Unintended consequences: the social context of cancer survivors and work

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Abstract

Purpose This article describes the ways in which socioeconomic characteristics and workplace contexts shape the unintended consequences that cancer survivors can experience as they return to work. The study was conducted in an employment setting where there is a major focus on productivity and economic growth in the business sector.

Methods Five focus groups (N=33 participants) were conducted in 2012 in Singapore. Questions were directed at obtaining information related to the meaning of a job and reactions to return to work as a cancer survivor completes primary cancer treatment. A thematic analysis using a two-staged analytical process was conducted to identify (1) work-related challenges faced by survivors as a result of the interplay between their self-identity as someone with a critical illness and organizational structure, and (2) unintended social consequences (USCs) related to the interaction between the workplace and cancer survivor.

Results Eight emerging themes of work-related challenges and unintended consequences were categorized. Fear of losing out by compromising one's expectation, downplaying illness to avoid being a burden to others, working harder to meet expectations, and passive acceptance to perceived discrimination. Unintended consequences were also observed

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in relation to policies, procedures, and economic factors in the context of a heightened economically driven social climate

Conclusions This study contributes to the understanding of how cancer survivors perceive their work situation. These findings can inform health care providers, employers, and policy makers regarding the challenges faced by cancer survivors as they return to the workplace in a culture of a rapidly growing emphasis on economic concerns.

Implications for Cancer Survivorship These findings offer a new perspective on the complexities that can occur when cancer survivors interact with their workplace. Awareness of the existence and types of unintended consequences in this context can help provide a more comprehensive understanding of the cancer survivor and work interface.

Keywords Cancer · Communication · Culture · Return to work · Workplace support · Unintended consequences

Introduction

For many cancer survivors, being employed and keeping a job are often regarded as an indication of complete recovery [1], a sign that the worst of their battles with cancer are over [2]. Others view work as a form of distraction and a means of adjusting to their new situation [3]. While medical treatment is central to bringing normalcy back to cancer survivors' lives, self-identity and social aspects of life are of equal significance in cancer survivorship. Studies estimate that 62–84 % of cancer patients return to work after treatment [4].

Several meta-analyses or systematic reviews have summarized major factors related to various work outcomes [5–7]. Many of these factors relate to perceptions of the affected



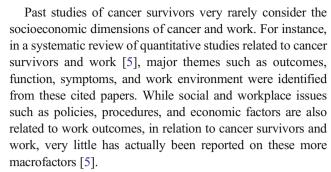
employee, emotional and behavioral reactions of coworkers and employers, as well as the underlying policies of the workplace and the society in general regarding the work environment's flexibility to accommodate the individual's needs. Cancer survivors may also experience persistent symptoms and illness behaviors (e.g., time off for doctor visits) that are not consistent with a high-achieving employee.

Unintended social consequences

A potentially useful way to conceptualize the basis for much of the friction that might occur between worker and workplace that can also influence the short- and long-term outcomes of work was proposed several decades ago by Giddens [8, 9]. First, the theory of unintended social consequences develops an interpretation of social life that highlights the double relationship between an *agency* (interaction or action) and its *structure* (rules and resources). To apply this to the workplace, the agency is identified as the two-way communication between a cancer survivor and his/her colleagues and/or superiors.

Second, Giddens explained that the "unanticipated consequences" related to social practices and policies that occur as a result of a certain course of action or "choice of agency" that an actor or agent had chosen but was not expected to occur. Unintended consequences usually occur as individuals attempt to create a structure in social settings in order to accomplish expected goals. Based on this description of social behavior, certain decisions, behaviors, and perceptions can lead to a result that the actors did not initially intend to create. These outcomes can be positive or negative, expected or unexpected [10], and can help describe how macro-sociopolitical factors can impact an individual's perception of self and the environment in which they operate.

Unintended consequences occur daily in various aspects of our lives; in family, in public places, and at work. In relation to cancer survivors and work, policies can influence the social context and work environment or climate, which could have a major impact on work outcomes [5–7]. Cancer survivors can also encounter unintended consequences performing everyday work tasks because of the physical and psychological challenges they may experience following primary treatment. This experience can be further complicated in a workplace situation where supervisors, co-workers, and cancer survivors all may be experiencing unforeseen negative or positive consequences of the return to work or efforts to sustain a work status. To date, prior literature has not addressed the complexity of unintended consequences as a result of workplace communication as cancer survivors return to or remain at work.



A systematic review of 25 qualitative studies [11] revealed that social factors at work and home can influence the individual's self-identity, family and financial context, and work environment. In particular, a good relationship with an employer/manager was a major influence on return to work [12]. Breast cancer survivors experienced diminished qualify of life and daily functioning associated with the presence of "chemobrain" [13] and reported experiencing unwanted changes in their jobs and job responsibilities, in addition to changes in their relationships with co-workers and employer [14].

