ORIGINAL ARTICLE



Negative and positive life changes following treatment completion: Chinese breast cancer survivors' perspectives

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Abstract

Purpose Although we acknowledge the negative and positive aspects of the cancer survivorship experience, we have little information on this issue from the perspective of Chinese breast cancer survivors. This study aimed to explore the perceptions of negative and positive life changes following treatment completion among this population.

Methods Using purposive sampling, 29 breast cancer survivors were selected from the attendees of a local cancer selfhelp organization in middle China and proceeded with semistructured in-depth interviews. Each interview was transcribed verbatim and analyzed using directed content analysis.

Results Two predetermined categories were identified to represent participant perception of the breast cancer survivorship experience, namely, negative life changes and positive life changes. The first category included fear of recurrence, symptom experience, poor body image, altered sexuality and intimacy, and financial burden. The second category consisted of new life perspective, personal growth, and enhanced relationships with family.

Conclusions Our findings contribute to the emerging evidence on the duality of breast cancer survivorship. This enhanced understanding of the specific negative and positive changes experienced by Chinese breast cancer survivors can

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assist health professionals in addressing survivorship issues by designing appropriate interventions to minimize negative consequences and enhance positive growth.

Keywords Breast cancer · Survivorship · Chinese · Qualitative research

Introduction

The increase in long-term survival for cancer has substantially boosted the interest in post-treatment survivorship. The definition of cancer survivorship has been extended from the diagnosis to the balance of life but now considerably emphasizes the post-treatment phase [1]. This phase is marked by the fact that cancer survivors experience a spectrum of late and long-lasting life changes subsequent to the illness and its treatment, with tremendous impact on the quality of life [2, 3]. The profound influence of cancer perception on life changes is a prominent focus area in survivorship research [4].

Cancer survivorship is a dynamic process of living with the negative and positive changes that the illness brings [5, 6]. This is mainly from studies in which the two opposite life changes are examined separately rather than concurrently and predominantly from standardized measures rather than survivor narratives [7, 8]. However, there is a small but growing body of literature that seeks to simultaneously examine cancer survivors' experience of negative and positive life changes due to the illness [9–13]. These studies have found that cancer survivors, similar to those following other traumatic life events, report having negative experiences that focus on illness-related fears, body image concerns, and financial problems, whereas positive experiences involve enhanced interpersonal relationships, positive life outlook, and increased health behaviors [9–11]. Nevertheless, such findings are debatable

because standardized measures may fail to tap into the salient aspects of life changes that are important for individuals [14]. For example, cancer survivors report body image problems that are socio-culturally relevant [15].

Although various theoretical accounts and qualitative narratives have attempted to explain both negative and positive life changes in cancer patients, the social-cognitive transition model of adjustment remains the most promising one [5, 16]. This model posits that the two aspects of life changes experience result from a dynamic process of adjustment to cancer by continuously revising one's assumption and expectation of the world. According to this model, the assumptive world reflects the socio-cultural context of individual experience. However, research on this area of survivorship is principally derived from western countries [17]. Little is known about the life change experience of those from the other socio-cultural backgrounds.

Research in the cancer survivorship is rare in China where cancer survival is historically poor. Rapid economic development and the improvement of treatment modalities have remarkably increased survival for some cancer types [18]. For example, the 5-year survival rate for breast cancer in Tianjin, China, was 82 % from 1991 to 1999 [19]. Despite this, China's cancer control efforts remain to focus on the treatment phase; little attention is given to survivorship. Furthermore, Chinese cultural philosophies (i.e., Confucianism, Taoism, and Buddhism) largely shape the individual perception of health and illness, which are fundamentally different from Western cultural foundations. For example, in understanding positive life changes following a traumatic event in Chinese culture, studies have often provided culturally linked explanations that life is viewed as a journey naturally fraught with suffering and impermanence and that acceptance of the transient and impermanent nature of life can induce positive changes [20]. These socio-cultural factors are key considerations in exploring the perception of life changes among Chinese population. However, little published work is available on Chinese perspectives and survivorship experiences. Therefore, this study aimed to explore the perceptions of negative and positive life changes following treatment completion among Chinese breast cancer survivors.

