Changes After Cancer Diagnosis and Return to Work: Moving Forward Without Direction

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Research article

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Abstract

**Background:** The purpose of this study was to understand the unmet needs of cancer patients and identify the necessary factors to develop a vocational intervention program based on cancer patients’ work-related experience after cancer diagnosis.

**Methods:** Semi-structured individual in-depth interviews were conducted with 50 cancer patients who were working at the time of diagnosis at a university hospital in Seoul, South Korea from July to September of 2017. Interview data were analyzed using qualitative content analysis.

**Results:** ‘The changes patients experienced after cancer diagnosis’ were categorized into Personal and socio-environmental changes. ‘Personal changes’ were changes within the patient that were further divided into ‘physical’, ‘psychological’ and ‘spiritual’ changes while ‘socio-environmental changes’ were changes in either ‘attitude’ and ‘relationship’ of other people cancer patients encountered. In addition to these post-diagnosis changes, the following 4 major factors related to return-to-work were identified to affect patients’ experience: ‘fear of cancer recurrence’, ‘financial status’, ‘informational support’, and ‘working environment’.

**Conclusion:** Cancer patients’ working status was determined by the interaction between the patients’ post-diagnosis changes and 4 factors related to return-to-work, with the factors’ positive or negative effect leading to return-to-work. In particular, cancer patients faced difficulties processing and appropriately responding to the potential changes occurring after cancer diagnosis due to lack of information. Based on these findings, we plan to develop an educational intervention reflecting these factors to promote cancer patients’ return-to-work. Educational materials and intervention programs informing patients on these changes and factors may facilitate their return-to-work after diagnosis.

Background

Work is a source of life that provides economic benefits, social status, and a sense of affiliation [1, 2]. Among the many dimensions that support daily life, most adults commit the largest amount of time and energy to work. For cancer patients, likewise, work carries significance as it helps to maintain one’s financial stability and social network, to confirm one’s contribution to society through self-esteem and psychological well-being, and to restore health [3, 4]. The efforts for cancer prevention, early detection, and advanced health care technology have recently increased the 5-year cancer survival rate to 70.6%, from 42.9% in 1993–1995; in South Korea alone, there are over 1.86 million cancer survivors [5]. Thus, it is predicted that a far greater number of cancer patients are to become long-term survivors (with a continuation of daily life and work) after receiving a cancer diagnosis.

Outside of Korea, it has been reported that, despite differences arising from factors such as cancer type and social welfare system, approximately 49–91% of cancer patients return to work within a year [6–11]. On the contrary, a study in Korea in 2007 reports that 53% of cancer patients lost their jobs after receiving a cancer diagnosis, while only 23% were reemployed [12]. A study in the following year reported that 47%
of cancer patients lost their jobs within a year of their cancer diagnosis; after six years, only 30.5% were found to have been reemployed [13]. In a subsequent study in 2019, only 42% of cancer patients were found to have returned to work, indicating a level still lower than that present outside of Korea. This may be attributed to various reasons, but the key influencing factors seem to be: gender, age, occupation type, level of income [13], the level of understanding from colleagues, the social support system available to the patient, information sharing [15], the prevailing stigma towards cancer patients, and the presence/absence of discrimination towards cancer patients [16]. To address and resolve such challenges (as encountered by cancer patients), studies over the last decade have initiated discussions in Korea, and have been accompanied by community-centered efforts – such as efforts led by the Cancer Survivorship Resource Center. Despite this, no study has yet developed a work-related educational platform, materials, or intervention programs for cancer patients. Moreover, there is a general lack of studies in Korea regarding practical information or strategies for helping cancer patients return to work after receiving a cancer diagnosis, nor regarding the expectations or demands of health care staff by cancer patients.

Outside of Korea, the importance surrounding a cancer patient’s return to work has long been recognized, and various methods have been applied at the level of the hospital, region, or nation in establishing intervention programs that could help cancer patients return to work. These include programs which minimize the physical challenges endured during cancer treatment, while providing knowledge concerning the patient’s return-to-work, as well as programs with a diversity of contents regarding psychological-educational, physical, and occupation rehabilitation [17]. However, only a handful of studies have evaluated the effects of the intervention programs and have reported a statistically significant result; this is due to the fact that the measured variables were inappropriate for evaluating the programs, or because the interventions had not been helpful in the actual return-to-work of the patients [17]. In addition, social welfare policies for cancer patients are different in each country, including Korea. As such, in developing the return-to-work intervention program for cancer patients in Korea, foreign intervention programs – or appropriate measured variables – should not simply be benchmarked. Instead, qualitative studies should first be conducted on cancer patients in the Korean context so as to accurately analyze their experiences in relation to work after having received a cancer diagnosis, as well as the difficulties that most frequently arise in such a situation. Qualitative studies in Korea that examine cancer patients' work-related experiences after receiving their diagnoses are limited to breast cancer patients [15, 18], or to the experience of a small number of cancer patients [19–21] – despite investigating different cancer types. Therefore, a thorough understanding of cancer patients' work-related experiences cannot be achieved based on previous studies – as such, it is necessary that further studies be conducted regarding cancer patients' experiences.

