Original Paper

The Maturity Processes of Breast Cancer Survivors in a Self-help Group

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(Accepted August 1, 2005)

Key words: cancer experience, breast cancer survivors, self-help group, self-object, maturity

Abstract

In this qualitative study, the author reports the maturity processes of breast cancer survivors in a self-help group. The subjects were 59 breast cancer survivors who had written about their cancer experiences in the memoir, "I have a gift from illness". This is a collection of memoirs published by a cancer self-help group, "1, 2 no 3 de Onsen ni hairukai", which consists of members from all over Japan. Data were derived from the memoirs discussing breast cancer survivors' experiences. The author makes reference to Watson's descriptive phenomenological methodology when analyzing the data. As a result, data were classified into six core categories: 1) "reactions to the impact of breast cancer", 2) "the confrontation with breast cancer and the self", 3) "finding new relationships", 4) "the sense of pleasure and satisfaction", 5) "living as a more mature person", and 6) "the woman of one's dreams". And the author attempts to structure these categories. It is noteworthy that the encounter with "the woman of one's dreams" and the relationship between the representative and members of the self-help group fosters and accelerates the maturity processes. It seems to the author that the relation between the representative and members of the self-help group is the "self-object" to which Kohut refers.

Introduction

Breast cancer is regarded as a chronic illness because breast cancer survivors have to live in chronic fear of systemic metastasis and the risk of recurrence. A lot of study is being conducted about the experiences of breast cancer patients and chronic illness [1].

The Ottawa Charter [2] for Health Promotion (WHO, 1986) suggests, "strengthening community action to enhance self-help and social support", as one of the five areas of cooperation needed for effective health promotion. Furthermore the Jakarta Declaration [3], 1997, encourages governments to "increase community capacity and empower the individual", as one of the high priorities for health promotion in the twenty-first century. It requires those engaged in Health, Medicine & Welfare to have a new perspective to raise community capacity and empower individuals by self-help activities. In this light, it is an important challenge that medical professionals should take on to support breast cancer self-help groups.

In recent years, researchers started to pay more attention to breast cancer self-help groups [4-6]. A lot of studies [7-9] have acknowledged that self-help groups are providing important social support, in particular in their services of emotional support and information provision. Gray R. [10] specifically reports the following: "Some

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women pointed out that certain types of information should not be expected from health professionals, and in fact, those who have experienced illness and treatment provide the best information." There are still few qualitative studies, however, that analyzed breast cancer survivors' experiences in self-help groups.

It is, therefore, the purpose of this paper to analyze breast cancer survivor's experiences in a self-help group qualitatively and to consider the structure and meanings of the group.

Subjects

The subjects are the members of a national wide cancer self-help group in Japan: "1, 2 no 3 de Onsen ni hairu-kai (Let's take hot spring baths together, one, two, three, go!)" headed by Ms. Moeko Tawara [11], one of the most famous writers in Japan. Data were derived from the memoirs of 59 breast cancer survivors each of who wrote, "I have a gift from illness". The reason why the author has chosen this collection to take data is because memoirs include the valuable matured experiences in which they have regarded their cancer as a gift.

The author would like to introduce the background of the self-help group that has assumed a very unique nature. It all started from the hesitation of a breast cancer survivor to take a public spa bath. She discussed and consulted about it and the organization was established with an objective to take a spa bath together. In this regard, this self-help group is different from other breast cancer self-help groups. It started out with 50 members in November 2001 and has grown to some 400 throughout Japan as of November 2004.

Methods

- 1. Design: The design of this research is a qualitative descriptive research method using the descriptive phenomenological methodology that Watson J. had proposed as a reference [12]. The author would like to summarize Watson's methodology below. Watson J. describes her research methodology: "The subject matter of phenomenological research is human experiences—their types and their structures, along with their subjective meaning, essence, and relationships". And Watson also talks about research protocols as follows:

