

Breast Cancer Survivors' Experiences in the Writing and the Poetry Therapy Group Process

Johanna Holopainen

University of Jyväskylä, Finland

johanna.e.holopainen@jyu.fi

ORCID: 0000-0003-4278-4942

Abstract

This conference paper describes what kind of encounters the breast cancer writing group offered to its participants and how they found paths to cope with their experiences of breast cancer by writing and sharing them in a poetry therapeutic setting.

The paper is based on my dissertation entitled *Writing about Breast Cancer Experiences: A Study of The Poetry Therapy Process and Its Meanings*. The study setting was empirical and I explored the poetry therapy group process and participants' writings about breast cancer experiences. I gathered data from the group that I led and I used poetry therapy methods to address cancer-related experiences. The data consists of interviews, writings produced during group meetings, and questionnaires about the therapeutic writing process. I analyzed participants' experiences of the group by using phenomenography. I employed interpretative phenomenological analysis (IPA) to analyze participants' writings.

The results show that participants found the group atmosphere enabled them to express their emotions and discuss them, as well as their experiences. They felt understood and supported, and they supported others. The writings they produced at the meetings revealed how breast cancer had affected their lives in physical, psychological and social contexts, and how they had coped and moved forward.

In conclusion I illustrated the poetry therapy group process, and suggested that writing and using the poetry therapy methods could be useful for coping with breast cancer experiences. Developing and organizing poetry therapy groups for breast cancer/cancer survivors could be an effective way to support their rehabilitation and increase psychosocial support.

Keywords: breast cancer; poetry therapy; reflective writing; meta-reflection; group process; experience

Introduction

Breast cancer is the most common cancer in women in Finland and in the world. Previous studies show that physical, mental and emotional changes are traumatic, life-changing and cause uncertainty, anxiety, pain and suffering. Illness challenges the perception of self, identity, body image and femininity (Leino, 2011; Fuchsia et al., 2007). Breast cancer survivors have a need to face challenging and difficult emotions, to understand the illness associated with the illness and the strengths that have emerged in oneself. They experienced that after illness, helping others and expressing oneself is important (Collie & Long, 2005). There are also many texts written by breast

cancer survivors (poems, blogs, biography texts etc.). This observation made me think that there must be a reason why breast cancer survivors' want to write and share their stories.

I wanted to explore: 1. How does the poetry therapeutic framework fit in with handling breast cancer experiences, and 2. How are breast cancer experiences made meaningful through written narratives. I also had another motive, I wanted to help breast cancer survivors handle and explore their cancer experiences and related feelings and express themselves through writing. As a trained poetry therapy instructor, I organized a writing group in which I used poetry therapeutic methods and guided participants to write about their cancer experiences. The interaction was important because it involved group activities and participation in them.

My starting point was phenomenological and I used phenomenography and interpretative phenomenological analysis (IPA) when I analyzed the data. My data consists of interviews, writings, and questionnaires of individual's writing process. The purpose of this conference paper is to illustrate the participants experiences about breast cancer through their writings and how they experienced the participation in the writing group. The excerpts were coded participant1 (P1) etc. I also describe shortly the methods which I used in the group meetings. In the end I present the poetry therapy group process which I have constructed.

Empirical research setting

After the ethical evaluation and positive statement from The Ethical Committee of the University of Jyväskylä, I started recruit participants in cooperation with Middle-Finland cancer association and Breast Cancer association. I interviewed the (applicable) participants before the group's first meeting and after the group's last meeting.

When the group started in January 2019, there were six participants who had completed breast cancer treatment. The group met 18 times in 2019. The group aimed to support handling breast cancer experiences by writing and sharing written experiences with other participants.