Cancer and the social culture in Singapore

Culture also can be an important factor in determining the importance of work and workplace response to chronic illness and work [15]. Each ethnicity has its distinct interpretations and concepts of health, disease, and healing [16]. The way perceptions are formed about how individuals live with chronic health (physical and behavioral) problems are influenced by cultural values [17]. Research on illness and work in general and cancer and work in specific in Asian cultures, particularly given the rapid change in expectations related to work and productivity over the past decade, provides a unique opportunity to study return to work among cancer survivors living with a chronic illness.

Singapore, with its multicultural landscape, has an economy that highlights growth; yet most people continue to hold on to many traditional beliefs. Employees in such a business environment have been characterized with power distance, collectivism, long-term perspective, moderate masculinity, and low uncertainty avoidance [18]. Despite living in an international city, the Singaporeans, influenced largely by traditional Chinese and Malay cultures, still believe that everything happens for a reason and human beings cannot change those conditions. This attitude is characterized as "subjugation to nature" [19]. In a health care context, this value can help shape the ways cancer survivors view cancer and learn how to cope with it.

Along with a paternalistic government structure, the role of citizens in Singapore in policy making has been confined to very limited areas and the ability to affect change is minimal [20]. Patient groups in Singapore seldom go beyond public



awareness campaigns to directly lobbying the government for changes in laws or representing patients in legal action to support their personal interests [21]. Unlike North America and Europe, cancer patients in Singapore are not protected by employment policies or categorized with disabilities or chronic illness [22]. To date, only one Singapore study has been conducted related to work and cancer survivors [23] using a small public opinion survey. Results of the study found that although the majority of Singaporeans are comfortable working with a cancer survivor, many would not consider employing one. Misconception of cancer is one of the reasons for such attitudes, which hampers survivors' transition to normalcy in the society.

This study focuses on the return to work experiences of those posttreatment for cancer and interested in remaining employed. Using the context of a society driven by economic development in Asia Pacific, an emerging major sense of urgency for economic growth, a strong cultural history of acceptance, and anecdotal reports of the challenges faced by cancer survivors attempting to return to or remain at work. The present paper explored the employment issues and challenges experienced by cancer survivors in this country. The paper also describes a systematic qualitative analysis of the identification of unanticipated consequences as cancer survivors responded to work related challenges within this cultural context.

Method

Given that "unintended social consequences" are occurrences are difficult to observe empirically as cancer survivors may have faced them but were not fully aware of them at the time, a qualitative approach was selected in the present study to allow participants to reflect on their experiences and think carefully and retrospectively about the results of their purposive actions. Five focus group meetings were conducted. This qualitative method encourages an open discussion on the issue of life after cancer in a group setting. A focus group approach also allows human interactions and reflections to be taken into account as participants who share similar experiences converse with one another [24]. People often listen to other people's opinions and stories to reflect and then form their own answers [24, 25], which allows them to be mindful of unanticipated concerns that they may have not been fully realized when first encountering those situations.

Recruitment

Ethical approval for this study was granted by the SingHealth Institutional Review Board. Talking about cancer publicly is considered a taboo in some Asian societies mainly because of the social stigma and passing on "bad luck" [26, 27]. This created a challenge for the researchers to recruit cancer

survivors to share their experiences in the study. An email invitation was circulated among the cancer support group emailing lists at a national cancer center which was followed by participation in the focus group activity.

Participants

Five focus groups and 33 participants were recruited. Each group consisted of 4 to 11 participants subject to the time availability of the individuals during the Chinese New Year period. Singaporeans with a "good" or "fluent" command of English were included. All participants had reported paid employment prior to diagnosis. The majority of the participants returned to work after treatment while the remainder were looking for jobs (N=4). In terms of ethnicity, 27 of them are Chinese, 5 are Malays, and 1 is Filipino. Table 1 summarizes demographic and work-related characteristics.

Focus groups

The participants were first asked about their personal views on the meaning of a job as cancer survivors and how much they enjoyed their job. This served as an ice-breaker. Then, participants were asked questions specifically on employment matters (e.g., challenges they face at work, employment guidelines, role of the immediate supervisor, and colleagues in terms of behavioral or attitudinal changes) and shared their personal stories related to relationships with employers, immediate supervisors, and co-workers. For example, some questions asked were as follows: "How did you view your current employer handle your situation?", "What are some of the behavioral changes or changes in attitude toward you that you noticed at the workplace?", and "How did you feel about yourself at work?" Participants were also asked how they were treated after returning to work by fellow colleagues who found out about their cancer diagnosis. This helped capture the unintended consequences through the reported behaviors and attitudes toward the survivors.

Data analysis

The recorded focus group discussions were transcribed verbatim and analysis was conducted by categorizing the data into recurrent themes [24]. Using the thematic content analysis process described by Green and Thorogood [28], we identified themes that emerged from the data after an initial reading of the transcripts. A two-staged analytical process first established the work-related challenges faced by survivors as a result of their acquired self-identity as a cancer survivor and the organizational culture. In the second stage of analysis, the cancer survivors' experiences of unintended consequences emerged as a result of their purposive responses to the work-related issues and challenges.