 1) The researcher obtains naive descriptions from people about their experience of a given phenomenon. 2) The researcher derives essences using those descriptive and reduction methods. 3) The researcher aims to find an objective description of the subjective variation obtained. The author has deemed this technique appropriate for this paper. It is because the author aims to analyze in a qualitative way the unprocessed descriptions of experiences that breast cancer patients in the self-help group themselves wrote, and review and consider the structure and values of their emotional support as found in the self-help group.
- 2. Methods: The author analyzed the memoirs of 59 breast cancer survivors. She based her analysis on Watson's descriptive phenomenological methodology: 1) Reading to get a sense of the whole. 2) Driving the protocol into "meaning units" or constituents as expressed by the subject. 3) Considering the meaning units as "codes", and naming as "subcategory". 4) "Category" was extracted from subcategories. 5) "Core category" was extracted from categories. 6) Making the model from core categories. There were discussions with $2\sim3$ researchers on the analyzing processes.
- 3. Confirmation of the reliability of the data analysis: The author carried out the following to better understand circumstances surrounding the self-help group and improve the reliability of the qualitative research: 1) The author has become a supporting member of the above self-help group. 2) In order to conduct field work, she participated in a wide range of activities of different groups from October, 2003 to March, 2005. 3) She perused the bulletin of the above self-help group [13-16] and the books of the group head [17-19]. 4) The category classification was developed with a plurality of researchers who have nursing education and qualitative research experiences. 5) She interviewed the representative and

members of the group and verified the analyzed results.

4. Ethical considerations: 1) The author interviewed a representative from this self-help group, and presented the purpose of the study using a document. 2) She presented the purpose of the study using a document in a management meeting of the self-help group and obtained agreement. 3) She later sent the group the document asking for collaboration for the study and got consent. 4) The publication of the study results has been decided to be done anonymously.

Results

It was impossible to identify ages and the post operation time of the subjects due to the nature of the memoirs. As a result of the analysis, 6 core categories, 14 categories, and 71 subcategories were identified out of 933 codes. Table 1 shows 6 core categories and 14 categories. Fig. 1 shows the relationships between the core categories and the categories. These categories are explained below:

- 1. Reactions to the impact of the breast cancer: The information of a diagnosis impacts on their selves. The strength of the impact is the severity of the pain for them. The bigger the impact is, the bigger the reaction to themselves is. This core category consists of the following 3 categories. The category and a typical code are described below:
- 1-1 The rage against illness: Most of the survivors wrote about the impact they had felt when they had been informed of a diagnosis. They are strong emotions that come from the denial and the rage of an unexpected illness.

I could not stop weeping, with lots of thoughts circling in my mind such as "Why me?", "What did I do?", "Something is wrong with this picture".

1-2 The grief over the loss of femininity: Sexuality is part of the fundamental existence of the human being. The loss of a breast, a symbol of sexuality means the loss of femininity. It is possible to say that this experience could threaten the identity of an individual.

My husband's words, "The woman who doesn't have a breast is · · · · · · ", have depressed me. I cried bitterly in the bathtub when I was allowed to take a bath and realized for the first time that one of the breasts was gone.

1-3 The uncertainties of illness and treatments: They have experienced the illness and treatments as uncertainties. There is no way to get reliable answers. They, however, come to select some of the uncertain treatments. This experience brings about the decline of the subjective feeling about health.

Coughing, I feared it had spread to the lung. With stomach pain, I suspected metastasis to the stomach. The fear tormented me day in and day out and drove me up the wall. I got menopause soon after the mastectomy. What is worse, a menopausal disorder came. And worries about recurrence and metastasis never left me. I was very concerned when I felt ill.

- 2. The confrontation with breast cancer and the self: This is an attitude to confront the disease squarely without negating it. It represents a big positive change. They chose not to be passive, explored a way of life best suited to themselves and tried to live it. This core category 2 consists of the following 3 categories. The category and a typical code are described below:
- 2-1 Asking oneself: In this category the breast cancer survivors ask themselves what they want to do for themselves and what they ought to do about this incredibly absurd event. The author considers it a

very significant stage as they are leaving existence-related suffering and distress behind them and trying to find a direction for their subsequent lives.

Nearly one year has passed after the discharge. I now believe it is best that I do something that makes me happy. Perhaps this serves as a kind of vitamin supplement so that I can live together with the disease.

2-2 The awareness of one's role: This category follows the above category of asking oneself the questions. They keenly come to realize about not only their social role but their role in their own life that is faced with sufferings.

I don't want to die. I will not die, making my only daughter of grammar school age motherless. I need to get operated on as soon as possible. Unless I come home sooner, things would not work at home.

2-3 Facing the disease: This category represents a condition that they squarely look at the disease after recognizing they are inflicted with hardship by it. Therefore they are not edgy. They are able to analyze things rationally, accept the disease as is and stay firm.

I suffered so much from anticancer drugs. They distressed me greatly and made me "want to die" and "feel very bitter" everyday. I could not sleep at night and I always asked myself, "why?", "Why only me?" Everyday it was just too much to tolerate, driving me insane, so I stopped the medication after 8 months.

