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Experiences from having breast cancer and being part of a support group. Notes written in diaries by women during radiotherapy

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ABSTRACT

Objective: The purpose of this study was to examine the experiences of breast cancer patients participating in a support group.

Method: This study explores 28 stories of women with breast cancer as expressed through written diaries. Diaries were written during a 5-week period in parallel with radiotherapy and participation in a support group in a hospital. Answers to six open-ended evaluative questions concerning the support group were included in the majority of the written diaries. A qualitative content analysis was used to identify themes.

Results: Three themes were constructed during the analysis: “positive group development.” “Inhibited group development.” and “the individual living with the disease.” Hopes and fears for the future in regards to illness and getting better, the value of family and friends, and feelings related to daily life with breast cancer such as fatigue and changes in body image were also expressed in the diaries.

Significance of results: The findings suggest that the women with breast cancer found it valuable to be able to share experiences with other women in a similar situation in the context of a support group. Being part of such a group provided a space and an opportunity for reflection.

KEYWORDS: Breast cancer, Diary, Support group, Women, Qualitative content analysis

INTRODUCTION

Expressive writing and processing feelings in written form after a traumatic event, such as being diagnosed with breast cancer, can improve mental health for those affected (Pennebaker & Beall, 1986). Expressive writing has been shown to have the best effect among those who do not avoid talking about their illness. If avoidance in talking about the diagnosis is present, writing about the illness can lead to a greater level of stress (Stanton et al., 2002). Expressing one’s emotions in writing can lead to a decrease in physical symptoms, measured as fewer visits to the doctor (Pennebaker & Beall, 1986; Stanton et al., 2002).

The first year after being diagnosed with breast cancer is a time of turmoil in which many questions and needs arise. One’s own mortality becomes obvious and worries about bodily changes are common. Adjusting to expectations from family, friends, and healthcare staff can cause stress. People who are ill might feel a need to have a “poker face” when trying to avoid burdening family and friends with their worries (Beatty et al., 2008).

Those who are placed in the new life situation of being ill have a need for knowledge and information.

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Meeting others in a similar life situation, for example when having been diagnosed with breast cancer, is a common need. There is a need for sharing experiences with people whose understanding of the situation cannot be replaced by those who have not been diagnosed with cancer. Support groups and self-help groups are two examples of forums for group meetings. Support groups are characterized by being led by a professional leader, whereas self-help groups are characterized by a non-hierarchical composition in which the group members' own resources provide the force behind the group's existence and development (Gray et al., 1997). A self-help group may also have a leader, but the role of the leader is usually just to kick-start the group and to only come forward when there is a need for this; group members are the experts on their own experiences (Magnusson, 2004).

Studies have shown varied results regarding the use of a diary as a tool to express and process feelings; it is useful for some people but not for others. Analysis of the negative words written can be used as a measurement to grade anxiety and depression, but quantity and frequency of writing are not necessarily associated with equal level of anxiety and depression (Smith et al., 2005). Writing in a diary, like painting, can be a useful tool in enabling one to come to a greater knowledge about oneself and one's situation, and it can be a helpful way to bring one's own needs and limits to one's consciousness (Öster et al., 2007).

The purpose of this study was to describe the content of diary entries written by women with breast cancer while simultaneously undergoing radiotherapy and participating in a conversational support group.

METHOD

Participants and Sampling Procedure

This study reports part of the results from a case–control study conducted between February and November 2008 at the Oncology Clinic at Umeå University Hospital in Northern Sweden. Thirty-nine women were invited orally and by letter to participate in a study group including support groups, answering questionnaires, and writing a diary. Five women turned down the invitation to the study before inclusion and six women who were included in the study did not write a diary. Hence, 28 women, 41–78 years old (median age 58.8), were included in the analyses reported here.

The criteria for inclusion in the study were: referral for curative radiotherapy, being an adult, and being able to speak Swedish. The criteria for exclusion were mental or physical disability that made active participation impossible. A control group ($n = 33$) was recruited before the intervention part of the study, and the participants in the control group were asked to answer the same questionnaires as participants in the intervention group. Recruitment of patients to both groups was done consecutively because of the limited number of patients simultaneously undergoing radiotherapy.

Intervention

Participating in the intervention group consisted of taking part in a support group focusing on the communication between group members, answering questionnaires, and writing a diary during the 5-week period of radiotherapy. The diaries, which were handed out to the women during the first group meeting, had the following instructions on the first page:

> In this diary you may write freely. You may write about thoughts, joys, questions, and worries. You may write about how you feel about your participation in the conversational support group. Nothing is wrong or too small to write about.

Participants were informed orally that writing a diary was optional. The women were divided into a number of groups, depending upon when their radiation treatment took place. Each group consisted of four to seven women. The conversational group meetings lasted for 90 minutes each, and took place once a week in a conference room at the Oncology Clinic. Each group met four to five times in parallel with the 5-week period of radiotherapy.