One of the group participants described the group's meeting as follows:

"The fact that we wrote in a group and it didn't matter that there were different kind of people in that group. It was so clear when you gave us the assignment and then we wrote and discussed it. It was a group activity. After the writing it was nice to read aloud the text to others. It was a peer-to-peer experience when someone replied that it sounded familiar." (P5)

Reflective writing in the group

The writing group's focus was on reflective writing and I applied Nicholas Mazza's RES-model (Mazza, 2003/2017) when planned and described the group's meetings. Orientating element (Mazza's receptive, prescriptive) meant in this context the material, which inspired and gave a point of views to writing. I used texts, poems, cartoons, songs and lists. The lists were created by the participants themselves and covered topics such as good and bad encounters during the illness. The second section (Mazza's expressive/creative) involved the way of writing I suggested to the participants and described the method how to write. I used free writing technique, "minute-exercise", poem writing, descriptions and personification. Closing rituals (Mazza's symbolic/ceremonial), which I used were for example "gifts" to other participant (verse, greetings),

discussions (positive things, desires, dreams etc.), picture cards and farewell letter to breast cancer. Closing rituals changed, but every meeting we followed the same structure: a start, a writing exercise, a discussion, a coffee break and a closing (Holopainen & Ihanus, 2024).

One participant described how she felt about writing:

“Writing is wonderful. It makes me feel good every time. Even if I feel depressed or bored at first, but when I write, my mind gets sensitized and I feel better. And in the end, I feel really calm and happy. Writing is really therapeutic.” (P4)

Every meeting had a theme which we followed. Themes that we handled were for example emotional process, encounters, identity work, outsiderness and belonging, medication, womanhood, corporeality and death (see Holopainen & Ihanus, 2024).

When we handled medication, I designed writing exercise based on personification. Personification is a literary technique; which writers use to add human qualities to non-human things. When I planned our meeting, I got inspiration from Michael White’s thoughts and his idea of a conversation in which the problem is outsourced. White is known as the founder of narrative therapy (see White, 2008).

Writing exercise consisted of four parts:

First, I asked them to make a list of all medicines they had had during treatment for breast cancer. We spent about five minutes doing this and after that we went through the lists together. The most discussed drugs were cytotoxic and cortisone.

Next, I asked them to choose a few medications and name and characterize them. We used five minutes and again going through together. It is important to make sure that everyone is allowed to tell. They named cytotoxic as ‘Gandalf-The Saviour’, ‘Red devil’ and ‘Back-stabber’. The names reflect the nature of the medicine.

In the third part I asked them to write a story about some medicine. I gave them 10-15 minutes and after writing, they got to read their story or just tell about it.

One participant wrote a story about Gandalf:

“When Gandalf came into my life, I felt and knew here is my saviour. I met Gandalf a second time. Our meeting was not long. Almost as soon we met again, I blushed and gasped. Gandalf was too harsh for me. Still that character is my savior, and I will always remember it with a certain warmth and gratitude.” (P2)

Afterward we discussed the technique. The feedback was that it made the memory come to life, it was easier and fun to describe things even if the moment in the past was hard, and it opened a new dimensions and ways to think. Personification was the good way to re-built one’s life-story (Holopainen et al., 2021).

Things that needed to be written

I used interpretational phenomenological analysis when I analyzed participants’ writings. Based on analysis, I formed themes. Themes described how personal meanings about breast cancer were formed with help of reflective writing. The main themes are *Being seen and heard as a breast*

cancer survivor; *The Traces left by the disease*; and *I live and breathe despite the disease* (Holopainen & Ihanus, 2024).

Being seen and heard as a breast cancer survivor

First main theme is *Being seen and heard as a breast cancer survivor* and it describes the encounters that they had with healthcare professionals and relatives. It includes two subthemes: The importance of support and presence from healthcare professionals during the illness and Involvement of significant individuals present how markable the support was in serious situation.

One participant wrote how important was, when healthcare professional understood that she needed comfort at that very moment, and she (the participant) remembered the words word for word.

“This woman had time for me and she could say exactly what was supposed to be said in that moment to a scared, feverish cancer patient: ‘This gets better, life goes on, everything will be fine.’” (P4)

The importance of support and presence from healthcare professionals during the illness-subtheme embodies that participants needed encouragement, knowledge and understanding from healthcare professionals. In addition to the example, the same interpretation can be made of other texts as well.

Involvement of significant individuals-subtheme includes the descriptions which participants described the support which loved ones gave them with concrete actions. In many writings had also described how relatives took notice of the sufferer in different ways as shown in the excerpt below:

“Whenever I could, I would sit at least an hour and a half in the cooling sauna. Sometimes, my husband would come to check on me to ensure I hadn’t fainted there.” (P3)

The both sub-themes represent the interactional needs emerging from the illness. Participants’ writings represented emotional statements and at same time writings can interpret through the reflective and transformative writing process. The moments had become one’s memories in a part of life.