Table 1 Descriptive data of focus group participants (N=33)

Characteristics	Percent	n
Gender		
Male	24	8
Female	76	25
Time since diagnosis at	interview (y	ear)
Below 2	10	3
2–4	55	18
5–7	24	8
>10	11	4
Age		
30–39	11	4
40–49	33	11
50-59	52	17
60–69	4	1
Ethnicity		
Chinese	81	27
Malay	15	5
Filipino	4	1
Marital status		
Single	21	7
Married	68	22
Divorced	11	4
Education		
High school	55	18
Some college	15	5
College graduate	21	7
Postgraduate	9	3
Job status		
Full-time	70	23
Part-time/freelance	19	6
Looking for job	11	4
Job role		
Service work	10	3
Administration	30	10
Professional	39	13
Managerial	21	7

Following this two-staged analytical process, an open coding process whereby a line-by-line microanalysis of the data was conducted to extract new information within the text. The themes that emerged from this procedure were then meaningfully organized by grouping similar ideas. Eight overarching themes emerged that reflect the participants' choice of *actions* (or agencies) toward the RTW issues, including their coping methods and unintended consequences, were reported in relation to the perceived work environment. Additionally, eight themes emerged from the policies, procedures, and socioeconomic factors in the social context that shape the unintended consequences structure cancer survivors can experience as they return to work.



Results

All participants expressed a desire to live "normally," or to come across as "normal." Normal in this context was consistently defined as having the ability to fulfill one's life desires through one's own merits. Survivors struggled with changes in their physical appearances and body image and nearly all of them reported some type of limitation, whether physical or emotional. However, emotional limitations affected them more severely than physical limitations, as they were mostly regarded as physically fit for work and general activities. Eight emerging themes of cancer survivors' choice of agencies (or actions) toward work-related issues were identified as illustrated in Table 2. These themes were broadly categorized as "cancer survivors' ways to cope with work-related issues" and "unintended consequences" related to the work experience.

Choice of action: unintended consequences among cancer survivors at work

Adopting accepting attitude

Throughout the focus groups, some participants showed that they have not only accepted whatever has been given to them, but were resigned to their cancer fate. When asked about her expectations, one participant said, "Oh, nothing to expect. I am a cancer patient, you know, so they already know, they just take me as what I am." This participant, as well as many others, indicated that she just felt grateful that she still had her job. Such an attitude, be it a grateful or fatalistic response, enables some cancer survivors to live their lives contently, without having major reports of unmet needs, self-expectations, or expectations from others. This view of self-identity while leading to an accepting attitude may also inhibit the cancer survivor from becoming proactive in creating positive changes for their own lives.

Try (la), send (la). You reply okay (la), good luck, no reply also never mind (la). Think of a way to survive yourself. (P6)

I would think that I can't really see the future, you know, go for whatever that is for me. But I don't think the so-called future is as bright as what I see in the past. (P7)

Unintended consequence: holding grateful attitude toward employer to retain one's job

The negative perception toward their illness in relation to their own employability leads to the cancer survivors feeling easily satisfied with their current job situation. The cancer survivor could have originally been hired based on their ability,

Table 2 "Choices of Actions": unintended consequences among cancer survivors at work

Cancer survivors' ways to cope with work-related issues

Cancel survivors ways to cope with work-related issue

(1a) Adopting accepting attitude

I would think that I can't really see the future, you know, go for whatever that is for me. But I don't think the so-called future is as bright as what I see in the past.

(2a) Facing unjust treatment in employment

Suddenly my ex-boss was asking me to quit the company to become a freelance consultant—he was very firm—I sensed a sense of rejection. Suddenly I understood the word—rejection, and also associated it with 'isolation'. I must say that there is job discrimination.

(3a) Maintaining a job to retain one's ego and power

What about those people who need the money and then they have to look at their son's face, their daughter's face, their wife's face, you know. I think this is cruel. Getting a job for people like me, is extremely important for survival, and also a level of dignity, to get back into the mainstream of life and to enjoy a little bit of the quality of life.

(4a) Working harder to meet expectations (personal and others)

This reminds me I have to prove that I can work so I even now I make my boss forget that I am a patient. I work harder than previous years. So he never questioned me about this in the past 2 years. You have to prove that you can work, and don't let your boss remember you are a patient.

Unintended consequences actions toward work-related issues

(1b) Holding grateful attitude toward employer to retain one's job

I'm just so grateful that, at least there's a place for me. You know what I mean, I don't have to resign and then go and find a new job.

(2b) Passive acceptance to perceived discrimination

When I stated my illness, the administrative officer replied, 'Oh you have (cancer), you are a cancer survivor? I think you can't take this job. It's quite tough for you.' I didn't say anything.

(3b) Downplaying illness to avoid being a burden to others

I feel that I'm the same as my colleagues; not like I have cancer, I don't think I should do less work. I should do my fair share when I'm working. We're paid to do the work, so why complain when colleagues complain about too much work.