A problem started after I had been discharged. While I was hospitalized, I went to the movies and to have dinner with my friends. I was in the center of life. But everything changed when I had to come home. After my husband went to work at 8 o'clock in the morning, I was left all alone at home until 8 or 9 in the evening when he came home. I always felt anxiety, loneliness, and irritated because I was very physically inactive. I could not move around very much at all, so I lay down soon after housework.

- 3. Finding new relationships: It is in this category that they find a new relationship. It is formed in the process of addressing the disease rationally. Reaching this level is only possible when they are done with mourning for the lost part of themselves. It represents the discovery of a new relationship between themselves and people surrounding them.
- **3-1 The relationship with others:** The others in this category include the family, friends, acquaintances, self-help group members and medical professionals. The breast cancer affects not only patients but people around them as well. This influence drives reciprocal mental energy going among them. This energy in turn forms new relationships between a cancer patient and the people around her. In this relationship one can find mental support people when around her are willing to provide inclusive care, compassion, and attention.

My hair came off and I suffered from ulcer pain and a swelled anus. My husband ran to a store to buy ice cubes, my daughter prepared cold food, a friend brought me lunch as I would be by myself at home during the daytime and another friend knitted me hats, as many as three. It was their assistance that had kept me going with anticancer drug treatments for a half-year. I take their love to heart, always cherishing it.

My mother died a very sudden death as if she had been waiting for my discharge. I sure I am convinced she took my disease away with her. Thank you, Mother.

3-2 The relationship with medical professionals: This category describes relations with the medical professionals who are engaged in breast cancer medical care. Trust is an important ingredient for these relationships.

I have no way of explaining how the warm words of the doctor and nurses healed my mental scars that were eating my heart up during the hospitalization. I came to realize the importance of the mental care as well as the physical care.

I was embraced in a sense of relief as if light had come into my heart. I was taken care of for another 9 years and 7 months by a physician who I trusted very much. Later I came to learn he was a famous physician of high reputation.

3-3 The support within a self-help group: This category represents the support experience that members of the self-help group gave and received. It is because they experienced the same disease that they can support each other by sharing emotional experiences and relating to one another. This provides a mutual support function within the group.

I was feeling uneasy about a general meeting at Atami that I was attending for the first time. Despite my worries, however, I was surprised that I could obtain peace of mind when I was there with fellow members who had the same pain. I was very content as I got hope and power.

I met many fellow members. Sometimes I was encouraged and at other times we took each other's hands for joy. Now I feel I have many "mothers", which gives me strength.

Then, I went to a new-year's party of the branch association. I am thankful after visiting an executive meeting at the head office which was full of sincerity and enthusiasm. I now want to help in any small way I can.

Tears flowed down the cheeks for a very long time. Why was I so rigid about my disease? Why was I so obsessed by it? The disease is not a thing I should be ashamed of or feeling servile to. It is time now that I take courage and look at and accept myself and to love my body as it is.

- 4. The sense of pleasure and satisfaction: This category is defined by satisfactory feelings comprising pleasure and satisfying experiences which are obtained through the fusion of their selves and others. Those feelings are really irreplaceable and cannot be gotten by themselves but only through interactions with others.
 4-1 Playing and the sense of pleasure: When someone lives a moment best is when they are genuinely having a good time or immensely enjoying themselves at something. How much of this moment one can
 - Correction bras will be a constant headache for me from a fashion point of view. Every woman wants to look beautiful both mentally and physically regardless of age. I came to realize this truth better now, as a result of my cancer, than at any other time before.

obtain determines subjective happiness.

I feel that I scrubbed off all pains I had had in the past. The experience gave me satisfying content feelings and a lot of energy. It is already a month since then but the warmth of a spa, which I took for the first time in a long while, still stays with me and I often reminisce about it.

I cried out, "Banzai!!" A moment of intense excitement. As if I would have felt every sensation of "get a kick" warmth that ran throughout my body, I took the big bath and the outdoor hot spring bath three times, almost in a way to make up for the loss up until that time.

4-2 Loving one's life: This stage can be attained through interactions with others by learning how precious the time with them is and how much they mean to them, and ultimately realizing how irreplaceable they, the cancer survivors themselves, are. They learn how to respect themselves as they are only when they respect and love others. This self-esteem enhances their love for their own life.