The present study, thus, provides an in-depth analysis of cancer patients' work-related experiences as a qualitative study in order to provide a useful foundation for developing intervention programs and educational materials that would help such patients successfully return to work. The purpose of this study is to explore and understand the cancer patients' work-related experiences after receiving a cancer
diagnosis, and to describe the findings thereof. The central question for this study is “What experiences do cancer patients undergo in relation to their work after cancer diagnosis?”

**Methods**

1. **Study design**

This study takes the form of a qualitative content analysis, based on individual in-depth interviews involving cancer patients who used to work at the time of their cancer diagnosis. A qualitative content analysis allows us to explore the patients' work-related experiences after having received their cancer diagnosis.

2. **Study subjects**

The inclusion criteria for participants was decided to include the following: cancer patients aged 19-64 years; patients who had partook in economic activity as an employee or independent contractor at the time of their cancer diagnosis; and patients with an ability to communicate fluently in Korean. The exclusion criterion was decided to encompass all individuals who are unable to participate in an in-depth interview due to a cognitive disability.

The participants were recruited using various methods, including via: a poster attached to the notice board at the outpatient center of the Comprehensive Cancer Center of a university located in Seoul; a post on the website for the Cancer Education Center; an introduction by the attending physician or nurse, based on purposive sampling in cases where the cancer patient has been confirmed to have a record of employment or self-employment at the time of their diagnosis.

3. **Ethical considerations**

This study has been conducted following the approval of the institutional review board at the hospital to which the researchers belong (IRB No. 2017-05-166). Prior to the study, all participants were given a detailed explanation of the study and voluntary written consent was collected. For ethical protection of the participants, the data related to the interview contents were used strictly for study purposes only, while the information was coded for security reasons – both of these measures were explained to each participant. The contents of all interviews were recorded using an audio-recorder. Each participant was notified that the recording would begin at the start of the interview and that all recorded data would be transcribed. Participants were also notified that the recorded data would be discarded completely at the end of the study and that the quotations in the study would not indicate the identity of the participant in any way. The explanation also included the fact that the participant could withdraw from the study at their will and that no harm or disadvantage would be incurred by their withdrawal from the study. Upon completion of an interview, the participant was given a small gift of appreciation for participating in the study.

4. **Data collection**
The individual in-depth interviews used in this study were conducted between July 14 and September 26, 2017. All interviews were conducted by author KB in the consultation room at the hospital with which the patients were familiar with. This one-time semi-structured interview lasted approximately 50 minutes. Prior to the interview, the researcher provided the patient with a questionnaire containing 11 items; the questionnaire assisted in determining the participant’s basic personal information, as well as their occupation at the time of receiving their cancer diagnosis, their past work experience, and whether they were currently working. At the start of the interview, each patient was again notified that the interview would be recorded from the beginning. Meanwhile, and throughout the entirety of the interview, KB made notes regarding the patient's linguistic and paralinguistic expressions, the atmosphere, and any other important matters which may not be conveyed via the audio recording alone.

The interviews consisted of semi-structured questions based on the above-mentioned questionnaire, which was developed via a literature review and professional advice. The questions were selected according to the patient’s circumstances and the study’s purpose. At the beginning of the interview, the mood was softened through conversation concerning the patient’s daily life and current treatment; the interview then began with an open, extensive question – such as: “Please feel free to tell me what experiences you had, in relation to the work you used to have, after receiving your cancer diagnosis.” The questions focused on the patient's own thoughts regarding: work; having to work while receiving treatment; undergoing the process of sick leave; suspension or resignation from work; and reemployment, as well as how people reacted or changed, and how the patient subsequently dealt with them. At the end of the discussion, and to close the interview, the patient was asked if he or she could describe the feelings they had experienced during the interview and to share any further stories. Author KB completed the transcription of the interview within one or two days so as to record the atmosphere and all relevant feelings at the time of the interview as accurately as possible.

5. Data analysis

In this study, the interview materials and the notes made during the interview for each patient were transcribed on a computer at the end of each interview so as to ensure a regular cycle of data collection and analysis. All collected data were processed for qualitative content analysis, following the procedure suggested by Elo and Kyngäs [22].

After transcription, authors KB and JC read through the interviews for a general understanding. Thereafter, and through repeated readings, the data were categorized based on meaningful units, and the key word or sentence for each unit was searched for, followed by open coding. The categorization based on the similarities and differences between each type of coding led to the grouping of larger and more meaningful units; by integrating those units, the final abstract theme was derived. Through ten subsequent meetings – where both researchers checked the data of one another and discussed and converged the points for which the opinions varied – the final result of the data analysis was produced.