Methods

Design and participants

The research was a sequential explanatory mixed-method study that explored the breast cancer survivorship experience in Chinese women. The study consisted of two phases, namely, cross-sectional survey (phase I) and in-depth qualitative interviews (phase II). The purpose of phase I was to examine QOL and its associated factors in Chinese breast cancer survivors, and the phase II aimed to explore their survivorship experience. According to the classical typology, there are five common theoretical purposes for employing mixed-method design, including triangulation, complementarity, development, initiation, and expansion [21]. For this study, the primary purpose was development, which sought to use the results from one method to help develop or inform the other method. Specifically, key results of phase I were used for purposive sampling and for developing the semi-structured interview schedule for phase II. As clinical experience (and literature) has suggested that survivorship experience involves negative and positive life changes, the current study was drawn from phase II study with the aim of exploring the perceptions of negative and positive life changes following treatment completion among Chinese breast cancer survivors. The other findings relating to fatalistic voluntarism and social support derived from both quantitative and qualitative phases of the study have been reported elsewhere [22, 23].

The research was conducted in a local cancer self-help organization in Jiangxi province of China. This self-financed organization was led by cancer survivors, which aimed to establish a platform for mutual support and information exchange among peer survivors. Participants were either referred by the local hospitals or joined on a voluntary basis. The organization has its own website, which provides relevant information on cancer rehabilitation, as well as a free-access meeting place for gatherings. Various kinds of activities, such as educational talk and medical consultation, are also provided on an irregular basis. Participants were selected from 100 women who completed phase I, and they were those aged >18 years, at the first diagnosis of breast cancer, completed breast surgery and adjuvant chemotherapy and/or radiotherapy, and are fluent in Mandarin. The selection criteria of purposive sampling for phase II were based on the regression analysis results of phase I, which allows those with different characteristics to share their diversified survivorship experiences. Specifically, those who had high or low level of quality of life, annual household income, as well as different time since completion of treatment were specified for inclusion in phase II. Data saturation was achieved at 29th participant when no new category and subcategories emerged.

Procedures

Ethical approval was obtained from the Survey and Behavioral Ethics Committee of the university. Consent to conduct the study was also given by the cancer self-help organization. Prior to the interviews, the first author (CH) contacted each participant to confirm the interview date, brief them on the study, and obtain written consent. A semistructured interview schedule was used to guide the interview process and facilitate consistency and subsequent data analysis. The interview schedule was developed based on a literature review and the quantitative results of phase I. During the interview process, participants were encouraged to freely share their life changes experiences following treatment completion. The major question, which was relevant to the focus of this study, was asked: "To what extent do you feel that your life has changed as a result of breast cancer and its treatment?" Subsequent questions explored specific life changes, for example, "Can you identify any changes in your family situation since you recovered from breast cancer?" Probing questions were used when appropriate. The interviews were conducted in Mandarin, which lasted 50 min on average. Each interview was audio-recorded with participant permission.

Data analysis

Qualitative content analysis was employed to analyze interview data. Among three content analysis methods, a directed approach was chosen as it is particularly suitable for validating or extending existing knowledge about a phenomenon [24]. This analytical method usually starts coding with a theory or relevant knowledge. For this study, two major categories of "negative life changes" and "positive life changes" were predetermined in accordance with the clinical experience (and literature) and the aim of this study [24]. The interview data was transcribed verbatim and analyzed under the abovementioned categories. We commenced coding with data immersion by repeatedly reading the transcripts and systematically examining the meaningful units relevant to the focus of study. By comparing and contrasting the data, we grouped and coded the recurring information in the transcripts using the words of participants as much as possible. These codes were further sorted into subcategories based on their relation to each other. Finally, depending on the interrelationships between subcategories, we grouped them under predetermined categories.

Rigor

The issues of rigor in qualitative research remain a controversial topic and varied perspectives over its quality evaluation criteria exist. Some researchers insist that a rigorous qualitative work must satisfy a unique set of criteria particular to the naturalistic paradigm such as trustworthiness and its four aspects, namely, credibility, transferability, dependability, and confirmability [25]. However, other researchers accept the traditional terms of validity and reliability as the pertinent constructs that can be applied to evaluate the quality of any study [26, 27]. Considering the nature of the present mixed-method study, we adopted validity and reliability as the evaluation criteria for both the quantitative and qualitative phases of the study to ensure the consistency and rigor [23]. Furthermore, we also agreed with Morse et al.'s ideas in qualitative research [28] that validity and reliability should not be tested at the end of the study because potential threats to the quality of the study are inherent in the entire process, including study design and data collection and analysis. Following the work of Morse et al. [28], we conducted several verification strategies to attain the rigor of the study. To address the issues of validity, we initially established methodological coherence by ensuring that each component matches the research objective and also is consistent with its methodological assumptions. Secondly, we maintained the principle of appropriate sampling by ensuring that the 29 participants purposively selected from phase I were appropriate and adequate for providing in-depth understanding of the research topic. Thirdly, a mutual interactive process of concurrently collecting and comparing data was also viewed as a method for verifying the validity of the study. On the other hand, reliability was primarily demonstrated using a single researcher and the same interview schedule to increase the consistency of data collection.

