Research Note

From a healthy young woman to a woman with breast cancer—the breast cancer trajectory

Abstract

Objective: By using blogs written by young women diagnosed with breast cancer the breast cancer trajectory was described and interpreted

Methods: Twenty-six blogs, from Sweden and Brazil, written by women aged between 20 to 39 and diagnosed with breast cancer, were analysed using qualitative thematic analysis.

Results: A main theme was identified: From a healthy woman to a woman with breast cancer. This main theme was generated via four turning points: the message-getting the diagnosis, pre-treatment, treatment, and post-treatment. These turning points illustrate affecting moments over time. These young women went through a struggle, which gave them new perspectives due to the “before and after” experiences of becoming a cancer patient.

Conclusion: The women underwent a breast cancer trajectory from a healthy woman to a woman with breast cancer and did so via four turning points associated with facing a new and unexpected reality. Existential issues are raised. Young women with breast cancer need to be supported in this transition so they can master the changed situation and replace feelings of distress with a sense of well-being.

Keywords: Breast cancer, young women, blogs, thematic analysis, Sweden, Brazil

Introduction

Breast cancer is the most common cancer worldwide. The risk of breast cancer increases with age; it is most common after the age of 50, but although small, the incidence of breast cancer in young women has been growing every year, showing an increase in the incidence and mortality in young women i.e. <40 years of age. An Australian report shows that although breast cancer in young women is relatively rare, the number of women younger than 39 years of age diagnosed with breast cancer is not insignificant, with more than two young women diagnosed with breast cancer every day. Despite the low incidence when compared with women over 50 years of age, young women have a worse prognosis and a higher rate of mortality from the disease. In a study presenting data from all regions of Brazil for the period 1980 to 2011 showed that the mortality rate (per 100,000) for breast cancer in women >50 increased by about 13.8 % in this period, while in the group <50 years of age, it increased considerably, by about 96 %. Similar figures are shown internationally. Breast cancer is the leading cause of death in both developed and developing countries. According to the Australian Institute of Health and Welfare breast cancer is the cause of more than one death among young women every week. The incidence of invasive breast cancer is increasing steadily, while mortality continues to decline. Breast cancer has a great impact on many women’s lives. Although a diagnosis of breast cancer is distressing at any age, this occurrence in young women brings several unique challenges and problems, since breast cancer is diagnosed at the most productive time in life. There are concerns about fertility, sexual functioning, breast cancer during pregnancy or postpartum, body image, and sexual attractiveness. These problems are also related to psychosocial matters affecting daily life as career and work but also uncertainty about disease relapse. Younger women with breast cancer, in comparison with older women with breast cancer, seem to have a greater symptom burden, more negative long-term psychosocial and socioeconomic problems, and poorer quality of life after breast cancer diagnosis and treatment, and younger women uses blogs as a healing tool to manage these problems. Therefore, the aim of this qualitative, exploratory study was, using blogs written by young women diagnosed with breast cancer, to interpret and describe the breast cancer trajectory.

Method

This is a qualitative and exploratory study. By using thematic analysis (TA) according to the method of Braun and Clark, we as researchers were analysing and reporting patterns and themes within data. Breast cancer is a universal phenomenon, and since the researchers were from Sweden and Brazil it seemed logical to use blogs written by Swedish young women and Brazilian young women with breast cancer. We were not aiming for comparing the women’s experiences but identifying their trajectory.