The Traces left by the disease

Second theme is *The Traces left by the disease* and it includes three subthemes: *Physical/corporeal changes caused by the disease and treatments*; *The impact of the disease on personal relationships*; and *Presence of cancer after treatments*. The theme with its subthemes illustrates how widely breast cancer and its treatment can extend. Based on the excerpts as follows, participants described the effects in physical, psychological and social contexts.

The first subtheme *Physical/corporeal changes caused by the disease and treatments* illustrates how visible traces can affect the thoughts and state of mind. Also, the visible traces make the experience more real as the example below shows:

“I looked at myself in the mirror for a moment and thought, ‘I’m so hideous.’ I think I said it out loud. My first feeling was confusion—had all that really happened to me? Bald head, long red scar on the left breast, slightly smaller scar on the right. The skin on the left breast next to the scar was blue-red. It made me cry.” (P3)

The impact of the disease on personal relationships-subtheme included both positive and negative impacts of the relationships. The participants wrote about the issue objectively and analyzed themselves possible causes and consequences of what happened by writing. The following excerpt shows how rationally the participant is able to reflect on what has happened.

“At first, he slept next to me, and once I fell asleep, he would leave. In retrospect, he was already pulling away. Why? Because I was bald? Because I was sick, and my skin was sore? Because I didn’t want him inside me, I wanted him next to me?” (P2)

The third subtheme *Presence of cancer after treatments* shows that cancer is a part of one’s life in good and bad. They maybe fear of recurrence when some new symptoms appear or mammography visits is approaching. On the other hand, cancer may have been accepted as part of life like the excerpt below shows:

“A whole new world has opened up. It used to be terrifying to know that someone had cancer. Now, I understand it is just a part of someone’s life. I realize that it doesn’t stigmatize a person or define every moment of their life.” (P6)

I live and breathe despite the disease

Third theme *I live and breathe despite the disease* and its subthemes: *Survival mentality*; *Initiation of spiritual growth spurred by the disease*; and *Living in continuous interaction with the disease*. These represent how participants described coping mechanisms and awareness that they can survive, how they became aware of the limitations of life and what is personally important in life and how they accept the changes that followed cancer.

Survival mentality-subtheme shows that participants described that they actively seek the ways how to handle treatments and related side effects. They have positive state of mind that cancer can be treated, and they will survive even though there were bad moments and fear present. Treatment-proneness emerged like the one participant described as follows:

“When I leave the cancer ward, I feel relieved in a way. Another step forward. Now I just have to deal with the consequences and get fit for the next time.” (P6)

Initiation of spiritual growth spurred by the disease-subtheme includes the ways how cancer affected participants acts, values and thinking. They were thinking about the future and how they wanted to live the rest of their lives. They reflected by writing about these changes as the excerpt below shows:

“I changed during the treatments. Time stopped. The here and now became important. Being with people for real became important. I realized who cared about me and who was important to me. During treatment I learned a lot about friendship and trust. When you’re afraid of dying, you understand who wants to be present in your life. My life values were redefined.” (P2)

Third subtheme *Living in continuous interaction with the disease* includes how they continued to live, even though cancer-related issues were present at times. They had to learn to live with, for example, permanent physical changes and the side effects of long-term medication (e.g. hormone therapy). When they feel good, they don’t think so much about cancer and if they get sick or have symptoms the fear of cancer recurrence increases. On the other hand, side effects that have already become familiar can be tolerated, as described in the excerpt below:

“At the moment I don’t think much about cancer, probably because I’m feeling pretty good and have much nicer things to think about. I’m so used to the side effects of the drugs that they don’t bother me much anymore.” (P3)

Meta-reflection: discussions and the new meanings

Meta-reflection was formed and based on participants experiences about peer activity, guided activity, sense of community and reflective activity. Peer activity experiences born in identifying experiences, providing support and being understood, and receiving support. Guided activity based on oral instructions for assignments and writing, sharing written texts, and receiving guidance were markable actions as a part of the poetry therapy process (Holopainen, 2024b).