(4b) Fear of losing out by compromising one's expectation

I asked for a transfer, then I was given an answer by my supervisor and I told myself: I've been working here for 11 years, if I need to go somewhere else, start all over again, as a new hire, I will have to go to a new environment, quite stressful. I have to start all over again and with my condition, I think it will make me feel very, very down again. So I told myself, oh well never mind, just stay put where I am, think positive and look positive. Just go day by day.

knowledge, and experience. However, because certain cancer survivors reported this resigned view of their own employability and chronic illness in general, many held on to the idea that they were lucky to be employed or retained. This attitude might be particularly destructive in a workplace where cancer survivors dare not speak up for themselves because of their over-appreciation for their employer or a devalued-self.

I'm just so grateful that, at least there's a place for me. You know what I mean, I don't have to resign and then go and find a new job. (P25)

(As I am a new employee), my employer is more than humane. In terms of compensation, perks and all that, because I was out of action and really I couldn't ask for more. So even when I would go back to work, I really have no expectations. (P28)

I don't think I have the courage to find another job. I thought of having a career switch in a university but I'm quite fortunate that I didn't get the job because there is so much benefit I can get from having my long service. (P18)

Facing unjust treatment in employment

Cancer survivors experienced different levels of workplace discrimination. They also defined discrimination differently. For example, those who were already distressed or unhappy with their jobs might also be more likely to notice and define experiences as discriminatory. We realized that some cancer survivors have trouble distinguishing certain acts that were discriminatory based on their medical history, or other external factors.

Suddenly this episode of my ex-boss asking me to quit the company to become a freelance consultant—it came to me very strongly—I sensed a sense of rejection. Suddenly I captured this word—rejection, and also associated it with 'isolation'. The same organization, they sent me away but they kept asking me to come back and work as a volunteer. (P21)

When you go for applying for a job, there is a form given two questions. One question is saying that—'Have you ever suffered any serious, major illness?' Second thing, 'Are you on long-term medication?' Because of these two questions, for us, the society gives us a very low chance to get a job. (P3)

(The prospective employers) won't tell you it's because of your medical, but because you don't speak Mandarin or because of your age. They never tell you it's because of your medical condition. (P11)



Unintended consequence: passive acceptance of perceived discrimination

Certain unfair acts from employers were experienced by some participants, and believed to have been a result of their health issues. Yet, similar to the previous theme, participants chose to hold back their frustration rather than responding to the perceived discriminating acts of their employers, simply to secure/maintain a job.

My boss said we cannot just plan the roster to suit my monthly medical appointments, we have got other team members. Both were equally important, but I wanted to keep the job much more. So I told them I would just take any shift that they give me and told my doctor that I couldn't make it and just postponed the appointment. There will be times in a particular month that I cannot go and see my doctor. (P2)

When they rush me, I get confused (feel like I'm lost). I think it's the emotional part of me. I have to adjust my momentum to calm down and take it easy, just have to be very calm. (P22)

When I stated my illness, the administrative officer replied, 'Oh you have (cancer), you are a cancer survivor? I think you can't take this job. It's quite tough for you.' I didn't say anything. (P31)

Maintaining a job to retain one's ego and power

Being able to cope with cancer and accept it as a part of life was a sentiment shared by many survivors. Cancer survivors continued with their current job, chose to change, or were forced to change their jobs. Most cancer survivors also chose to work to reinforce in others and themselves their strength, competency, and independence.

When you have a job, you will feel like you are recognized, that you are contributing to the department, to the work and all that you are doing. (P14)

I am very grateful that I can still work, because during the treatment for the 11 months, I have always wanted to go back to work. It was a very hopeful feeling. Now (that I am employed) I feel that I still have this ability—and it is something to be grateful about. (P22) It's like challenging myself. I want to prove that I can still lead a life like a normal person after cancer. So I went all out and cancer journey actually drains us off financially. (P2)

According to some participants, they expressed low perceived job security because of the loss of self-confidence after cancer. Yet, they struggled to maintain their independence and dignity, by not relying on other people's assistance and sacrificing benefits or status from their job. In addition, financial necessity can push survivors back to work before they feel ready [29].

Although nobody gave me pressure to step down, I took the decision myself because I no longer have the confidence to really do that level of job. (P26)

Work is like independence; I'm able to pay for my own medical bills, etc. (P13)

What about those people who need the money and then they have to look at their son's face, their daughter's face, their wife's face, you know. I think this is cruel. Getting a job for people like me is extremely important for survival, and also a level of dignity, to get back into the mainstream of life and to enjoy a little bit of the quality of life. (P5)

Unintended consequence: downplaying illness to avoid being a burden to others

Cancer survivors felt that they should not be a burden to their loved ones or co-workers. Asian culture emphasizes collective society [30], and most cancer survivors do not like to cause problems for their employers and loved ones, as a form of prioritizing collective goals over individual ones. One participant talked about how she always tried to appear healthy around her relatives and co-workers and did not want them to make a big deal of her illness. As such, they accepted whatever was given to them and did not demand more as it is seen as selfish in this collective society. In an Asian workplace context, this attitude and self-presentation of cancer survivors resonates with the collectivistic culture.