6. Verification on the trustworthiness of information
As a qualitative study, the trustworthiness of information in this investigation was increased through complying with the criteria of qualitative studies as suggested by Shenton [23]. First off, in order to increase their credibility, the interviews were led by author KB alone, and the results of the subsequent data analysis were discussed with four experts on the topic of cancer patients (a professor, a cancer-specialized nurse, a nurse, and a researcher) in developing a consensus. Author KB had built an adequate level of background knowledge on the interview questions through the review of numerous previous studies published both in Korea and abroad regarding the occupation and return to work of cancer patients, making it possible for her to collect the data with a sufficient degree of theoretical sensitivity to context and meaning. Secondly, in order to increase the transferability of data, the respondents’ age, gender, and cancer type were taken into account so as to allow for diversity in participants to be included in the interview. The data were collected until saturation was reached and so that more in-depth descriptions could be obtained. Third, to increase the dependability and confirmability of the results, the data collection and analysis procedures were described in detail, and care was taken to avoid interpreting the interview conditions and experiences within the subjective frame of the researchers.

7. Researcher training and preparation

Author KB, PhD and a senior researcher at a Comprehensive Cancer Center of a tertiary hospital, is a cancer-specialized nurse with 15 years of experience in clinical studies concerning cancer. She has a rich and in-depth understanding of the field, and has given lectures on qualitative studies at a graduate school level, has participated in seminars and conferences on qualitative studies, and has reviewed a large body of books and articles on the methodology, developing a consequent expert level of competence in performing qualitative studies.

Results

1. General characteristics of the subjects

The general characteristics of all 50 participants (at the time of the interviews) were as follows: patients had an average age of 45.72 years; 26 were male (52.0%) and 24 were female (48.0%); 41 were married (82.0%); and 39 had an undergraduate degree or above (78.0%). No participant refused to participate or dropped out of the study. For clinical characteristics, the most frequent cancer type was breast cancer – experienced by 19 patients (38.0%) – followed by 12 patients with lung cancer (24.0%) and 9 patients with lymphoma (18.0%); the most common stage of cancer recorded was Stage 0 and 1 – in 21 patients (42.0%) – and Stage 3 – in 17 patients (34.0%). On average, 20.46 months had passed since the respondents’ cancer diagnosis. For occupational characteristics, the number of patients with a job (at the time of the interview) was the largest – at 23 (46.0%). For the type of job, office clerks accounted for the largest number at 39 (78.0%). The average number of working years was 15.72 (Table 1).

Table 1. Characteristics of All Participants (N=50)
| Characteristics                                    | n (%)          |
|--------------------------------------------------|----------------|
| **General Characteristics**                      | 45.72 (7.51)   |
| **Age (years), mean (SD)**                        |                |
| **Sex**                                           |                |
| Male                                             | 26 (52.0)      |
| Female                                           | 24 (48.0)      |
| **Marital status**                                |                |
| Married                                          | 41 (82.0)      |
| Single/ divorced/ separated/ widowed              | 9 (18.0)       |
| **Highest Level of Education received**           |                |
| ≤ High school                                    | 11 (22.0)      |
| ≥ College                                         | 39 (78.0)      |
| **Monthly Income (10,000 KRW)**                   |                |
| < 500                                            | 27 (54.0)      |
| ≥ 500                                            | 23 (46.0)      |
| **Clinical Characteristics**                      |                |
| **Type of Cancer**                                |                |
| Breast cancer                                    |                |
| Liver cancer                                     | 19 (38.0)      |
| Lung cancer                                      | 4 (8.0)        |
| Lymphoma                                         | 12 (24.0)      |
| Others                                           | 9 (18.0)       |
| **Stage**                                        | 6 (12.0)       |
| 0/I                                              |                |
| II                                               | 21 (42.0)      |
| III                                              | 7 (14.0)       |
| IV                                               | 17 (34.0)      |
| Unknown                                          | 2 (4.0)        |
| **Time since diagnosis (months), mean (SD)**      | 3 (6.0)        |
|                                                  | 20.5 (22.80)   |
2. Analysis results

The participants' work-related experiences after receiving their cancer diagnosis could be divided into two categories, six subcategories, and 17 codes (as presented in Table 2). The categorical structure is shown in Figure 1. The results show that patients experienced personal and socio-environmental changes due to cancer and along with these changes, four factors affecting the decision to return to work modified participants' ultimate decision to continue working or not, whether the latter meant taking a leave of absence or permanently leaving the job.

Table 2. Work-Related Experiences of Cancer Survivors

| Current Employment Status     |        |
|-------------------------------|--------|
| Continued working             | 26 (52.0) |
| Changed jobs                  | 1 (2.0) |
| Leave of absence              | 16 (32.0) |
| Resigned                      | 7 (14.0) |

| Job Categories               |        |
|-------------------------------|--------|
| Blue-Collar                  | 4 (8.0) |
| Sales or Service             | 5 (10.0) |
| White-Collar                 | 39 (78.0) |
| Self-employed                | 2 (4.0) |