Findings

Participant characteristics

Of the 29 participants, 25 were married. The mean age was 53.9 years, ranging from 41 to 69 years. Majority of the participants had an annual household income of less than 30,000 RMB (US\$4822), had secondary education, and were not working at the time of interview. The length of survivorship since diagnosis ranged from 6 to 180 months. All participants underwent mastectomy and chemotherapy, 27.6 % underwent radiotherapy, and 69 % had on-going/completed hormonal therapy.

Major categories

Two major categories emerged to represent the experiences of breast cancer survivorship among participants: 1) negative life changes and 2) positive life changes. The first category included a) fear of recurrence, b) symptom experience, c) poor body image, d) altered sexuality and intimacy, and e) financial burden. The second category consisted of a) new life perspectives, b) personal growth, and c) enhanced relationships with family.

Category 1): Negative life changes

Subcategory a): Fear of recurrence

Fear of cancer returning was voiced by almost all the participants when responding to the possibility of

recurrence. They mentioned that recurrence was seen as hopeless and often accompanied by devastating physical and social consequences, for example, painful cancer treatment process and heavy economic stress. These problems were commented by participants as difficult to endure. Such an overwhelming feeling was captured by the following statement:

"I am scared most of recurrence. Once cancer recurs, I would lose all hope. I cannot imagine going through it again. If it does happen, would I really want to keep on living?" (54 years old, 45 months since completion of cancer treatment).¹

However, fear of recurrence was not always present among participant but was intensified by various specific situations instead. Some participants stated that the fear was triggered upon hearing of someone's recent recurrence. For the majority of participants, the sudden onset of physical symptoms might imply recurrence and, subsequently, evoked fearful emotions. For example,

"I developed heat rash this summer. The rashes were large and red and were all over my body. I felt so scared and went to see an oncologist. I asked, 'Is it skin cancer?' He replied, 'No! It's not'...I suffered from a fungal infection rather than cancer recurrence. Consequently, I was psychologically relieved" (63 years old, 37 months).

Subcategory b): Symptom experience

Majority of the participants mentioned that single or combined symptoms (e.g., cognitive problems, lymphedema, and fatigue) significantly influenced their survivorship. Cognitive problems were cited as more common than the other symptoms as a result of the combination of chemotherapy and aging. These symptoms, as indicated by participants, imposed limitations on their daily activities, for example, in relation to household chores and social activities. For example, a participant described her fatigue experience:

"I used to be efficient in doing my daily chores such as cooking, but now I feel incapable of doing them. After doing household chores for some time, I never stopped in between chores. I'd hardly get tired then; now, I really need to take breaks." (41 years old, 40 months). Several participants also expressed frustration on these symptoms being chronic and incurable. A participant who had been living with lymphedema for more than 7 years had this perspective:

"I am not confident in the recovery of my arm. All around me, I've seen people with swollen hands that could not be restored anymore" (47 years old, 90 months).

Subcategory c): Poor body image

More than half of the participants identified poor body image as a significant negative change. However, their experience of losing a breast was perceived differently, with some participants reporting feeling less feminine and attractive. By contrast, most participants described a sense of disfigurement, making them feel abnormal. For example, "When taking a bath, I look at myself with only one breast in mirror. How I look right now, it is abnormal. If you ask me if I am the same as a normal person, I am definitely not!" (50 years old, 60 months).

Several participants also expressed their worries of people noticing their disfigured bodies, despite being very careful about clothing styles. For example, "After my breast was removed, dressing myself well proved to be impossible. No matter how well you dress, you'd still feel very ugly" (57 years old, 135 months).

Participants also cited a lack of appropriate external prosthesis as the major reason they were dissatisfied with their body image. One participant with a commercial silicone prosthesis said, "When I mopped the floor at home wearing the silicone breast, it always fell out" (41 years old, 40 months). The other participant with a self-made prosthesis said:

"I made a fake breast by cutting up used bras. When I wear a dress, the fake one always shifts up" (63 years old, 18 months).

Subcategory d): Altered sexuality and intimacy

Many participants described a remarkable reduction or complete cessation in sexual activities, although they did not place considerable importance on these changes. According to their descriptions, engaging in sex was harmful to physical health and could increase the risk of recurrence. A 45-yearold woman stated:

"I heard that once afflicted with cancer, the couple should not have sex; otherwise, it will recur. We have not had sex for four years since my diagnosis" (45 years old, 58 months).