I was very happy when my 39th birthday came. The meaning of the birthday changed greatly for me, who had arrogantly said before, "It's just another birthday to get older!" I prayed that day that I would greet the 40th birthday peacefully.

When my condition is good and I do not have anything to worry about, I admire the sky, clouds, budding leaves in spring and bare trees in winter. They are beautiful. Good days come and go without any particular good news. I want to spend such days as many as I can.

For me, the breast cancer told me acutely how complacent I had been until then and let me learn how important, gratifying and valuable to have my husband, children and friends are.

I have got enlightenment and learned what is important in this life and what true happiness is. I have improved my sense of values.

I thanked the breast which was transformed and became ugly, while my body was swinging to and fro slowly in the spa amongst other members. This breast has given me the happy time with wonderful people like them.

- 5. Living as a more mature person: This category represents a stage that they can obtain as more mature selves though pleasure and satisfaction, and advance one step further in their respective lives. They find a more mature and seasoned person in themselves only after dealing with their difficulty and appropriately overcoming challenges they face in their development as a person. This self leads a life with a new perception of the world.
- 5-1 The retrospect of one's life: In this category the author sees the attitude that they recall the path they have come from by using the inherent introspective power. By looking at the past with this retrospective viewpoint, the existence of the self becomes clearer and self-esteem rises up.

22 years have passed since I became ill. The aftereffects vanished. Time has given me vigor that keeps me going.

I gratefully receive power from people around me. It will be almost five years soon.

It is already this season this year again that vegetation starts budding and Japanese apricots blossom. Time flies very fast. It was March nine years before (when I fell ill).

5-2 To live better: People are endowed with a discerning ability between things that can change and those that cannot. They have courage to accept the latter and they deal with the former actively. In this category the author sees their effort to make themselves and others happy.

My daily life has changed completely. I used to be able to move around freely, to a degree I was happy with, whenever I wanted. I am now forced into an inconvenient life. I had often thought that I would choose this experience ten years or twenty years ahead if I have to undergo it. I am more resolute now to face the reality squarely and live each day to the fullest with pleasure.

I was so disheartened. Ms. Tawara's book told me, "I have no choice but to die when the disease is incurable." But now I look at life and think, "If I can live even a day longer, I will

live it happily."

- 6. The woman of one's dreams: This category represents a big influence on the maturing processes of breast cancer survivors in self-help groups. It can be compared to plants and the sun. They form desires after the encounter with the woman they adore, wishing to be embraced by her charisma and to become like her. These desires produce hope to live and drive them into actions. Therefore, "the role model", that they mentioned about the woman they adore is considered an important factor for the maturity of the breast cancer survivors.
- 6-1 The encounter with Ms. Tawara: Ms. Tawara is a very famous and attractive essayist. It is her social activities she has performed all these years that have made middle-age women idolize her. Then she was taken ill herself by the same disease and that makes them feel that they can relate to one another better now. It may be said that this is an exciting and stimulating relationship going beyond their social status and structures.

I read an article about an establishing organization of breast cancer patients. I wanted no group, "pitying on one another who has the same disease". Although I always thought that way, this group caught my attention and my curiosity arose. I wondered about, "What is 'Ichi ni no san de onsen ni hairu kai'?" I thought that this might be a kind of joke at first and laughed.

One of books at the hospital library led me to this association. It was, "To live is to begin", written by Moeko Tawara. The book told me that Ms. Tawara also suffered from the same pain and an article in Asahi Shinbun Newspaper reported on the association, both of which prompted me to join the group.

On one of days I was feeling ill, an article by Moeko Tawara caught my eye with very strong magnetism that read, "We are not afraid of a hot spring if everyone is together to take one." I became happy to read this article in a way a fish would be when it gets into water. I could not believe that I was going to take a spa with the lady who has influenced me very much with her very positive views toward life.

Core category Category Reactions to the impact of the 1 breast cancer 1-1The rage against illness 1-2The grief over the loss of femininity 1 - 3The uncertainties of illness and treatments 2 The confrontation with breast 2-1Asking oneself cancer and the self 2-2 The awareness of one's role 2-3Facing the disease 3 Finding new relationships 3-1The relationship with others 3-2The relationship with medical professionals 3-3 The support within a self-help group 4 The sense pleasure and 4-1 Playing and the sense of pleasure satisfaction Loving one's life 4-25 Living as a more mature person 5-1 The retrospect of one's life 5-2To live better 6 The woman of one's dreams 6-1The encounter with Ms. Tawara

Table 1 Cancer experiences of breast cancer survivors

Discussion

Figure 1 was developed based on the category table of the study results. The author believes that these core categories develop progressively parallel to the time axis and are related to the maturity of the breast cancer survivors. Also, she thinks that the encounter with the woman of their dreams had an influence on all of the 5 categories. Worth noting here, in particular, is that establishing a new relationship is the key to maturity? The new relationship means interactions with people around them, medical professionals, and fellow breast cancer survivors.