| Duration of Work (years), mean (SD) | 15.72(10.92) |
| Categories                               | Subcategories      | Codes                                                                 |
|------------------------------------------|--------------------|----------------------------------------------------------------------|
| Changes after cancer diagnosis           | Personal changes   | Changes in appearance                                               |
|                                          | Physical           | Physical Weakness (fatigue)                                          |
|                                          |                    | Physical discomfort (pain, numbness, nausea, vomiting, lymphedema etc.) |
|                                          | Psychological      | Identity changes                                                     |
|                                          |                    | Mood changes                                                         |
|                                          | Spiritual          | Meaning of work / Changes in priority                                 |
| Socio-environmental changes              | Attitude of others | Change in how they perceive me/ Perceiving me as “a cancer patient”   |
|                                          | Relationship with others | Maintaining social relationships                                     |
| Factors influencing the return to work   | Fear of cancer recurrence | Anxiety, uncertainty                                                  |
|                                          |                    | Work-related stress                                                  |
|                                          | Financial status   | Being financially responsible for the family                         |
|                                          |                    | Burden of health cost                                                |
|                                          | Informational support | Unverified information/                                               |
|                                          |                    | Lack of available information                                        |
|                                          | Job-related work environment | Uncertainty of employment                                           |
|                                          |                    | Lack of substitute workers                                           |
|                                          |                    | Flexibility of work                                                  |
|                                          |                    | Support of workplace                                                 |

2.1 Category I: Changes after cancer diagnosis

After being diagnosed with cancer, participants were found to have undergone two main changes regarding work-related experiences; personal and socio-environmental changes. For each change, there were cases where the change had a substantial impact on increasing the patient’s challenge to continue working, and cases where the change had a negligible impact on the patient – posing no significant challenge to maintaining their previous work.

2.1.1 Personal changes
(1) Physical changes: Among the changes experienced by cancer patients, physical changes included physical discomfort caused by the treatment of cancer – such as those commonly known to accompany chemotherapy, radiotherapy, and hormone therapy. Firstly, changes in appearance – such as hair loss, changes in skin tone and complexion, and weight loss – are shown to have contributed to the resignation or avoidance of returning to work for many female patients, as in the case of Participant 35, and was the most significant factor in preventing return-to-work for service workers and patients with tasks that require a considerable number of face-to-face encounters. Second was the reduction in physical strength due to fatigue, which was complained as the most substantial physical change experienced by all cancer patients participating in this study. Third and last physical change patients experienced from receiving treatment were changes due to treatment side effects – such as pain, numbness in hands and feet, lymphedema, nausea, and vomiting. Experiencing these physical changes ultimately led participants to permanently leave work or take a leave of absence and even for those patients who continued to work, such changes exerted a negative impact on patients’ ability to work, nonetheless.

I'd lost my hair – as well as my eyebrows – and I couldn't even draw the eyebrows because (laughter) there was nothing at all to draw on. The anticancer drug was also, you see, the drug causes this edema, so my face... well... one may say “why does it matter when you are ill?”, “why is it a problem when it is [an issue of] life or death?”. But, you see, if you actually go through all of this, you know, a woman wants to be a woman at any moment (Participant 35).

(2) Psychological changes: The psychological changes were divided into two domains of changes in personal identity and emotional changes. In some cases, patients would place the stigma of a ‘cancer patient’ on him or herself, subsequently feeling devalued and diminished, regardless of their past career. In this context, the patient contemplated the potential disadvantages that may incur when he or she disclosed the news, thus avoiding telling anyone.

I just thought I might receive unnecessary stares, [such] as, ‘Is (s)he like that because (s)he can’t take care of her/himself?’, ‘Is (s)he able to get the work done as (s)he did before?’, ‘Is (s)he backing out even when (s)he could do more?’ I mean... you sort of have it labeled as a cancer patient who always makes things difficult for others (Participant 26).

For emotional changes, the sense of social isolation, in particular, was noted upon as the patient viewed him or herself as a ‘good-for-nothing person’ and felt ‘distanced from the society’ after having stopped the work he or she had been engaged in. In many cases, the patient also had a feeling of ‘frustration’ or ‘despair’ that developed into the thought ‘My life is over now’, causing depression and torpor.

If I leave work, I become a quitter just because of an illness. My work is half of my life. Leaving work would add on to the already existent frustration or despair, you know. The thought of my life being over would grow and to a degree, I would feel as if I’ve become a good-for-nothing person, you know. Out of touch with society, that sort of feeling (Participant 23).
(3) **Spiritual changes**: In experiencing a serious situation such as a cancer diagnosis, patients were given time to deeply reflect on the work he or she had been doing so as to evaluate the true meaning and values of the work. This is a part of the concept of workplace spirituality [24] and, in the experience thereof, patients underwent a process of transformation regarding their understanding of the meaning of work and the values of life after cancer, when work used to fill the largest portion of their life. As in the case of Participant 20, work used to be the most fulfilling aspect of life in the past; but now, living a healthy life through ‘letting go of desires’ and ‘coordinating aspects regarding their work’ was the main goal in life.

How others thought of me was important to me. I think I used to want things to be done the way I had decided it to be; I wanted specific outcomes, and that [would lead] others [to] see me as a perfectionist. But from now on, I want to let go of desires and coordinate aspects regarding work. I used to have too many desires. That probably was what deteriorated my health. (Participant 20).