The support groups were based on the idea of self-help groups. The participants made an oral agreement at the beginning of the intervention that they would do their best to make attendance a priority. The group leader was an experienced female nurse from the radiotherapy unit (A-CS). During the first group meeting, she explained her role as facilitator in the group, and made it clear that she intended to talk as little as possible. She recommended rules for the meetings and suggested how these could be structured in order to ensure that the participants felt it was safe to share their experiences (Johnson & Lane, 1993; Magnusson, 2004; Karlsson, 2006).

At the next to the last group meeting, the leader handed out an anonymous evaluation sheet with six questions, for the women to fill in their own experiences:

1. To me the possibility to share experiences in the group has meant. . .
2. What has been positive about the group meetings?

3. What has been negative about the group meetings?
4. Did you miss something or was something unnecessary?
5. Do you feel that you have had the time to talk about what you wanted? If no, would you like to write down what you had wished to talk about?
6. Do you have other thoughts about the group meetings?

The written diaries and the answers to the six questions were collected during the last group meeting.

Analysis

Twenty-eight diaries and sets of answers to the six open questions were included in the analysis. The diaries were initially transcribed verbatim. A method of qualitative content analysis inspired by Graneheim and Lundman (2004), consisting of several steps, was used. In the first step the two authors (SE and KO) read the text as a whole to get an overall impression. SE and KO then marked individual meaning units in the text. Next, a search for and interpretation of the core meaning in the marked meaning units resulted in creating condensed meaning units. The condensed meaning units were coded, and themes were constructed and written down. Any uncertainties about the codes in relation to the themes were addressed via continuous joint authors' discussions (SE, KO, IÖ, A-CS) as well as going back to the transcribed texts of the diaries in order to shed new light on the process of analysis and interpretations (cf. Kvale, 1997; Graneheim & Lundman, 2004; Polit & Beck, 2008).

Ethics

The study was approved by the ethical committee at Umeå University: Dnr 07-120M.

RESULTS

Structure of Writing

Twenty-six of the 28 women chose to answer the six evaluative questions in their diary and five of these only used the diary to answer these questions, leaving a total of 23 women who wrote notes other than answers to the six questions. Most women wrote notes that were dated. The lengths of the notes varied: eight women wrote several short notes (<50 words), seven women wrote one or more notes that were generally of 50–200 words, and eight women wrote one or more lengthy notes (>200 words). One of the women in this study began her writing by excusing having dyslexia. She stated that when she was informed about the diary she felt "a lump in her stomach." This woman, however, provided the greatest quantity of writing, >6000 words, and at the end of her writing she expressed that the writing process had been of great value to her.

Themes

The analysis resulted in three themes. Two of the themes characterized the interaction between the individuals and the group: *positive group development*, and *inhibited group development*. The remaining theme concerned *the individual living with the disease*. Table 1 gives an overview of the themes and sub-themes.

Positive Group Development

Mutual sharing of experiences was regarded in a positive manner by the majority of participants. A valued fellowship was often expressed and the support group was often mentioned as a place where it felt safe to exchange thoughts and find support and consolation. Three sub-themes were constructed: *exchange of experiences, affinity, and fellowship; a safe space for consolation and support; and insight and the need to adapt.*

Table 1. *Overview of themes and sub-themes, with themes shown horizontally in bold and sub-themes shown vertically*

Positive group development	Inhibited group development	The individual living with the disease
Exchange of experience, affinity, and fellowship	Reluctance, demands, and disappointment	Experiencing meaningful relations
A safe space for consolation and support	Not feeling well in the group	Experiencing success
Insight and the need to adapt	Being an outsider and wanting to fit in	Feelings of relief, gratitude, and joy
	Feelings of limitation	Feeling worried
	Lack of structure and theme	Feeling ambivalent
		Experiences of altered body-image and side effects

Exchange of Experience, Affinity and Fellowship

The exchange of experience was an important factor, mentioned by almost all women. It was viewed as an opportunity to compare oneself to others, and through the experiences of these others to gain an understanding of other people's personal experiences and situations.

> Exchanging experiences in the group has been positive; some experiences have been similar and others have not, but it feels like we are in the same boat.

The group meetings provided a way to connect to others. The fellowship found in the group sometimes led to social fellowship and gatherings outside the meetings.

> The best thing with the group meetings was that you had the opportunity to meet others in a similar situation and we have had so much fun during our time here and talked with each other about all that we've been through during this hard year.

A Safe Space for Consolation and Support

The conversation itself and the recognition of others in a similar situation were, for nearly half of the women, expressed as a source of consolation and support.

> You get to know others with similar problems with whom you can talk about different things on different levels, these conversations gives you comfort and make you stronger.