Study participants

A purposive sampling strategy was used. Inclusion criteria were: blogs should be written by young women who had been diagnosed with a breast cancer when between 20 to 39 years of age. The blogs should be: open, accessible, and available and the women should be: open, accessible, and available within data. Breast cancer is a universal phenomenon, and since the researchers were analysing and reporting patterns and themes within data. Breast cancer is the most common cancer worldwide. The risk of breast cancer increases with age; it is most common after the age of 50, but although small, the incidence of breast cancer in young women has been growing every year, showing an increase in the incidence and mortality in young women i.e. <40 years of age. An Australian report shows that although breast cancer in young women is relatively rare, the number of women younger than 39 years of age diagnosed with breast cancer is not insignificant, with more than two young women diagnosed with breast cancer every day. Despite the low incidence when compared with women over 50 years of age, young women have a worse prognosis and a higher rate of mortality from the disease. In a study presenting data from all regions of Brazil for the period 1980 to 2011 showed that the mortality rate (per 100,000) for breast cancer in women >50 increased by about 13.8 % in this period, while in the group <50 years of age, it increased considerably, by about 96 %. Similar figures are shown internationally. Breast cancer is the leading cause of death in both developed and developing countries. According to the Australian Institute of Health and Welfare breast cancer is the cause of more than one death among young women every week. The incidence of invasive breast cancer is increasing steadily, while mortality continues to decline. Breast cancer has a great impact on many women’s lives. Although a diagnosis of breast cancer is distressing at any age, this occurrence in young women brings several unique challenges and problems, since breast cancer is diagnosed at the most productive time in life. There are concerns about fertility, sexual functioning, breast cancer during pregnancy or postpartum, body image, and sexual attractiveness. These problems are also related to psychosocial matters affecting daily life as career and work but also uncertainty about disease relapse. Younger women with breast cancer, in comparison with older women with breast cancer, seem to have a greater symptom burden, more negative long-term psychosocial and socioeconomic problems, and poorer quality of life after breast cancer diagnosis and treatment, and younger women uses blogs as a healing tool to manage these problems. Therefore, the aim of this qualitative, exploratory study was, using blogs written by young women diagnosed with breast cancer, to interpret and describe the breast cancer trajectory. The blogs should also be written by women from Sweden and Brazil. In total, 26 blogs were identified via the search terms and all fulfilled the inclusion criteria. The women in the 26 included blogs ranged from 21 to 38 years of age (median 30.25) when diagnosed with breast cancer. Thirteen out of the 26 women had children. Six women had a family history of breast cancer. (Seven of the women had passed away. This was noted in the blogs).
Data collection and analysis

Blogs were used in this study as the data corpus and the links of the selected blogs were saved in Excel spreadsheets in order to check their accessibility. Data extracted from the blogs were inserted in a particular file for analysis; in chronological order, from diagnosis until the most recent post message. No comments from blog follower were taken into account for the analysis. The data body comprised almost 800,000 words. The data corpus on the internet is expanding, as are the possibilities for researching it and due to that, ethical considerations are also evolving. Confidentiality, privacy, and other ethical principles were carefully considered by the researchers both before and throughout the study. Bloggers make conscious privacy choices that must be respected and discerned by the researchers, even if those blogs that are identified via search engines and open to responses from others are considered as public blogs. Ethical approval was obtained from the Research Ethics Committee of the University in Brazil with a waiver of presentation of consent form (TCLE No: 1,119,556) and Ethical approval was also obtained from the Regional Ethical Review Board in Sweden (Record no: 2014/498-31), who made special requests concerning the women’s confidentiality. Due to these request no statements/quotations are provided since it would be easy to identify and recognise the women on the internet.

The analysis was based on blog text in Brazilian, Portuguese, and Swedish. When qualitative research involves data in a language other than that in which it was collected, some particular considerations must be taken into account. The present study considered established guidelines for evaluating cross-language research (Squires 2008). In order to authenticate the translation, the Brazilian author conducted an analysis in English, based on the Portuguese text, and the Swedish author did exactly the same with the Swedish blogs. The Brazilian and the Swedish authors then compared their analyses, discarding the points where agreement was not reached. In this way, the findings were validated and the nuances in the language were preserved.15

The six phases of TA16 were followed for the analysis:

1. Familiarising: by reading and re-reading the data several times to gain familiarity.

2. Generating initial codes; by identifying codes in data that conveyed interesting information important for the research question.

3. Searching for themes; clustering the initial codes relevant to the research question into a theme.

4. Reviewing themes; the themes clustered from each blog were compared and contrasted, resulting in the identification of common themes.