2.1.2 **Socio-environmental changes**

(4) **Recognizing the changes in the attitude of others**: The changes in the attitude of others mostly originated in the prevailing social prejudices against cancer. Notably, in regard to the respondents, it was tremendously difficult to see those colleagues who used to appreciate him or her in the past change their attitude and to avoid working with him or her. Their changes were perceived to be based upon a prejudice that the respondent’s work ability would not be the same, thinking that ‘the work won’t be as complete as it did before,’ ‘their ability to perform tasks won’t be as it was before,’ or that ‘the work won’t be reliably performed.’ In many cases, patients who received a cancer diagnosis lost their chance to participate in important tasks or to show their ability. On the other hand, the attitude by which others treated them as a patient and showed too much attention, was a considerable burden to patients.

Before cancer, I used to be a hard worker, and the superiors all used to show appreciation for my work. Then, once I began taking sick leaves for treatment, they said: “I know you can handle it but take it easy”. I heard many of them say the same thing to me. I kept hearing it over and over, and when there came a task that I wanted to be a part of, [that I] really put myself into, they kept interrupting me so eventually I kind of let it go. You often get this feeling that others seem to think, (s)he can’t do it anyway so why is (s)he so eager (Participant 24).

(5) **Recognizing the changes in their relationship with others**: The most significant changes in the relationship with others at work was shown to originate from the decrease in, or disappearance of, the time shared with others—such as lunch or dinner with colleagues, company dinners, or get-together events after work. What used to be a close relationship either diminished or fell apart, and the patients said they experienced social exclusion, such as being purposely ignored at meetings or being excluded or isolated from the team. However, some colleagues showed patience until the treatment was over, maintaining the same attitude as before, so that the relationship further strengthened based on loyalty and a deep appreciation of the thereof. In both cases of company-employment where much time is spent among colleagues, or self-employment where good relationships should be maintained with contractors, the relationship dynamics were regarded as being highly important by the patients.
Now, whatever task they ask me to do, they do seem to feel uncomfortable, and... well... when there is a company dinner or something... it feels like... a bit... that I am being excluded. Before, we used to drink together and everything, but now... I am a cancer patient, so... Ah, no drinking, you know, so... it feels like I'm being excluded from everything (Participant 14).

2.2 Category II: Factors influencing the return to work

In experiencing various changes, cancer patients face a number of critical factors that influence their decisions regarding whether or not to continue working. Four such factors were found in this study, as follows:

2.2.1 Fear of cancer recurrence

The fear of cancer recurrence was expressed via anxiety, uncertainty, and task-related stress. The respondents seemed to think that, as they returned to work in a physical condition that differed from the past, they would overwork or get more stressed, which may at any time cause the recurrence of cancer. Thus, even while working or planning to return to work, patients found themselves reluctant to focus on their work as they had done before, given the fear of undergoing cancer again, which was thus recognized as a significant factor.

[There is] a lot of work to do... and frankly, my body is not as healthy, and if something goes wrong, cancer could recur, and these thoughts continue to haunt me day after day. 'Am I going to die from the pressure and stress I get from working as I did before cancer?' It almost feels hopeless (Participant 40).

2.2.2 Personal or family financial status

Most of the male respondents, in particular, had a main goal of maintaining a livelihood as the breadwinner who ‘must take financial responsibility for the family,’ as in the case of Participant 24. In addition, patients without a spouse had numerous reasons for continuing, or starting, to work – for the purpose of maintaining a livelihood. Meanwhile, some respondents were able to take time to prepare for reemployment or could take a long leave from work without financial difficulty. In some cases, these individuals quit or retired from work altogether.

If I had a lot of money, I wouldn't have returned to the company. I have to earn, anyhow, so that I can financially support my family without difficulty. If I take time off for too long, so that I fail to readily adapt to the work and quit in the end, then I will have to look for a new job, and I'll be caught in a vicious circle. These reasons, along with the thought that I should stay employed for a long time, drove me to return to work rather early (Participant 24).

To be honest, the medical cost itself wasn't too much of a burden financially, and I received some benefits from the insurance company and I have my savings and all – even though I am not as well off as I did before. It isn't like “Ah... I don't have any money now! I should quickly return to work to earn money!”
Frankly (laughter), I don’t really want to go back. I want to take time off [for] at least two more years (Participant 12).

Despite the relatively large benefits received from both the Exempted Calculation of Health Insurance and private insurance in regard to the medical costs, frequent visits to the hospital – with the consequent expenses of transportation, food, and lodging – were viewed as a significant financial burden to respondents. In particular, the place where this study was conducted is a large general hospital in Seoul, the capital city of Korea, and many of the patients had to take an express train from a provincial region for consultations and appointments, thereby requiring the need to find lodging and food while staying close to the hospital for the treatment, adding on to the already existent financial difficulties.

I come from Mokpo, and the transportation alone costs 120,000 won. But for the treatment, I only pay 1,700 won; then, I eat something and take the high-speed train nearby hospital... You see, the time and money spent for coming to Seoul is much more (Participant 7).

### 2.2.3 Informational support

Above all, cancer patients expressed their frustration at the extremely low level of informational support with respect to cancer and work. Regarding work, the respondents reported feeling confused while sharing non-professional content acquired from the Internet or TV programs in an indiscreet way, rather than being provided with accurate and credible information. Even at the hospital – their only source of professional information – there was a general lack of educational materials or programs and, in many cases, patients found it difficult to obtain accurate information on cancer and work from the medical staff who were busy throughout the day.

