will feel normal once the symptoms such as pain or coughing disappear.

To me, being normal is going to work and being able to financially support my family.

Survivors often have different expectations for their recovery and the “new normal” status. Some survivors said that they expected a 100% recovery and that life would return to a state comparable to that before cancer. Others reported feeling grateful for surviving and the lack of recurrence of cancer. However, most participants did not expect a full recovery, indicating that recovery of 80% of their pre-cancer status would be an acceptable “new normal status.” In terms of physical conditions, survivors tended to assume they would not enjoy full physical functions if part of their lungs were resected, although many did not take this view from the beginning. During the early phases of survivorship, some anticipated a 100% recovery, but as time passed, they came to accept that such a goal was unrealistic. Some complained about not being informed ahead of time about the likely changes and what would constitute a new normal.

Barriers that prevent survivors from achieving a “new normal”

Many survivors hesitated to consider themselves a normal person (life before cancer) due to physical symptoms such as coughing or shortness of breath. Survivors reported feeling close to normal when symptoms resolved. When symptoms worsened or reappeared, they reconsidered themselves as patients again and limited their own activities.

Sometimes it hurts like a knife stabbing with no pre-signal. I usually forget that I had cancer, but when I have symptoms, it reminds me that I am a cancer patient.

Often, physical symptoms increased survivors' fear of cancer recurrence (FCR) and limited their activities. FCR is a common barrier that prevents survivors from returning to normal. Many respondents reported trying to forget about their lung cancer and live as they used to but were often haunted by the idea that cancer may return at any time. The major problem posed by FCR was that it kept survivors from planning for the future. Some survivors tried to overcome FCR by exercising more, improving their diet, and refraining from smoking and alcohol consumption. Nevertheless, some often became helpless and were not able to find meaning in their lives.

I live a 3-month life. My life will be extended for another 3 months after the doctor's confirmation. In this way, every three months, I earn another three months.

Body condition is fine. But I always think about death, and I cannot plan the future. My wife and I, dreamed about having a house in the countryside in our 20s. Now I have money and time, but I cannot do it because I am worried that cancer might come back.

It's been nearly 4 years since surgery, and I am satisfied with my condition. But it is difficult to plan for the next 10 and 20 years because cancer might come back anytime.

Survivors said that expecting 100% recovery was a barrier to returning to life before cancer. Younger survivors who were healthy when they were diagnosed with lung cancer expressed embarrassment and tended to be disappointed that their conditions were not improving. One survivor mentioned that he tried to resume carrying out a normal level of work soon after the treatment, expecting that it would help with recovery. However, his condition worsened, and it took more time to recover.

I didn't know (lung cancer) surgery would be this hard. I thought it would be a simple procedure. My doctor had told me that everything would be fine soon, but it was not that soon. I didn't know that I would be in pain for this long. If someone had told me about the process of recovery and difficulties that I would face after surgery, I would have expected and prepared myself for these difficulties.

Many survivors reported that psychological stress and guilty feelings could be more burdensome than physical impairment. Many had practical concerns regarding their employment or career, and economic problems were a source of worry and psychological stress. Some survivors were obsessive about managing their health, eating a more healthful diet, and exercising daily, and some were overwhelmed with fear and guilt when they were not able to meet their own expectations. For some survivors, the desire to resume beneficial behavior can cause psychological problems itself.

Cancer can come back anytime whenever I loosen up. I can't stop working out, even for a single day. I feel compelled to keep my workout routine as consistent as possible. I am responsible for doing all I can, and I feel guilty if I neglect it.

Needs and support for normalcy

Many survivors reported that they did not get enough information about what the new normal would be like during or even after treatment. They expressed a desire for more information on expected trajectories after treatment, including when and how they could expect to recover from changes after cancer. Participants reported that visits to a doctor were too brief to discuss such issues. Instead, they relied on non-professional sources of information, such as YouTube. Several reported needing better information on symptom control, stress management, exercise, and nutrition after treatment.

I rely heavily on YouTube. I try to get information by watching what the survivors are eating and doing. I am not sure, but I think a video with a high number of views is reliable.