5. Defining and naming themes; an understandable pattern was formed by the themes in relation to the data set as a whole. The content of the themes guided their naming.

6. Producing the report, presenting the themes and perhaps illustrating them.16

Findings

The analysis of these Swedish and Brazilian blogs identifying the trajectory of breast cancer in women younger than 40 years resulted in a main theme: From a healthy woman to a woman with breast cancer. This main theme was generated via four turning points: the message—getting the diagnosis, pre-treatment, treatment and post-treatment.

From a healthy woman to a woman with breast cancer

Getting the message about breast cancer was something totally unexpected. The women were shaken to their foundations. There was fear about losing control of life and maybe facing death. They realised that time was sliding through their fingers and they experienced no sense in all hustle and bustle of everyday life.

The women raised existential questions about life and death. There were also concerns about how treatment would affect their body and mind, and how it might affect their femininity, and their perceptions about themselves in society changed.

The treatment caused the women to experience more embodied worries; the body was mutilated, changed and acted differently. Some changes were manageable and others they had to accept. The main focus was on staying alive—becoming a survivor.

After treatment, the women were marked by the cancer threat. No matter what the prognosis was or what kind of treatment, there was always anxiety about recurrence or the disease worsening.

The women just wanted to be the person they once were, but daily life was affected, and life would never be normal again. The struggle they went through gave them new perspectives due to the “before and after” experiences of becoming a cancer patient.

The message: getting the diagnosis

Getting the diagnosis, the women meant that this was the worst day of their life—facing the fear of the disease of breast cancer. There were also feelings of anger and disappointment. Why did everybody, including physicians or other people around them, tell them that they were too young to have breast cancer and that they should not worry. These statements put the women in a position of false security. So, there was no need to hurry, the lump would probably go away, just wait and see. So, some of the women had a delay in getting the diagnosis by which time the cancer had spread.

Most of the women associated breast cancer with death. Getting a breast cancer diagnosis brought anxiety; they were too young to die. They did not want to die now; there were so many beautiful things to do. Falling in love, getting married, having children, raising a family. There was a fear of death but also how this breast cancer would affect their femininity. If they survived, what would they look like; without hair and without breasts. There was fear about death and fear about the future with all treatments. They felt they were losing control over life. Some women felt fear but at the same time they accepted that what would happen would happen. They did not want to die but, they would plan their funeral and they would write blogs as a testimony to their children, families and friends. They accepted the fact that they had breast cancer, and they would struggle and try to live as long as possible and live a good life. There might be facing a death sentence, but they would live until they die, for the sake of their loved ones.

Pre-treatment

There was one issue that concerned the women most—whether the cancer had spread. After the diagnosis was given, all the women had been informed that the first treatment would be surgery. After surgery they would know how to proceed. There were also thoughts about what kind of treatment there would be; chemotherapy or radiation or both in a combination, and then reflections on hormones. The women knew that no matter what kind of treatment they had there would be side effects. There would be nausea, perhaps pain, but they must
From a healthy young woman to a woman with breast cancer—the breast cancer trajectory

endure these if they wanted to be cured. But these side effects would also affect their femininity and their identity.

Surgery would change their bodies; they may appear asymmetric with one breast, but this issue could be resolved later, and could be hidden. For these women, the threat to body image was mainly due to the “mutilation” of the mastectomy. For them, a disfigured body represented the personification of the cancer, and that is how they felt the others would see them. The image they would have did not correspond to the self-image they had structured throughout their lives which represented their identity. The chemotherapy would affect their fertility, so there was a need to plan for the future and freeze some eggs. Actions taken to treat the women with hormones for egg production could be a bad thing regarding the breast cancer, if it was hormone-dependent. There were also worries about losing hair, becoming bald and even losing eyelashes. The hair was an important attribute as a woman, part of their identity. Becoming bald also made the cancer visible to everyone around. A hard task was to explain to their children why their bodies had changed, and why they looked weird. Another reflection concerned whether they needed to be treated with chemotherapy and the anti-hormone treatment, which would cause an early menopause. After all these thoughts and reflections, the greatest issue was survival. The women had to manage the treatment no matter the effects and side effects. They wanted to live and live a good life. Many of them had just started to have relationships and build families. Some had children and they wanted to see them grow up. The women tried to mentally and physically prepare themselves for what was to come; the new life as breast cancer patients.