The group meetings provided a safe place where the women could discuss their worries and fears, which they sometimes felt hesitant to do in their private sphere.

> During the meetings we have been able to control the subjects of discussion ourselves. We have been able to converse in a free manner and see that we have both similar and different experiences of our treatment.

Insight and the Need to Adapt

Through relating to the experiences of the other group members, one third of the women described developing a deeper insight regarding their own experiences. Some women expressed that meetings with the group processed thoughts about their illness, whereas during the time before the group meetings had begun, some women had not thought much about the illness.

> It has partly given me a deeper understanding of my own situation and broadened my thoughts and perspective.

Inhibited Group Development

A pattern of inhibited group development was also seen in some descriptions of the interaction between the individual and the group in the diaries. Five subthemes were identified: *reluctance, demands and disappointment; not feeling well in the group; being an outsider and wanting to fit in; feelings of limitation;* and *lack of structure and theme*.

Reluctance, Demands and Disappointment

Four women expressed that they felt it was the "duty" of all group members to share their experiences. Demands from group members to talk and share were also described, as was feeling forced to socialize with the group outside the meeting when staying at the outpatient lodging during the weeks of radiotherapy treatment.

> After our first meeting the group started spending more time together. In the beginning I felt this to be a bit demanding, we were to eat together, spend time together both daytime and evenings.

Six women felt disappointed by the atmosphere that was created when sharing experiences.

> There's too much whining and negativity, but all of us are different.

Not Feeling Well in the Group

Six of the women felt that the exchange of experiences was hard to deal with, as many feelings and thoughts surfaced as a reminder of being ill. This was regarded as draining one's energy.

> At this point it feels tough, so many thoughts and feelings have been touched. I don't feel well, perhaps because were ripping apart old wounds.

Being an Outsider and Wanting to Fit in

The feeling of not fitting in to the group was described by a handful of women. Some women expressed missing someone that they could identify with apart from having the same diagnosis. Loneliness inside the support group because of differences in personality was also described.

> We are all different and maybe I would have been better suited in another group.

Feelings of Limitation

Eight women described that they experienced the group meetings as too restrained in some aspects, which did not allow group members to elaborate freely on related areas.

> We talked about what we would do after treatment. If someone said something outside the subject we were quickly steered back to the subject again. I feel like these meetings are more of a board-meeting.

Lack of Structure and Theme

Five women described a lack of theme or subject during the meetings. On the other hand, greater discontent was noted when there had been a theme for the meeting that had not been followed. Another source of discontent was when someone used too much time in relation to other group members.

> I wish there had been a certain subject for discussion during the meetings.
>
> There should be a time limit for each person so that everyone can talk. No talk outside of the subject.

The Individual Living with the Disease

The women's diary entries described living with the disease for better or worse, and expressed both successes and difficulties. The six sub-themes were: *experiencing meaningful relations; experiencing success; feeling of relief, gratitude, and joy; feeling worried; feeling ambivalent; and experiences of altered body-image and side effects.*

Experiencing Meaningful Relations

The family was described by most of the women as important, and missing one's family was commonly described.

> It's good to be home again with my man and my cat. I believe the cat has missed me, it usually doesn't want to sit in my lap.
>
> Sleeping alone and not being able to crawl up against my partners strong back feels lonely.

Five women described the importance of friends. Some women also described the friendship in the conversational support group as important.

> We have become friends for ever. We laugh and have so much fun.

Experiencing Success

A few diaries included descriptions of personal success in terms of achieving beyond one's expectations. Physical success as well as social and psychological success was expressed.

> Today is the first day that I could walk up the stairs without getting tired. My room is on the third floor. That's always something.

Feelings of Relief, Gratitude, and Joy

The women sometimes described that things could get better despite the illness. Being able to live and enjoy the present as well as having an insight to what the future with the illness might bring was also described.

> When I'm sitting on my porch in the autumn sun I only have positive thoughts. I feel SO well.

Gratitude toward the people working at the hospital and the help provided during the illness was also expressed.

> I'm so grateful that there's someone who has the strength to help us emotionally. It has helped me a lot.

Feeling Worried

Worries about how the disease had affected or would affect the women in the future were commonly described in the diaries. These included both worries regarding prognosis and the threat of disease in progress and worries about a lack of coping abilities and handling being ill. Others described uncertainty about how to cope with their situation.

> I'm so afraid that the cancer has spread. The eternal waiting for lab-results is driving me crazy.
>
> When I started to feel well, this happened. So what happens now? Will I be able to handle it?

Feeling Ambivalent

Ambivalence about the illness and everyday life was brought to the surface in four of the diaries. This was described as feeling both sadness and joy at the same time or being somewhere between hope and despair. The uncertainty of the possibility of relapse was also described.