Survivors and their families may have different expectations or perceptions of recovery. Many survivors said that they were able to get through the difficult process of cancer treatment thanks to family support. Others reported feeling hurt by family members who did not understand their situation and had different expectations for recovery. Survivors are expected to need continuing support from family and society to manage their disease and recovery.

When I was sick and struggling, my family provided unlimited support to me. But as time went on, they questioned me, "Isn't it time to be normal?" I want to tell them that I am still recovering.

Discussion

"Can I go back to the life I once had?" is a critical question for many survivors (Burg *et al.* 2015). We found that most survivors were unfamiliar with the term "new normal" but reported that their lives had changed in a fundamental way after cancer. As reported previously, the majority of survivors in our study did not expect that it would be possible to return to their pre-cancer lives. It was not like that in the early survival phase, but they have come to accept realistic goals over time. Survivors in our study defined the "new normal" differently, and the definition of the new normal is subjective as it can be influenced by the achieved health status and the cultural background (Henshall *et al.* 2017).

"New normal" is a relatively novel term for cancer survivors (Burrell 2014; Canadian Cancer Society 2022; National Cancer Institute 2019; Victoria 2022). Most education on survivorship focuses on managing physical symptoms; surveillance or healthy lifestyles rarely deal with the new normal. Given that adjusting to physical, psychological, and social changes is essential to regaining a sense of a "new normal" (Henshall *et al.* 2017), communication with survivors about a realistic new normal after cancer treatment can be useful. It is important to discuss (and introduce) expected changes due to cancer from the day of diagnosis to ensure patients are prepared to cope with the coming changes. Many survivors in our study indicated that the time of diagnosis would be the optimal period to receive information about changes to be expected after cancer. They reported that nobody had explained to them beforehand the practical things they would encounter in daily life, and they were embarrassed when they experienced difficulties during recovery. Although clinicians provide all necessary information and education at diagnosis, survivors may not remember receiving such information or find it difficult to use it for coping strategies. Further studies are necessary to identify efficient ways to support survivors to adjust to the new normal.

In our study, achieving a "new normal" took several months for some survivors but years for others. Little *et al.* suggested 2 liminal phases in cancer survivorship: (1) acute liminality, which involves initial diagnosis and treatment stage, and (2) sustained liminality, in which survivors construct and reconstruct meaning for their experience through the use of narratives (Little *et al.* 1998). Crouch and McKenzie added one more phase, which comes between 5 and 12 years after diagnosis, at which point survivors feel "normal" again (Crouch and McKenzie 2006). However, based on a qualitative study of breast cancer survivors, Trusson *et al.* suggested that "a new normal is a continual process of renegotiation of identities, daily lives and futures as time passes and lives evolve," rather than an achievable state (Trusson *et al.* 2016). It is not static but changes with time and one's own condition and expectations (Henshall *et al.* 2017). Participants in this study noted that their expectations and lifestyles changed over time as they adopted newer versions of themselves. This suggests that it is important to inform survivors that recovery is a continual process, and that the length of recovery can vary. With such information, survivors may be able to more readily adjust to their new life at their own pace.

The most common reason survivors believe they cannot return to their pre-cancer status was FCR. Survivors with FCR are uncertain about their future and the chances of returning to normal. However, recurrence rates decrease over time, and conditional 5-year recurrence-free survival can reach 90% several years after cancer (Shin *et al.* 2021). The recurrence rate approaches around 2% per year after 5 or more years of cancer diagnosis, particularly for early-stage lung cancer (Shin *et al.* 2021). However, almost all

survivors have FCR regardless of the time since treatment (Simard et al. 2013; Trusson et al. 2016). It would be helpful to educate survivors about conditional survival to reduce unnecessary FCR. In addition, psychological interventions, including cognitive behavioral therapy, would help survivors achieve a “new normal” by reducing FCR (Butow et al. 2017; Tauber et al. 2019).