Treatment

The women underwent surgery, chemotherapy and radiation, mostly in that order. Sometimes they had chemotherapy before surgery with the aim of shrinking the tumour. Many of the women had genetic or hormone-sensitive breast cancer so they had to add several treatments cycles and years of treatment to the standard form. These treatments continued for months, even years, with one week in between that was treatment-free. The women tried to enjoy themselves and relax during the treatment-free week; enjoy the fact that they were still alive. Sometimes there were also opportunities to have a break from the treatment. The women were pleased, but at the same time worried about this. They had thoughts about how this break would affect their cancer disease, and whether it would spread.

The surgery was frightening, but was performed to remove the cancer and to give the women information about the status of the cancer. Pain after surgery was normal and would only remain for a few days. Afterwards, the women realised that their bodies had become asymmetric or ugly, with a breast replaced with a scar.

At the start of treatment the women were worried about some side effects such as nausea, pain and especially losing their hair. They knew that there were different drugs to mitigate both the pain and the nausea. These side effects seemed manageable. But losing the hair was something else; some of the women based their identity on their hair, eyebrows and eyelashes. There were feelings of sadness at losing their identity as a young, beautiful woman, a nice mother and a model for their daughters. Some women asked for some old fashioned drugs, just to keep their hair, but these were not always successful. Step by step the women went through the treatment, surgery, chemotherapy, and radiation, and those women who were Her2Neu positive also had treatment with Herceptin.

During the treatment the women were tired, having fatigue and feeling pain. There was an emotional rollercoaster and daily life was affected. Some continued their work and academic functions even with disorders triggered by the treatment. It was extremely important to maintain part of the routine before the cancer, which encouraged them to remain strong in the fight against cancer, and showed that having breast cancer did not incapacitate them for many things, although they felt limited in some situations. Those who were used to being active and taking on responsibility now had to rely on other people. Another side effect that scared the women was the cognitive effect of treatment. They had to accept that they had problems focusing, and it seemed as if the brain was working slower. Besides these larger side effects there were plenty of small ones, all affecting the daily life negatively, such as sensitivity to warmth, losing taste, obstipation, etc. They felt that, more and more, they appeared to be cancer sick, visible cancer signs—first the breasts, then the hair and a vein catheter. They perceived this new image of them reflected in the mirror, which was like seeing another person’s image reflected; a young person, full of plans and ideas, but sick.

Post-treatment

The women realised that that they were bothersome, since they asked questions and they read about research results. Friends and workmates found it difficult to be around them due to fear of the cancer and not knowing how to behave. A common reaction from people around was that now the treatment was finished, the women are considered cured, so everything will be normal again.

The main treatment was over but there was further treatment that would last for at least five years more. It was not certain that they had been cured of their breast cancer—there could be recurrence and there could also be metastases. Some of the women had a very aggressive form of breast cancer and others had this heredity for breast cancer so they had to prevent themselves and their daughters, by taking hard decisions, about preventive surgery. So, the treatment now continued with Herpecetin, Taxotere and some would remove their breast to protect themselves. Those women who were the lucky ones with a treatable breast cancer and who had gone through the treatment and now seemed to be cured had to wait for their breast reconstruction. The women just wanted to be the person they once were. No matter in what situation these women were, there was always anxiety about recurrence or the disease worsening. Daily life was affected in many ways and it seemed as if life would never be normal again. The women now had a life-long struggle, which was short for some because they died. The trajectory of breast cancer had caused these young women to make a transition from young women to breast cancer patients and then cancer patients. Their bodies were marked, and their minds were invaded by the cancer monster. They were waiting for small signs to be awakened and to spread fear—living with the phantom of death. Due to the imminent death sensation the young women experienced a painful process, even though these experiences made them rethink their way of living.