One of the participants described the group activities during the process as follows:

“It is interesting to hear what thoughts the given writing assignments in others have evoked. They develop into fruitful discussions.” (P6)

Participants told that a sense of community emerged when they worked and wrote together and expressed their emotions because the atmosphere of the group was suitable. They felt belonging and experienced reciprocity with each other. Reflective writings made also base of meta-reflection and made meaning-making possible in the group. Participants named reflective actions for example shared writing experiences and the sensations that followed the writing, and the insights produced by writing (Holopainen, 2024b).

After the process one of the participants summarized the group process as follows:

“The fact that this (breast cancer) is our common thing when we share it together. Perhaps there it is where the sense of community came from.” (P5)

The Poetry Therapy Group Process

The interaction between the instructor, the participant and between the group members were the key factors what made possible to reflective writing and meta-reflection during the process. I constructed and introduced the poetry therapy group process as a figure (*Figure 1*, see Holopainen, 2024a).

As previously outlined in my dissertation, the process can be described as follows: The instructor plays a key role in initiating the meaning-making process for the participants. The participants themselves choose the intensity with which they are willing to participate. The group process and the individual process are intertwined; the individual process occurs when the individual is willing to participate and accept the group's methods. Accordingly, individuals' joint participation creates the group process which in turn has an effect on what the individual explorations ultimately produce.

The reflective and meta-reflective processes were central in the group interaction. Through reflective writing the participant examined breast cancer experiences and this allowed the interaction between the participant and the text. I as an instructor were enabler of the reflective writing as I planned and guided the exercises.

The meta-reflective process was formed by interaction between the participants and consisted of feedback for each other. Based on feedback the participants were able to form new personal meanings (Holopainen, 2024a).

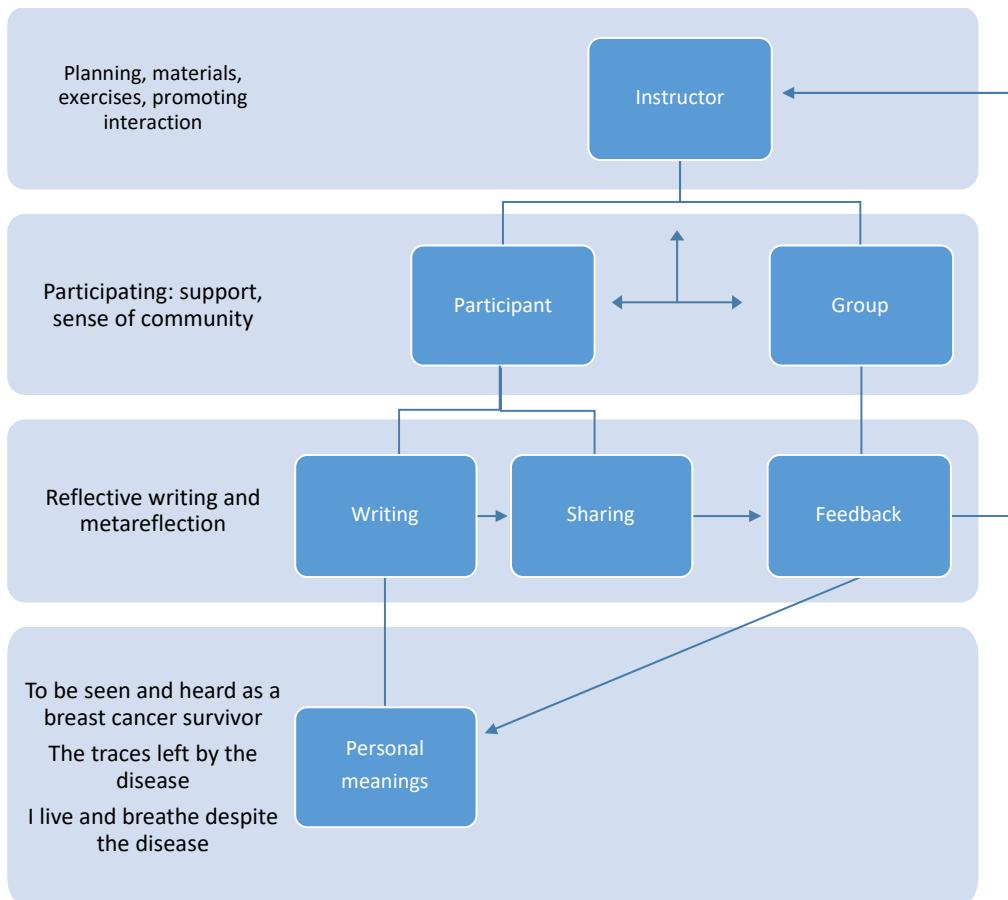


Figure 1. Poetry therapy group process (orig. source Holopainen, 2024a)