It's just the self-imposed challenges as in, when I told the number one man, my decision not to tell anybody because I don't have to tell anybody. There is no need to have the pre-conceived idea that people would have a different view of 'you as a cancer patient.' (P10)

I feel that I'm the same as my colleagues; not like I have cancer, I don't think I should do less work. I should do my fair share when I'm working. We're paid to do the work, so why complain when colleagues complain about too much work? (P14)

So I try not to be too imposing in case I react this way and I think others should be more understanding toward me. Why make life difficult for others just because I have an illness? (P33)

Working harder to meet expectations (personal and others)

Many cancer survivors worked harder to prove that they were completely cured and feel that they should strive to be on par



with their colleagues' ability so as not to be looked down by others. Thus, they put in more effort to prove that they have achieved normalcy, so as to be accepted in the workplace environment.

This reminds me I have to prove that I can work so I even now I make my boss forgotten that I am a patient. I work harder than previous years. So he never questioned me for this past 2 years. You have to prove that you can work, and don't let your boss remember you are a patient. (P24) I also do my best, whatever I can complete I will try to complete, within the day if not I will carry it on the next day. (P23)

My colleagues see me as a role model. For them, they feel like they are in a healthy stage, they should be better than me or at least in the same par. (P29)

Unintended consequence: fear of losing out by compromising one's expectation

When we asked the survivors about their expectations at the workplace, all of them told us that they had no expectations at all. When we asked them to elaborate, they explained that they have no expectations of their employers and their employment because of their illness (i.e., no bargaining power). However, this self-presentation of working harder to prove themselves contradicted with what they had said. Their responses indicated that they did have high expectations such as being treated normally and fairly—this may lead to compromised expectations of cancer survivors themselves. Their genuine expectations for employment are compromised and/or concealed probably as a form of self-consolation. A survivor painted us a scenario, "You see if you have ten applicants, if one has a medical problem, with nine healthy ones, for sure you will choose the nine healthy ones. You would not choose the tenth one (cancer survivor)."

This is the reality of the system, it's the norm. Once we are stricken with an illness like that.... we lost bargaining power. That's why I say, no expectations because I mean we also have to be realistic. (P25)

I asked for a transfer, then I was given an answer by my supervisor so I told myself: I've been working here for 11 years, if I need to go somewhere else, start all over again, as a normal person you go to a new environment, quite stressful. I have to start all over again and with my condition, I think it will be very, very down and depressed again. So I told myself, never mind, stay put as what I am, think positive and look positive. Just go day by day. (P12)

At the back of my mind, I need to space out and go slower, in my work. So I think in some ways (cancer) has affected the way I approach and handle work. (P20)

Structures: unintended consequences related to policies, procedure, and socioeconomic factors

Aside from the choices of actions, the following structural themes (i.e., work environment, policies, and social context) also contribute to the unintended consequences (Table 3).

Workplace support boosts/lowers self-identity at work

Although most cancer survivors tended to seek social support from family and friends, some confided in their colleagues about their illness. A supportive and encouraging work environment will affect a survivor's attitude toward work. One participant recounted the encouragement from her colleagues that made her go for a checkup for the pain in her right nipple. "And before I knew it, within 18 days, I was on the surgical table and had a mastectomy."

My bosses were very good, they actually allowed me to be away for 7 months. They recruited another colleague. Before I had cancer, I was doing the job alone. Now it's shared between the two of us. (P7)

I was away for over 1 year, it's like I don't know what to expect (when I return to work). One of my ex-staff, said, 'I'll be there to welcome you.' And then another colleague also came down and that meant a lot to me. (P18)

Similarly, discouraging and patronizing communication at the workplace might lower the esteem of a cancer survivor. One participant felt that her employer was not as understanding toward her illness, even after she shared her cancer experience with her boss. She felt that she was being pressured so that she would quit her job instead.

My colleague said, 'You're very lucky. We still keep you.' I have prolonged illness more than 1 year. She continued to say that if I left, I would have to resign then with my medical condition, no company would take me. (P12) My boss explained to me all my work that I can't manage were passed on to other colleagues, they were not happy having to do work on top of their own work. (P13)

I'm the type who likes to go out and help people. This instrument was spoiled so I carried and do something about it. My boss replied, 'you better not carry it, anything happens I won't answer for you.' (P19)

Only slight (positive) changes like some of my colleagues are compassionate, but some I could sense that they prefer to stay away from me—I don't know why. Maybe they're superstitious (bad luck). I can really feel it—they treat you differently before and after cancer. (P23)



Table 3 Unintended consequences related to policies, procedure, and socioeconomic factors

Policies, procedures, and socioeconomic factors

(1a) Workplace support boosts/lowers self-identity at work My colleague said, 'You're very lucky We still keep you.' I have prolonged illness more than 1 year. She continued to say that if I left, I would have to resign and with my medical condition, no company would take me.

(2a) Not involved in decision making on task modification or accommodation

I could not go back to my previous job because somebody was working there already. There were many, many things to do (in the news department) as I need to manage new staff.

(3a) Lack of written policies and clear guidelines

Somehow everybody knows about it but it's not implicitly written somewhere.

(4a) High values on competitiveness and economic achievement

Working in Singapore is not only to pass time, which is noble. But I think it's more like compulsory because the cost of living is so high.