Discussion

This study focusing on blogs written by young women, from Sweden and Brazil, with breast cancer show that this breast cancer trajectory is a universal phenomenon. The main theme, the transition from a healthy woman to a woman with breast cancer, was interpreted with support from four turning points; the message-getting the diagnosis, pre-treatment, treatment and post-treatment. Getting the
message about breast cancer was something totally unexpected. Getting breast cancer while still a young woman is a relatively rare situation and that is why the message—the diagnosis—comes as a shock. There are also feelings of anger due to delay in getting the diagnosis, having metastasis and all this fear of death, which conforms with that breast cancer has a worse survival rate among young women than older. They are young women and age has traditionally been used to define human development, which also is a component of transition: they are not supposed to die now. Those young women were expecting to have a future, a life ahead of them.

The women raised existential questions about life and death. This reaction agrees with another study, where a breast cancer diagnosis is seen as a death sentence. The women became aware that they were not immortal. This awareness made the women engaged in the transition process and they started to seek answers to different questions, identifying ways of living but also adapting to the new situation.

First, there needed to be treatment but how would that affect them, their body, their survival? Those women’s body image would change as well as their sexual functioning (including fertility) and this is what other studies also point out and also the psychosocial aspects of being out of “sync”—there was a disruption of the normal life course. Those women who did not yet have an own family, with own children was longing for that, especially the Brazilian women. All of a sudden the normal life course was interrupted. The women prepared themselves psychically and mentally, but they also adapted to the situation of starting treatment as a breast cancer patient and focused on survival. Those women having this awareness of their mortality also highlighted that they were still alive, they would fight to stay alive and that they would live until death, which conforms with findings from Vargens and Berterō. The treatment caused the women more embodied worries; they had to focus on different treatments, their side effects and how these side effects affected their body and mind. These worries were well-grounded, since younger women are at risk for more psychosocial problems related to development, body image and sexual functioning etc. During these treatments, daily life was affected and there was an emotional rollercoaster; they experienced tiredness, sadness, anger, problems with focusing and uncertainty about survival. In addition, they perceived themselves with this new image reflected in the mirror, where they saw a sick cancer patient. These emotional reactions were also found in the results of Adams et al.

After treatment, the women were marked by the cancer threat. Even though the treatment-cycles were finished, there was further treatment lasting for several years. It was not certain that they were cured—there could be recurrence and there could also be metastases. This agrees with what Thewes, Lebel, Seguin-Clair and Butow (2012) state, that fearing recurrence marks young breast cancer survivors. These feelings of uncertainty concerning the future meant that they could not control what would happen in life. The concerns about loss of control and independence or being a burden to others were there and these women just wanted to be the same as they once were. The women now had a life-long struggle, some a shorter since they died. The feeling of having an established “end of life” led to the experience of loss of their socially elaborated role. The trajectory of breast cancer had made these young women make a transition from young women to breast cancer patients and then cancer patients. They had to living life with a new normality.

Our sample comprised 26 blogs, which is a good sample size in qualitative research. There was an amount of data—and only the blogger’s own text was used. No comments were used in the analysis. The limitation is that there were no possibilities to get clarifications or to ask follow-up questions, which could be seen as affecting the trustworthiness negatively. On the other side, if we asked the bloggers they would probably change what they had written and we would not have obtained their own unaffected experiences about the breast cancer trajectory.

In conclusion the main theme; the transition from a healthy woman to a woman with breast cancer, illustrates the trajectory these women were undergoing. The women are via four turning points; the message—getting the diagnosis, pre-treatment, treatment and post-treatment, facing a new and unexpected reality. The women need to be supported in their transition so they can master the changed situation and replace feelings of distress with a sense of well-being.

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Conflicts of interest

The authors declare that there is no conflict of interest.

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