Conclusions

The starting points of the study were enabling writing, writing about breast cancer experiences and possibility to handle the written narratives in interaction with the group members.

The writings illustrate that breast cancer affects widely one's self, actions, and relatives. The written narratives made visible the ways how to survive, move on, recognize one's capacity, and find new ways to act in the future.

The atmosphere in the writing group enabled the expressing of emotions. It also initiated discussions about personal experiences and feelings.

The outcomes can be used as: supporting cancer survivors' rehabilitation and psychosocial support, when planning cancer survivors' rehabilitative actions and in the contexts of poetry therapy and of nursing.

In the future it would be interesting to study cancer experiences and corporeality. The writings contained references to corporeality not only in physical context but also in psychological and social context.

References

Collie, K. & Long, B.C. (2005). Considering 'Meaning' in the Context of Breast Cancer. *Journal of Health Psychology*, 10(6): 843–853. <https://doi.org/10.1177/1359105305057318>

Fuchsia, H.A., Bottorf, J.L., Balneaves, L.G., & Grewal, S.K. (2007). Punjabi Immigrant Women's Breast Cancer Stories. *J Immigrant Minority Health* 9, 269–279. <https://doi.org/10.1007/s10903-007-9044-z>

Holopainen, J., & Ihanus, J. (2024). Reflective writing about breast cancer experiences as part of an interactive poetry therapy group process. *The Arts in Psychotherapy*, 90, 102194. <https://doi.org/10.1016/j.aip.2024.102194>

Holopainen, J. (2024a). *Rintasyöpäkokemuksista kirjoittamassa: Tutkimus kirjallisuusterapeuttisen ryhmän prosessista ja merkityksistä*. [Writing about Breast Cancer Experiences: A Study of The Poetry Therapy Process and Its Meanings] Väitöskirja. [Article-based dissertation]. Jyväskylän yliopisto: Humanistis-yhteiskuntatieteellinen tiedekunta. https://jyx.jyu.fi/bitstream/handle/123456789/95023/978-952-86-0162-3_vaitos01062024.pdf?sequence=4&isAllowed=y

Holopainen, J. (2024b). Kirjoittaminen kuntoutumisen tukena - Rintasyövän sairastaneiden kokemuksia kirjoittajaryhmästä. [Writing as a support of rehabilitation—Experiences of breast cancer survivors in a writing group]. *Kuntoutus*, 47(2), 34–47. <https://doi.org/10.37451/kuntoutus.146320>

Holopainen, J., Maanmieli, K., & Kortesoja, S. (2021). Kohti traumainformoidun kirjallisuusterapian käytäntöä. [Towards the Practice of Trauma-Informed Poetry Therapy]. *Scriptum Creative Writing Research Journal*, 2, 1–44. <https://doi.org/10.17011/scriptum/2021/2/1>

Leino, K. (2011). *Pirstaloitumisesta kohti naisena eheytymistä. Substantiivinen teoria rintasyöpäpotilaan sosiaalisesta tuesta hoitoprosessin aikana*. Väitöskirja. Tampereen yliopisto: Terveystieteiden yksikkö. 30–35. <http://urn.fi/urn:isbn:978-951-44-8555-8>

Mazza, N. (2003/2017). *Poetry Therapy. Theory and Practice*. Routledge.

Tegner, I., Fox, J., Philipp, R., & Thorne, P. (2009). "Evaluating the use of poetry to improve well-being and emotional resilience in cancer patients." *Journal of Poetry Therapy*, 22(3), 121–131.

White, M. (2008). *Karttoja narratiiviseen työskentelyyn. □Maps of Narrative Practice□* Gummerus.