Unintended consequences

(1b) Over concern viewed as negative workplace support

My boss was very protective so he said nobody is supposed to contact me. On the other hand, there were people from other departments who arranged to come visit but I was too tired already. It's very hard to tell them not to come but I know it's something I'm not ready for.

(2b) No major workplace changes even when help is needed

Through this experience, I realized the most important thing of all, regardless of policy, is your boss. When he faced some pressure, he actually stood up for me and went to see the CEO so I was also wondering if he had not spoken up for me, would my role have been removed from me which if it had happened, it would have been very devastating for me

(3b) Immediate supervisor as gatekeeper

Through this experience, I realized the most important thing of all, regardless of policy, is your boss. When he faced some pressure, he actually stood up for me and went to see the CEO so I was also wondering if he had not spoken up for me, would my role have been removed from me which if it had happened, it would have been very devastating for me

(4b) Cancer survivors as less competitive workforce

What I'm trying to emphasize is not so much how you write to convince them. Even they see you, talk to you, like you, they want you but the moment you say cancer, everything is gone. So the word cancer really cancels you off.

Employers who have experience with cancer survivors at work and/or have personal experience with cancer tend to provide more positive support.

I'm very grateful because of my superiors and colleagues are very understanding because I'm not the only one who has cancer in my department. My other colleague was diagnosed 1 year before me. So my firm is very caring, so especially for me, my boss really fought for me a lot—insurance, medical, leave, etc. I really appreciate what she has done. (P22)

My boss was very supportive. In fact he gave me a lot of compassion. One is that he is very kind, two is that his mother-in-law has cancer. I was out of work for a few months and go back in 2011. (P18)

Unintended consequence: over concern viewed as negative workplace support

Providing social support is natural when working with someone with critical illnesses [31]. These supports are usually provided as emotional coping and/or accommodations for work challenges. However, an overly sympathetic approach at the workplace might also result in a negative emotion for the survivor. Some survivors expressed sadness, disappointment, irritation, and even distress about the comments or actions their supervisors and co-workers showed to them.

My boss was very protective so he said nobody is supposed to contact me. On the other hand, there were people from other departments who arranged to come visit but I was too tired already. It's very hard to tell them not to come but I know it's something I'm not ready for. (P18) Not to always remind me, 'You're sick you know? Can you do this?' (P31)

My boss constantly asked me, 'Can you manage this? Are you okay with that? Should I take away part of your work?' I know he meant well but don't remind me that I am incapable! (P26)

Not involved in decision making on task modification or accommodation

To cope with the changes cancer employees bring to the workplace, some employers take it on themselves to modify tasks assigned to cancer survivors. In only a few cases, the survivors themselves requested to have their workload adjusted to suit their current needs. For example, one participant



reiterated, "My boss trusted me. I interviewed the person who takes over my job. The moment I told my boss I was diagnosed with cancer, I stopped attending the department head meetings." In some extreme cases, few participants skipped the doctor appointments to accommodate work schedules. Many survivors, however, do not have the luxury of doing so and end up changing job duties involuntarily.

I've come to a stage where I feel that once I take my bonus, I will quit my job. My boss kind of sensed it and he told me, 'Hey don't do anything okay? We're making some plans for you.' By the beginning of this year, he told me he will transfer me to a much smaller branch—lower volume and pace—more ideal for me, which I was very thankful for. (P20)

My doctor indicated that I should have a light duty job. I wasn't put under normal work until 1 year. (P12)

My boss asked me if I want to go back to work in customer service. I said no. She asked me why and I replied, 'because I have hearing problem (from cancer treatment), I will have problem listening to my guest. I'll have problem answering the phone, let alone talking to my colleagues.' I told her I would rather she give me a job that I can work behind the scene. (P2)

I could not go back to my previous job because somebody was working there already. There are many, many things to do (in the new department) as I need to manage new staff. (P26)

Unintended consequence: no major workplace changes even when help is needed

Some cancer survivors discussed their work adjustment and accommodation with their supervisors after cancer diagnosis. However, in most cases, there are no significant changes in the scope and pace of work when they return to work after completing the treatment. Cancer survivors in fact face some limitations carrying out their usual duties, even though many of them do not have any changes in physical appearance.

So there was one time I went back to my old office to teach my successor because he was taking over for me. And that time I lost my hair so, I had to wear a scarf, my old boss was very sympathetic and very caring. Now I'm with the new boss who has not seen me during my treatment. I look normal right? Nobody can tell. And they just expected me to be just like any normal person and carry on. Unfortunately, my work was not regulated. (P25) That's what my present boss tells me, you don't look sick. You can come back and work, you're like a normal

person. If I don't give you work, people will question why don't you get work? Why I'm normal but I don't do work. She cannot give my job to other people. (P14)

When I went back, I was being placed back in the old position. In a way, there were some people who will tell you to go slow, but they still give you the same pace of work. (P20)

Even though my boss has been nice and keep asking me whether I can cope and all that, I think it is a little bit of lip service because I get the same amount of work, everything remains the same. (P26)

Lack of written policies and clear guidelines

Having unwritten policies in job accommodation and adjustment is a common practice among Singapore business organizations. These policies are usually flexible, can be changed often, and have no clear guidelines as to who exactly can make these requests because they are not official. Despite this, cancer survivors who have the opportunity to take advantage of these policies might still feel reluctant to take up this benefit and request these work adjustments. This is because, since these policies have not been explicitly stated and communicated, they are unsure if they have the right and/or how to make such requests.