¹ Each verbatim quotation is provided with participant's information on age and time since completion of cancer treatment.

Despite this, participants generally felt that their marital relationships did not change or improve because they were not built on sex but on mutual support.

"We are very close but no sex life. My husband does not view this as a significant problem. As long as we are together, as long as our family is harmonious, we do not necessarily need sex" (57 years old, 135 months).

However, three participants lamented that breast cancer aggravated their pre-cancer marital problems because their husbands did not adapt well to these sexual changes. "Our marital relationship has worsened, and this situation may be related to our sex life. We have less sex. I don't know how he thinks of me. I might no longer be sexually attractive to him" (41 years old, 40 months).

Subcategory e): Financial burden

Some participants mentioned that financial burden created constant pressure on them. This was because of unsolved post-treatment side effects and worries of over-exertion, making them difficult to work as usual and receive low income. For example, "I feel the strain on my finance. I used to work before my illness. Since I fear that working might aggravate my illness, I currently stay at home with no job" (62 years old, 46 months).

Participants also complained about the substantial costs incurred by continuing cancer care and health maintenance. For example,

"I take Latrozole each month, costing me 500 RMB. Besides, I need to pay for nutritional supplements, Chinese herbs and regular tests. A test currently costs no less than 100 RMB. My monthly retirement pay is 900 RMB and only covers hormonal treatment costs. How can I afford all of these expenses? The other expenses are paid by my son, despite his financial status is not that good" (62 years old, 46 months).

Category 2): Positive life changes

Subcategory a): New life perspectives

All of the participants expressed having new life perspectives as cancer allowed to reappraise what really matters in their lives. They realized that health and life were "impermanent" and "ever-changing," which prompted them to focus on the present instead of on the future. For example,

"I'm glad that I survived and I'm alive. I don't expect to live a very long life; I just want to live a happy life day by day and do whatever I want to do" (50 years old, 60 months).

Most participants reported a heightened awareness of the importance of health, which was the major lesson learned from this experience.

"What is the most important thing to me? Definitely, my health, I used to drink heavily, take late dinners, and sleep late, all of which were not good for my health. Now, my life has changed for the better. Early to bed, early to rise!" (54 year old, 45 months).

Subcategory b): Personal growth

Participants reported positive changes in their views of self after surviving cancer. They described relying on themselves to endure the hardship and gain inner strength, which strongly motivated them to face and cope with other life difficulties.

"I have become stronger when faced with difficulties. I have to take care of my father-in-law, who is over 90 years old and bedridden. Sometimes I feel upset but I remind myself to keep on doing" (69 years old, 75 months).

A few participants reflected that they learned to control their tempers and became tolerant of people and things.

"I am not as hot-tempered as before. When I get the urge of getting mad at someone, I make myself forgive them instead. For example, if my daughter-in-law says something unpleasant, I pretend that I didn't hear it" (65 years old, 53 months).

Three participants reported that they cultivated an open attitude toward the world and became outgoing.

"I used to keep everything to myself and didn't share with others. Now, I don't hide anything and I talk about everything with everyone" (45 years old, 58 months).

Subcategory c): Enhanced relationships with family

Participants reported having enhanced relationships with family because they strongly felt and valued the care received. Although they were not at the critical stage of disease, participants reported continuing to receive support from family. Nuclear family members (i.e., husbands and children), as viewed by participants, provided the greatest help in daily lives. "I feel that my children are willing to spend money on me more than they previously did. They give me money to buy whatever I want to eat or to take the check-ups I need. They keep saying, 'Don't hesitate to tell me if you need money.' I truly feel touched!" (63 years old, 37 months).

Discussion

This study investigated the perception of negative and positive life changes as experienced by Chinese breast cancer survivors. Our findings add to the emerging evidence regarding the duality of life changes in cancer survivorship [9–13]. Despite the specific negative and positive life changes that were identified in this study, which had been previously reported [11, 12], socio-cultural-specific changes relevant to the Chinese population are discussed as follows.

Negative life changes

Although Chinese women reported similar experiences in symptom experience and fear of recurrence to those reported in Western studies [3, 8], other negative life changes (e.g., body image problem, altered sexuality and intimacy, and financial burden) appeared to be greater among this population.