I think media are the problem. I mean they portray as if cancer patients have to go into the mountains. They provide no information on patients who, like me, live in the cities. Everyone seems to be drying and eating these wild flowers or some organic [foods they cultivate]... You can overcome cancer by regularly taking the prescribed medication and even stage IV blood cancer patients can survive with the right medication but the media is like “you survive cancer by living in the mountains”... well... all morning tv programs are like that. No one survives cancer from living the modern lifestyle like me. (Participant 41).

The easy access to the Internet in Korea has led many cancer patients to use online communities in order to exchange information with other patients with the same type of cancer and to receive substantial psychological comfort. In particular, the patients who had returned to work would connect to the Internet at any time to get the information in regard to being a cancer patient at work, to share the burden with other patients of similar jobs, and to ask and answer each other’s questions. However, almost no work-related information could be obtained from the medical staff at the hospital. Most patients spoke of an experience – as in the case of Participant 3 – where the medical staff was too busy to give him or her a change to ask about work, and when they did ask about returning to work, the answer was brief and without any concern for the type of work or the tasks involved; ‘you can work’ or ‘you can return to work’ was all they received; as such, patients felt uncertain whether it really was alright to return to work.
The professor didn't ask, and I had no chance to ask. They come in, and it's over in three minutes. They are busy, I know, but it's just [that] you don't have enough time or the conscience to ask anything in that short window of time... not enough time for just consultations either, because it's just the way it is... I have so many questions but what can I do? I just go to [an] Internet community to leave questions and get a lot of information there (Participant 3).

2.2.4 Job-related work environment

After being diagnosed with cancer, the greatest concern patients had was the uncertainty of employment. Even when it is guaranteed, receiving a negative performance assessment led to disadvantages in salary or promotion. Thus, some patients had to return to work immediately after surgery or never express the hardship they were going through during treatment. Some patients had lost their jobs after notifying the company of their cancer diagnosis and were, subsequently, job-seeking while in the middle of treatment. Due to the lack of substitute workers, it was highly difficult for cancer patients to use sick leave or a leave of absence for their treatment. Although the sudden cancer diagnosis, and the onset of treatment like surgery, made it inevitable, patients were sometimes criticized for being ‘irresponsible’ at work, as in the case of Participant 13. The pressure from colleagues regarding the extra work they had to take from lack of substitute workers aggravated the circumstance.

I was totally stressed out right up to the moment I took my leave of absence. This is, well... they didn't make it easy for me. You have to work, they said, because when you’re gone, another person has to take on your workload. That was their reaction. They told me that I was irresponsible (Participant 13).

The flexibility of work was a significant requisite for cancer patients who frequently visited the hospital for treatment and status examination. In some cases, it was possible to adjust the working hours until full recovery or to freely take an afternoon off or a day off for the chemotherapy or radiotherapy, or to take additional leave of absence or request for childcare leave – although these options were rarely available without restriction. On the other hand, patients seemed to be satisfied with the mere presence of a financial support system for sick workers or a separate place where they could take a rest, so that they expressed the willingness to quickly return to work.

When it gets hard while working, I go to the lounge and take a few minutes’ break. Because there is a place like that, I can ease the pressure from others a bit. I also live within a few minutes walking distance from the company, and when it gets too hard, I go home during lunch to have a nap for a while. The company has shown me that they understand all that, so I feel I should commit myself to this company (Participant 18).

Discussion

In this study, individual in-depth interviews were conducted with 50 cancer patients with an aim to understand the cancer patient’s work-related experiences after receiving their cancer diagnosis. A qualitative content analysis was carried out using the collected interview data, and the results show that
the cancer patients' work-related experiences after cancer diagnosis could be broadly divided into 'changes after cancer diagnosis' and 'factors influencing the return to work'. The discussion has thus focused on these two categories.

When the respondents visited a hospital due to simple physical discomfort, they received a devastating cancer diagnosis. Without taking time to reflect on the situation, they experienced various tests and surgery, followed by various immediate treatments – such as anticancer therapy or radiotherapy. The sudden turn in their life led the patients to undergo physical, psychological, and spiritual changes in relation to their work. Most previous studies on the return-to-work of cancer patients also points out the personal changes in patients. The most frequent complaints were lymphedema, cognitive dysfunction, fatigue, hair loss, anxiety, and stress [15, 18–21, 25, 26]. Such changes are found to have delayed the return to work, with a negative influence on maintaining the respondent's working life, while having an effect on task performance, changing roles, reduced working hours, and the adjusting the duration of a leave of absence [26]. The physical and psychological changes experienced after receiving a cancer diagnosis are already presented in many educational materials or programs so that they can be predicted prior to the treatment, and there are various drugs and interventions that can alleviate the symptoms to help such patients. However, to find the ability to thoroughly understand and prepare for the changes they might undergo after receiving cancer diagnosis is not easy for the patients. While it is said that a multidisciplinary approach should be taken regarding whether the health status of the cancer patient allows him or her to resume their work, whether the patient could begin job-seeking activities, and which jobs are available for the patient to return to work [21], the first and foremost concern would be for the patient to determine whether to return to work or take time off for recovery, based on the understanding of personal changes and continuous self-assessment [3]. The decision to return to work should be determined only after having analyzed all physical, psychological, and spiritual changes that have occurred, and having checked whether there would be challenges which might negatively influence the tasks of their previous work. It is, thus, a problem no one else other than the cancer patient him or herself could resolve with certainty. Therefore, for the development of a nursing intervention program, it is necessary that cancer patients are educated regarding the method of an objective self-assessment for the changes they might have experienced. Moreover, since it is possible for the patients to over- or under-estimate their current health status, the medical staff should explain the physical and psychological states of patients in greater detail so that they can objectively recognize the level of their wellbeing. Through this process, cancer patients will be able to prepare for their return-to-work with reasonable confidence in their current health status and competence, and the results of the objective assessment will also further enable employers to make fair decisions based on the understanding of the challenges facing cancer patients.