> I still think it's difficult to tell people that I have cancer, or have had cancer.

Experiences of Altered Body Image and Side Effects

Six women wrote in their diaries about how their body and self had been affected by the diagnosis and treatments. Loss of hair and eyebrows and changes in body image such as weight gain caused by treatment were described, as well as fatigue and weakened memory.

> I was really embarrassed and I didn't have the strength to put on make-up. Each time I passed a mirror I jumped back because I didn't recognize myself.

Six women also described side effects caused by illness and treatment. This could be about having difficulties eating or keeping food down or being extremely tired during both night and day.

> I feel nauseated as soon as I arrive at the diner and smell the smell of food.

DISCUSSION

The period after receiving a diagnosis of breast cancer is a time colored by uncertainty and vulnerability. Every human is unique, and one person's experience of her illness cannot be transferred to another person. In addition, an outsider can only understand other people's experiences and emotions to a limited extent. It must be remembered that the authors' interpretation of the experiences described by the participants in this study can never be as completely authentic as the private experience of living with breast cancer (see Hörnsten et al., 2004).

The diaries analyzed in this study revealed both worries and hope in connection with the future. The disease often "catches up" with the woman who has been diagnosed with breast cancer during the time of radiation therapy, and many feelings are processed at this time. Depressive symptoms can be more common during and after radiotherapy than in the period before therapy begins (Stiegelis et al., 2004). Participating in a support group can improve adaption to the illness and reduce levels of depression and anxiety (Zabalegui et al., 2005).

The written word can be a barrier for some people. One of the women in this study felt inhibited in writing by her dyslexia; however, dyslexia is not the only criterion for feeling uncomfortable with expressive writing. Another possible barrier to writing down thoughts and feelings might be the fact that the diary was handed out (and collected) by the group leader that participants probably recognized as a nurse at the radiotherapy unit. This might inhibit negative writing about participation in the support group and perhaps reflect a more positive manner regarding being part of the intervention. This is, however, unknown to the authors, as are other possible aspects affected in this study. The number of the women in this study who felt comfortable with the writing aspect of the study is not known.

Being part of a support group can help women diagnosed with breast cancer feel less isolated and alienated by their illness. The group can be used as a safe place and a source of exchanging experiences which can lead to a deeper self-knowledge and a greater control of one's life (Gray et al., 1997; Samarel et al., 1998; Stang & Mittelmark, 2010). Support groups and self-help groups allow people in a similar situation (for example people with the same diagnosis) to meet, and participation in either type of group can be helpful. The effects of participation in a self-help group have been found to be similar to the effects of being part of a professionally-led therapy group (Gray et al., 1997; Karlsson, 2006).

This study revealed the benefits of having the opportunity to be able to share experiences with others in a similar life situation that are going through a similar illness and treatment. A valued fellowship between participants in the support group was commonly described. This is in accordance with the results of other studies (Gray et al., 1997; Coreil et al., 2004; Power & Hegarty, 2010; Stang & Mittelmark, 2010).

This study also revealed a sense of compulsion, regarding both the women's own participation and regarding their relationship to other participants in the group. Some women experienced a demand to talk and share, which was not always easy. Other women expressed feelings of "a duty" to share experiences. A silent participant in a support group can induce stress in other participants and cause negative group development if lack of trust and fellowship is present (Stang & Mittelmark, 2010). The differing levels of balance, and safety experienced in the groups, can also be explained as coincidental, and caused by the random membership in the different groups.

Qualitative content analysis was shown to be a suitable method for this study. One limitation of this study might be that the diary writing was optional, and concrete guidelines about writing were not given. This may have been a source of uncertainty among the women regarding what was valid to write about, and could have led to a "natural variation" in what was written down. Expressive writing in a diary may also be affected by the knowledge that the notes written will later be collected as part of a study and regarded as something that were not private to the women. Another question is how the women's writing may have been affected by the fact that the group leader was also part of the healthcare team responsible for their radiation therapy. This may have resulted in suppression of needs and negative feelings toward the group meetings, but the opposite could also have occurred. It is also worth noting that most of the women answered the six open questions regarding the support group in their diaries, which will have weighted the corpus toward text focusing on answering these questions.

CONCLUSIONS

Our study shows both benefits and shortcomings of an intervention with support groups focusing on conversations between women undergoing radiotherapy. Most of the women expressed satisfaction with being able to share experiences with women in a similar situation. However, this was not always the case. Because of varied and complex group compositions, sharing experiences was sometimes expressed as difficult and demanding. Some women described a lack of structure and theme as being an obstacle for easily sharing experiences in the group, whereas others, conversely, felt held back by the presence of structure and theme. In forthcoming articles we will describe additional results regarding whether group participation had an impact on coping resources, anxiety, and depression, using pre- and post-intervention measurements from the same group of women compared to a control group.

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