Participants raised the same body image problems to those in western contexts but with different descriptions. They reported more of having distorted bodies instead of less feminine bodies upon losing a breast. Such findings may reflect the cultural differences exist in individual perception of breast functions and body image. Female breasts in Chinese culture are not emphasized as gendered organs symbolizing femininity the way they are in western culture; they are largely constructed as body organs that are important for maintaining body integrity [15]. Surgical removal of the breast due to cancer represents a bigger assault on survivor perception of body integrity than on her femininity [29, 30]. Such a unique perception of how breast cancer affects body image leads to the finding that the feeling of body disfigurement is greater among participants, when compared with the feeling of loss of femininity. Several participants also expressed their fear of being viewed as abnormal, and this finding is consistent with a study of breast cancer survivors in Hong Kong Chinese context [31]. Despite research on breast prosthesis indicating its positive role in improving body image and restoring a sense of normality among survivors [32], this aspect did not apply to the study. Given that external breast prosthesis was a selffinanced item, inaccessibility to professional advice on prosthesis used is common. Participants revealed ill-fitting and inappropriate problems of self-made or commercial

prosthesis, thus leading to greater body image problems. This issue should be further addressed by health professionals.

Participants described similar sexual problems as those in western culture [33, 34]. However, they were not concerned with these changes personally and more concerned about how this aspect affected their marital relationship. According to participant narratives, performing sex might cause cancer. This finding could be explained by the Chinese culture indicating sex needs to be regulated to preserve health [35, 36]. Therefore, participants chose to reduce the frequency of sexual activities to promote cancer survivorship, and perceived sexual activity as less important. With these understanding, the attitude of husbands to sexual changes is the key to maintaining intimate relationships and consequently sexual wellbeing. Thus, health professionals should consider the cultural understanding of sexuality when addressing sexual problems with survivors.

The reduction in regular income and substantial medical and health expenditures contributed to the financial burden experienced by participants in this study; these conditions were reported previously but were severe in China [37, 38]. Existing medical insurance systems primarily cover medical expenses for hospitalized patients, whereas outpatients with continuing cancer care costs are inadequately reimbursed [39]. Once cancer patients are discharged from the hospital, they shoulder the financial responsibilities for their long-term care and personally pay for health maintenance during survivorship. Thus, medical insurance system should be optimized in order to reduce the financial impact of survivors.

Positive life changes

This study identified that positive life changes were common among participants, including new life perspectives, personal growth, and enhanced relationships with family. These findings reflect the major changes in three dimensions: life philosophy, self, and relationship with others [40]. Despite the numerous explanations on the nature of positive life changes after a cancer diagnosis, one assumption is common: the illness shatters the core schemas of the individual and revises her worldview, which can induce positive changes [41]. Such interpretation is argued to emphasize the role of cognitive processing in influencing the perception of positive life changes within the western philosophical framework, without considering the socio-cultural contexts in which positive life changes operates [42].

The idea of positive life changes through suffering is deeply embedded in Chinese culture, which has long emphasized the human potential to "turn curse into blessing" [43]. Although participants did not directly articulate the concept of suffering, specific changes in life philosophy, relationship with others, and self, identified from data analysis, implied their positive interpretations of the negative cancer experience as circumscribed by suffering. For breast cancer survivors, awareness of an array of negative life changes, particularly related to the presence of possibility of recurrence and death, probably constituted the most important source of their sufferings, as cancer always connotes a potentially life-threatening situation. All these sufferings in Chinese culture are considered part of life and accepting suffering can induce positive changes [43].

With such views, participants believed that the breast cancer experience created the opportunity to turn suffering into positive changes. Instead of struggling to grasp the impermanent things in life, participants described having a greater appreciation of life and cherishing relationships with family. Suffering is also typically described as the Mandate of Heaven to strengthen the willpower of an individual and allow her to develop a new "self" [44]. This perspective is demonstrated by gaining inner strength and discovering improved personal character as experienced by participants. Such cultural concept of suffering may be perceived as the foundation for Chinese women to make sense of the illness experience and work toward positive life changes.

Study limitations

The study had several limitations. First, the study utilized a biased sample recruiting from a cancer self-help organization, thereby limiting the generalizability of the findings and understanding of life changes experience to the large population. Second, participants were interviewed at only one point in time because of cross-sectional design. Determining how life changes evolve over time is difficult; this should be addressed in future longitudinal studies.

Conclusion

Our findings are consistent with those from previous research concerning life changes following treatment completion and provided socio-cultural insights into specific life changes experienced by Chinese breast cancer survivors. These findings contribute to the emerging theory related to the duality of breast cancer survivorship. An enhanced understanding of the specific negative and positive changes experienced by Chinese population can help health professionals address cancer survivorship issues by designing appropriate interventions to minimize negative consequences and enhance positive growth.

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