When the negative emotional reaction, that is the rage against disease, the grief over the loss of femininity and the uncertainties about the disease and treatment, was hitting them hard, the woman of one's dreams, which is the sixth core category, gives big support to them as Ms. Tawara herself has gone through what they are experiencing with the disease.

The author would like to discuss the issue of the encounter with the woman of one's dreams by adopting Kohut's theory [20]. Kohut discusses functions of the "self-object" in terms of narcissistic injury and idealizing transference. Gabbard regards the self-object more as functions than as people. He regards it as indispensable for the growth of the self.

The woman of one's dreams is an "ideal leader" in one sense. This has happened as the result of idealizing transference occurring within the members of a self-help group. Breast cancer survivors may need such an ideal leader that can be a subject of their idealizing transference in the processes of the recovery of their self. In other words, they need someone that encourages them and confirms the validity of their existence, which Kohut [21] refers to as, "gleam in the mother's eye". That is because their narcissism has been badly impaired as they have lost a breast which is the symbol of femininity and their life is full of uncertainties.

The relations between Ms. Tawara, the symbol of the organization, and the members is a self-object because they want to bask in the charisma of the leader who they adore very much and one day they want to become like her. This self-object relationship can be characterized as an experience that is "the sense of unity in which the woman of their dreams" is sought after.

Kohut [22] stresses that we need self-objects in our environment for emotional survival as much as we need oxygen in the atmosphere for physical survival. In this sense, the author consider that the self-help group where Ms. Tawara assumes a central role provides the environment needed for emotional survival, which is a key for the recovery of the self.

Christopher A and Morrow L [23] studied about, "Evaluation of a Community-Based Exercise Program for Women Cancer Survivors". They proposed for women some practices which should promote psychological and sociological well-being.

Therefore, the author may be able to interpret this self-help group in the following ways: 1) a community-based exercise program, and 2) a therapeutic environment for self reorientation.

The members of the self-help group regard the cancer experience as "a gift". Such experience, called "a gift", seems to be obtained through the experience of this self-object relationship, which fosters the maturity of the self.

Future research and community-based nursing practices will be studied based on this study.

Conclusion

The author qualitatively analyzed the breast cancer experiences of the cancer self-help group and examined the structure and the significance of the emotional support by a self-help group.

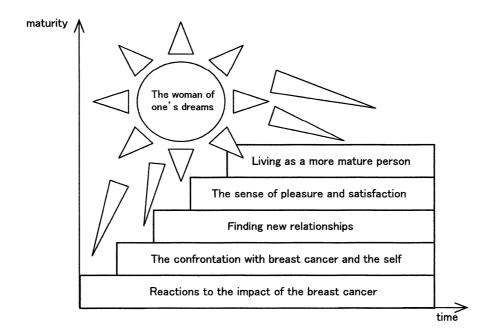


Fig. 1 The maturity processes of breast cancer survivors in a self-help group

Upon the analysis of the breast cancer experiences of the cancer self-help group members, they fall into the following 6 core categories: 1) "reaction to the impact of the breast cancer", 2) "the confrontation with breast cancer and the self", 3) "finding new relationships", 4) "the sense of pleasure and satisfaction", 5) "living as a more mature person", and 6) "the woman of one's dreams".

Analyzing the structure and the significance of the emotional support of the cancer self-help group, the author concluded that the cancer self-help group members grew in maturity over time. Specifically, it seemed to me that the maturity processes were reinforced by the "discovery of a new relationship" and the development of the relationship with others which was highlighted by the self-object relationship with the symbol of the association.

Acknowledgements

I appreciate the cooperation of Ms. Tawara and all of the members of the cancer self-help group as research participants. I also would like to thank former Professor Kazuko Kikui of The Kawasaki University of Medical Welfare, Professor Yoshiko Futoyu of Okayama Prefectural University and Associate Professor Keiko Takeda of The Kawasaki University of Medical Welfare for their help in providing qualitative analysis for this paper.

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