Among the socio-environmental changes noted, cancer patients are most sensitive to the changes in the attitudes of their colleagues. It is, thus, a factor that most effectively influences whether a cancer patient returns to work. The result coincides with the study reporting that the most significant support came from the workplace and colleagues [27], indicating that the influence of co-workers is substantial. The reason for the challenges cancer patients face in terms of socio-environmental changes seems to be the lack of
systematic and organizational support, rehabilitation programs, and a supportive work environment; on the national level, public awareness and understanding of cancer should be improved. However, many of the employers and co-workers said that they did not know what to do, although they wanted to help a colleague who had cancer, and that they did not know what would be the best responses for them [28]. This implies the need for developing an intervention program that can help both the cancer patient and their colleagues at work. Outside of Korea, educational materials are already available for cancer patients and their guardians, as well as for colleagues at work, the HR team, and the employers. The education being provided concerns the following: what physical and psychological changes are experienced by the colleague who has been given a cancer diagnosis; how to communicate with this colleague; what support could be given at the workplace; what legal rights cancer patients have; and the contact details in case help is needed [29–32]. As can be seen, to educate cancer patients and their colleagues regarding the methods of understanding the changes in one another, and of responding to various issues arising from a task, will help far more cancer patients to return to work and will be the driving force for patients to maintain a healthy relationship with their colleagues.

In addition to the various changes after receiving a cancer diagnosis, the ‘fear of cancer recurrence’ was the most influential factor influencing the work of the patient after having received their diagnosis. The participants in this study said that, despite having overcome the changes incurred after beating cancer and working as before, the anxiety that the cancer may recur at any time, and the uncertainty thereof, were the challenges they faced while at work. In a previous study, the fear of cancer recurrence was reported as a factor that posed a psychological challenge to cancer patients preparing to return to work, but appeared during the process of recovery from cancer. Based on this, cancer patients are reported to feel the empowerment of having survived cancer, as well as showing changes in life such as work adjustment [34]. Thus, it is presumed that an intervention that allows for a positive influence regarding the fear of cancer’s recurrence would provide help in the decision to return to work via the association with the patients’ reemployment. Although no such intervention is available in Korea, other countries have various nurse-led interventions for dealing with the fear of cancer recurrence [35]. Therefore, an effective, customized nursing intervention focused on the reemployment of cancer patients should be developed and applied in practice.

Interestingly, in terms of ‘personal or family financial status,’ the results of this study show that, in agreement with previous studies [21, 36], patients had to find a way to pay the immediate medical cost and to maintain a livelihood after receiving a cancer diagnosis, so that they strained themselves to continue working while receiving treatment. On the contrary, some patients could take time to prepare reemployment without financial difficulty or to quit or retire for a leisurely lifestyle. What should be noted here is the situation of cancer patients who had to strain themselves to return to work due to financial difficulty. The moment they take time off their work as a result of a cancer diagnosis, they are faced with problems in sustaining their livelihood – as a result, they would rather ‘put up with’ pain rather than take time off work. The pressure to maintain a livelihood for one’s family was the most influential if the patient is the breadwinner. In relation to these challenges, a number of studies discuss the burden of high medical cost on household finance, as well as the lack of sickness benefits [37]. Nonetheless, discussions
for determining the conditions that drive cancer patients to participate in even more unstable labor, and for the system or benefits that provide direct assistance, are insufficient. The policy to reinforce cancer insurance with a 5% personal contribution may have lowered the financial burden on cancer patients compared to the past, but the high level of contributions and extensive non-payment services are still posing challenges to the household finance of cancer patients. Thus, the policy aimed at reinforcing the insurance for medical costs does not allow adequate financial protection on its own and cannot protect the cancer patients' household from financial crises that may occur due to job loss. To determine what may be able to provide practical assistance, a large-scale approach on the medical, social, and national level should be taken.