My company has an unwritten policy that allows employees to request for lighter duties, opt to work part time or freelance on projects, especially if you have reason to do so, like illness. (P24)

Somehow everybody knows about it but it's not implicitly written somewhere. (P11)

If something is clearly spelled out, like a policy or handbook, we just need to refer. But it is not a common thing to happen in the office, you may not cover this area. (P20)

Unintended consequence: immediate supervisor as gatekeeper

An unwritten policy allows employees to ask for a regulated workload and, on a case-by-case basis, to be granted a reduced workload with or without less pay. However, there is no proper channel for cancer survivors to make such a request, or guidelines to educate them on how to talk about cancer at work. Hence, the immediate boss becomes a critical point for allowing and preparing the adjustment or accommodation. This idea was brought up throughout all focus group sessions.

As a company policy there isn't anything that engrained in gold. But because of personal relationship between me and my immediate supervisor, who could exert some influence over HR or the bigger managers and so on. So they could have special treatment for me. Because we work together well enough and I have a situation, my boss can allow me to work at home. (P10)

Through this experience, I realized the most important thing of all, regardless of policy, is your boss. When he faced some pressure, he actually stood up for me and went to see the CEO so I was also wondering if he had not spoken up for me, would my role have been removed from me which if it had happened, it would have been very devastating for me. (P18)

My boss fought for me, half a month's salary adjustment, etc. Basically, each company in our industry has its own employment guidelines. We don't strictly follow the government's guidelines. (P22)

High values on competitiveness and economic achievement

Aside from workplace environment, the economic and social culture factors also play an important role in cancer survivors' return-to-work situations. In particular, a country system forms the values and perceptions of human capital and bottom-line practices in terms of the employability issues toward cancer survivors.

Working in Singapore is not only to pass time, which is noble. But I think it's almost like compulsory because the cost of living is so high. (P5)

I feel that holding a job, in Singapore context, is more of finances. Even the air is not free! (P20)

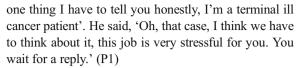
If you're a cancer survivor, the boss will tend to think that you will take MC, take time off, they also don't know if you can do the work. Whether you can take the job, they will worry if you can complete what a normal person can do. (P14)

I realize in our society, (employers) can't accept regardless you are cancer survivors or other chronic illness, as long as the age is about 50, no chance. This society is good for age of 20 to 50. (P8)

Unintended consequence: cancer survivors as less competitive workforce

Because of high values on competitiveness and economic achievement in Singapore, all participants shared their frustration and agreed that there is nothing they can change in the current system, unless the government steps up and regards this as a priority concern.

At the end of the job interview the guy asked, 'when you can start work and all this?' I replied, 'Immediate, but



What I'm trying to emphasize is not so much how you write to convince them. Even they see you, talk to you, like you, they want you but the moment you say cancer, everything is gone. So the word cancer really cancels you off. (P7)

This challenge is about identity... cancer is associated with the weak. In terms of health, it's a weaker group of people, and also, to some extent, may not perform at that level. (P21)

I'd like to know, ex-cancer patients or survivors like us, why aren't we given like special, the same support as exconvicts? The door is open for them to advertise that the company should take them in. Why can't they do it for us also? (P11)

Discussion

The emerging themes of work-related issues and unintended consequences experienced by cancer survivors in this study illustrate two broad areas that deserve attention in both research and practice. The first group of themes relates to attitudes and behavioral changes of cancer survivors toward work-related issues. This illustrates how cancer survivors chose to react to the challenges, or choices of agencies, as well as how their agencies perpetuate self-identities and attitudes that they unintentionally adopt or intend to develop. The second group of themes relates to structure (or external forces), including policies, politics, and economic factors, that highlights the pressures encountered by cancer survivors in this study. Changes in work-related attitudes and behaviors from cancer survivors can occur as a result of these structural barriers.

It is important to note that while the specific experiences of participants in this study were unique to Asian cultures, the emerging themes that captured their stories may be globally applicable. As the findings indicated, the ways cancer survivors in Singapore responded to their employment challenges were influenced by socioeconomic factors, workplace context, and social culture. At the same time, the identity as a "cancer survivor" forced these participants to unintentionally reinforce or focus on the challenges they faced in the workplace.