Survivors reported that physical symptoms such as shortness of breath, coughing, and operation-site pain were other sources of FCR that hindered resuming normal activity. While there are reports that overall quality of life is not clinically different between recurrence-free lung cancer survivors and the general population (Yun et al. 2012), other studies indicate that even long-term (>5 years) survivors substantially suffer from symptom burdens (Yang et al. 2012) and reduced quality of life (Rauma et al. 2015). Interventions targeted to alleviate these symptoms and enhance recovery should be incorporated to help achieve a new normal and should include postoperative pain management (Yang et al. 2012) and cardiopulmonary rehabilitation (Li et al. 2017). In addition, some cancer survivors try to re-establish “normality” in their lives through self-management practices (Henshall et al. 2017). Support for smoking cessation and maintenance programs (Warren et al. 2013), exercise training (Tong et al. 2020), and nutrition to prevent sarcopenia (Kong et al. 2020; Morley et al. 2010) would also be helpful and appreciated by the survivors.

Some survivors who wanted to return to their lives exactly as they were before the cancer diagnosis reported frustration as their physical health did not recover fully. Similarly, a previous study reported that survivors expressed feeling guilty due to their inability to fill their former roles as a family member, friend, or employee (Henshall et al. 2017). In this study, survivors who had such expectations experienced more difficulties returning to their “new normal.” Those who accepted their disease and had more realistic expectations for their recovery appeared to cope more effectively with their illness. For example, survivors who had a serious illness, such as ankylosing spondylitis, or a cerebrovascular accident resulting in hemiparesis, in the past tended to accept changes due to cancer compared with survivors without a history of other serious conditions. Also, elderly survivors were more likely to accept changes due to cancer and adjust to a new normal compared with younger survivors. This may be because elderly survivors already experience various limitations, such as a decline in physical function, senility, or social alienation, all of which are common in later years. For lung cancer survivors, management of expectations in a realistic way would be more helpful than just encouraging them to “go back to your (old) normal life.” Acceptance and commitment therapy, a form of cognitive behavioral therapy, may help some cancer survivors accept both the positive and negative components of the illness experience (Hulbert-Williams et al. 2015; Zhao et al. 2021).

Survivors may look normal and healthy on the outside (Henshall et al. 2017), but still be in a recovery process, both physically and emotionally. Their families or friends may not fully understand the cancer experience and not recognize the burdens of recovery. McKenzie and Crouch reported that cancer survivors feel isolated when they try to pretend to be “normal” with their close ones, although they actually find it difficult to maintain a positive disposition due to FCR (Crouch and McKenzie 2000, 2006; McKenzie and Crouch 2004). Indeed, some survivors confessed that high expectations from family members to stay positive and get “back to normal” were a burden. Being unable to share their existential concerns leaves them in a state of “dissonant interaction” (Crouch and McKenzie 2000; McKenzie and Crouch 2004).

It is, therefore, important that a family understands that survivors are not back to normal immediately after treatment, and ongoing patience and support are still needed while progressing to his/her “new normal.”

Our findings should be viewed in the context of study limitations. First, the sample was drawn from patients at a single cancer center. However, the sociodemographic characteristics of our study participants were generally similar to those of a national sample (Shin et al. 2019; Yoo et al. 2021). Second, while we recruited a relatively large number of survivors ($n = 32$), the samples did not include survivors with various sociodemographic and medical characteristics. The illness experience is multi-faceted and varies among survivors by age at diagnosis, treatment received, and other comorbidities. Further quantitative study that accounts for these differences should be carried out. Finally, as this study was performed in Korea, which is a relatively homogenous culture with a mandatory health insurance system that provides universal coverage, the generalizability of our findings to other countries would be limited.

In conclusion, survivors in our study defined the “new normal” depending on their expectations for recovery. Persistent symptom burdens, FCR, and high expectations of themselves or their families were the most common barriers, and the time and effort required to meet this “new normal” can vary depending on individual situations.

It is necessary for healthcare professionals to communicate with survivors about their expectations of “normality” from the beginning of treatment. Informing survivors about the “new normal” would make them prepared for changes and make a smoother transition. In addition, education for families about illness trajectories and new normal would be necessary so they understand and provide continuous psychosocial support to survivors. Furthermore, additional studies would be necessary to provide appropriate support to survivors to have a better quality of life after cancer.

Data availability statement. The data that support the findings of this study are available from the corresponding author upon request.

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Genehee Lee contributed as the first author to this study.

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Consent to participate. Informed consent was obtained from all individual participants included in the study.

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