The participants in this study, in particular, expressed a strong demand for 'informational support' with accuracy and credibility in relation to work. Many foreign qualitative studies point out the need for but the lack of information and the guidelines for the medical staff, regarding the decision-makings of cancer patients on reemployment [3]. In Korea, there is a complete lack of work-related information for patients who received a cancer diagnosis; as such, patients are collecting limited information by conducting portal web-searches or participating in online communities. The contents displayed in online communities, moreover, are non-professional and focus on the experience of patients and their guardians, with the effect of confusing cancer patients regarding reemployment [38]. As highlighted by non-Korean studies [29–32], in order to ensure patients can obtain work-related information during the period between cancer diagnosis and completion of treatment, the authorized institutions, universities, and hospitals should collaborate to develop educational materials and programs regarding health care, employment, and laws applicable to the patient’s situation. In addition, for workers who cannot easily spare time due to work, an online support system – including expert consultation – should be established, along with the construction of an online database that can be accessed at any time and at any place [38].

Lastly, the ‘job-related work environment’ is something that cannot be easily changed in its ability to influence cancer patients' return to work. As previously reported, even when issues of ‘fear of cancer recurrence,’ ‘personal or family financial status,’ and ‘informational support’ have been resolved, the nature of the individual’s previous work or workplace, along with the work-related institutions, can have a marked influence on the reemployment of patients. In this study, the stability of employment, the presence of substitute workers, the flexibility of work, and the support present at work, were all found to have a significant influence on a cancer patient’s decision to return to work or continue working. In line with this, previous studies reported that the flexibility of work [25, 39] is a critical factor, while facility-related support, a supportive work environment, and the type of workplace and level of tasks demanded [25] can also influence the decision. As can be seen, while it is important for cancer patients to safely return to work after receiving treatment, the institutional support – including sick leave and holiday for health management, flexible working hours, and a facility for repose – as well as reinforced supportive health care policies, should be established to help cancer patients maintain their quality work following reemployment. Furthermore, an employment policy for cancer patients, and the related institutions, should be implemented on the national level so as to allow cancer patients to receive treatment without concerns and to protect them from discrimination through job-loss, wage-cuts, or work adjustments. The
solutions for the work environment should also be established, so as to further prevent occupational damages or accidents following the reemployment of cancer patients.

In this study, the participants encompassed cancer patients at a single Comprehensive Cancer Center located in Seoul. As such, their monthly income and level of education were relatively high, with 80% of respondents being made up of specialized office workers. Hence, many patients continued to work after having received their cancer diagnosis or returned to work with relative ease. It is, thus, possible that the results do not reflect the cases of extreme hardship with respect to financial and psychological burdens. Nonetheless, interviews were conducted on a large number of cancer patients with a cancer type other than breast cancer. Based on the results, this study determined the changes and challenges related to work are experienced by cancer patients in Korea after having received a cancer diagnosis. Furthermore, through the comparison with non-Korean studies, similarities and differences were identified. As a result, the significance of this study lies in that possible supports a level of the hospital, workplace, and government have been identified, so as to ensure that cancer patients can continue to work after being diagnosed with cancer in Korea.

Conclusion

This study conducted individual in-depth interviews in order to examine cancer patients' work-related experiences after receiving a cancer diagnosis. Through a qualitative content analysis, their experiences were divided into two categories, six subcategories, and 17 codes. The respondents were found to experience various work-related changes after their cancer diagnosis, and the four factors influencing the return-to-work of cancer patients – a fear of cancer recurrence, financial status, informational support, and job-related work environment – were acting as either a positive or a negative factor in response to changes promoting or preventing the reemployment of cancer patients. Notably, the lack of insufficient information regarding potential work-related changes the patients may undergo after their cancer diagnosis, and on the factors influencing those changes, was shown to cause many cancer patients to feel frustrated. Therefore, various educational materials and intervention programs should be developed with respect to the potential changes and the factors which influence them in order to provide a direction for reemployment for cancer patients who feel lost and do not know where to start in their fight against the disease.

For further studies, the following suggestions have been made: first, far more diverse work-related experiences of cancer patients should be examined by recruiting a diversity of participants from different communities – including multiple hospitals and regions. Second, based on the changes identified in this study, along with the factors influencing cancer patients' return-to-work, a study should be conducted and verified to develop educational materials and nursing intervention programs for the reemployment of cancer patients. Third, the experiences of cancer patients showed minor differences between employees and independent contractors, although the data was not presented in this study. A small-scale business owner had to continue working without any help from colleagues or support from the workplace – as a result, they faced a greater number of difficulties. In future, it is necessary to also investigate the
experiences of the business owners and to consider the educational contents separately for employees and independent contractors. In addition, some participants reported an experience where the work-life balance was more important than the return-to-work itself. Therefore, the experiences following reemployment should also be investigated, so as to provide the help necessary in adjusting the balance between work and life for those afflicted with cancer.

Declarations

Ethics approval and consent to participate

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Institutional Review Board of the Samsung Medical Center (No. 2017-05-166). Informed consent was obtained from all individual participants included in the study.

Consent for publication

Not Applicable

Availability of data and materials

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

Competing Interests

The authors declare that they have no conflict of interest.

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Authors’ contributions

KB and JC designed and planned the study. KB collected data, performed the analysis and drafted the manuscript. JC performed the analysis and obtained the funding for the study. All authors have read and approved the final manuscript.

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