Low self-advocacy as a result of low self-identity and fatalistic cultural value

Patient advocacy in Singapore is at its infancy [21] and most Singaporeans are generally uneasy about fighting for their



rights because government takes the initiative to implement any change in society through laws and regulations. We have observed that the level of cancer survivors' advocacy or assertiveness regarding employment among those interested in work in Singapore is alarmingly low. Self-advocacy implies that survivors feel confident and empowered enough to communicate their cancer needs effectively and to take control of their cancer care needs [32]. The survivors tended to have no expectations at work—they were happy to be able to keep a job, or to be hired despite their medical history. Being realistic about their situations, even if they are unpleasant, survivors found such thoughts comforting in that they felt empowered in a powerless situation [33]. This way of handling stress in one's life is both consistent with traditional Eastern culture and approaches used to manage reactions to stress in the West through for example mindfulness meditation [34]. These various options for adaptation in the workplace need to be seriously considered as they appear to be at opposite ends of the coping spectrum [35, 36].

The survivors unanimously agreed that in reality, employers are less likely to choose a job applicant with cancer compared with another who is healthy. Given this expectation, these cancer survivors feel more fortunate than others because they are able to secure a job despite a cancer history; consequently, they feel that to ask for anything more would seem to be ungrateful. This passive acceptance confirms that traditional Singaporean culture maintains the subjugation-to-nature view and employers not to actively work toward changing the constraints forced on them [20]. This approach may not be adaptive given the current focus on economic growth.

Vulnerability as a result of unwritten policies and unclear guidelines

The structure (or work environment) in the study context also contributes to unintended behavior from the employers toward cancer survivors. In Singapore, the lack of transparency or systematic criteria for the decision making process in dealing with employees with cancer experience resulted in employers treating employees' health conditions and job performances on a case-by-case basis, or a "one-size-fits-all" approach with the same level of support across all types of illnesses.

Employers may find that the unwritten policies allow them to deal with all specific cases of employees' sickness with greater flexibility. Yet, as our study demonstrates, the unintended ambiguity in unwritten policies, coupled with the resigned social values and high emphasis on economic growth and competitiveness in the society, leads to the sense of vulnerability among Singaporean cancer survivors in a helpless situation. First, they may struggle with the idea that while they are considered "sick," they have to work hard (if not harder) to prove themselves at work, as discussed earlier. Second, they feel reluctant to ask their employers to make

adjustments in their workload because they want to be treated equally due to the fear of losing out. In addition, asking for help is considered troubling others in an Asian context; hence the Singaporean cancer survivors probably would not seek help until their employers take the initiative.

Compromised expectations stemming from workplace relationships and power struggle

A strong desire to appear normal at work through maintaining a job to retain one's position in life and retain a source of income can also result in a higher level of compromise by the cancer survivors. All participants expressed wanting to be accepted by their colleagues and to be treated normally, and it might reach a point where they would prioritize this image of normalcy over asking for help, even if they need it. Some survivors noted that work could be stressful when it was not regulated, but they compromised and tolerated the stress to maintain a strong front. Perhaps some cancer survivors are, in fact, discriminating against themselves in using this coping strategy.

Practical implications

Unmet psychosocial needs related to work and employment issues constitute a common and widespread concern among cancer survivors. Therefore, organizing employment-related support groups and counseling provided by specialists such as vocational counselors, occupational therapists, and physiatrists are highly recommended in many developed countries [37]. The findings in this paper imply that these bottom-up tactics may be somewhat effective in Western societies with certain policies and procedures in place for work disability and chronic illness but not in countries with the absence of such policies and low self-advocacy, such as in Singapore. Top-down approaches at governmental and work organization levels to provide the policy infrastructure to support cancer survivors' employment seem to be particularly warranted in such a situation as observed in the present study.

In addition, the strong fatalistic culture of Singaporeans is difficult to change but may not be adaptive in an everchanging society. Cancer organizations should partner with government agencies for policy change and initiative development so that cancer survivors could be empowered to take control of their lives. In the past, Singapore has launched successful nationwide campaigns to champion ex-offenders, HIV patients, and people with mental illness to reintegrate into society. The newly setup government agency, Tripartite Alliance for Fair Employment Practices, can proactively help facilitate discussions among employers, trade unions, and the government specifically toward work-specific issues for cancer survivors in Singapore.



Limitations and future directions

The small number of participants willing to take part in this study at the initial stage raises an important point and reiterates our findings. Cancer still remains a topic that many survivors do not wish to broach even after their treatment. Coupled with the fact that this study discusses their life at work, many did not wish to be implicated by their participation despite the anonymity assured, fearing that talking about their employers and jobs would affect their source of income.

While the findings are not generalizable to all types and stages of cancer and to many other cultures, this is the first study in Southeast Asia examining return to work issues from the survivors' perspectives. The respondents were largely from higher socioeconomic backgrounds and white collar occupations. Replication of this study is required with more diverse samples of cancer survivors, in a number of occupations such as cab drivers, hawkers, and technicians who form a significant number of cancer survivors in Singapore [38].

Future research should explore other types of USCs in different organizational structures, occupations, and countries. Although policies exist in many countries, the actual use of such policies may vary by organization and therefore be related to many of the unintended consequences reported in this study. Research comparing how cancer survivors from various cultures experience and deal with employment concerns along with the implications of various types of USCs may provide useful information for policy makers, employers, and cancer survivors. If future research indicates that the USC concept provides unique information related to work outcomes in cancer survivors, it should be investigated as an addition to existing work disability prevention efforts at both policy and individual levels.

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