

Listening to Women's Voices: Using an Adapted Photovoice Methodology to Access Their Emotional Responses to Diagnosis and Treatment of Breast Cancer

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Abstract

Introduction: The emotional impact of a diagnosis of breast cancer in women and listening to their affective needs is not widely reported in the literature. Recent policies globally emphasize the importance of incorporating patients' views in treatment. The aim of the study was to provide insights for health care professionals and make recommendations based on patients' experiences. Breast cancer survivorship is increasing, but the long-term support needs of such women are less understood. **Method:** This exploratory study asked 20 white women from 2 urban centers in the UK about their experience of diagnosis and treatment for breast cancer. It used an adaptation of the photovoice methodology to examine a health issue and identify issues of importance and relevance to patients. It recognizes their expertise in their situation. **Results:** The themes identified were: Fear/Shock; Waiting; Lack of Control; Communication/Practicalities; Body image changes; Specialist versus nonspecialist Centers/Staff; and Ongoing Support. **Discussion:** The women provided images, with a written summary of their meaning, and discussed them in groups. They identified good practice and suggestions for how to improve the experience of diagnosis and treatment of breast cancer. **Conclusion:** The photovoice methodology provides a low-cost, easy to implement a way for patients to provide insight into their experience and contribute their knowledge to improve clinical practice. Visual images and patients' words allow clinicians to have greater insight into the environment and priorities of patients which could have implications for their response to treatment and long-term care.

Keywords

patient perspectives/narratives, breast cancer, qualitative methods photovoice, clinician-patient relationship

Introduction

In recent years, patient participation in decisions about their care is recognized as important (1,2). More ethical practice occurs when clinicians and patients work together making shared and informed decisions. Mockford et al (3), in their systematic review of patient and public involvement (PPI) into research and clinical practice, identified a number of benefits from encouraging patients' involvement in treatment options and experience. For example, patients were able to provide insights and information about their experience both of treatment and about the condition itself. Thus, clinicians gained greater awareness of the condition as well as how and why patients could benefit. Patient and public involvement initiatives led to changes in the way in which clinicians worked with patients and increased their support for greater patient involvement in their treatment. Therefore, greater priority was given to using the patients' insider knowledge and

involving them in planning services. The UK Government has implemented a policy of "Nothing about me, without me" (1) aimed at identifying ways in which patients can take a more active role in expressing their views about their treatment. Ocloo and Matthews (4) identify that implementation of such policies often falters due to a lack of certainty as to how, and in what ways, patients can be included. Similarly, Lorenz and Chilingirian (2) explore the concept of Fair

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Process which is a model for including involvement in the whole of the patient's life into clinical decisions.

Mayfield-Johnson et al (5) used Photovoice with Black and Afro Caribbean women in the United States to explore the experience of Community Health Assistants (CHAs) working within their community about participation in breast and cervical awareness raising initiatives in screening programs. However, participants were CHAs rather than patients.

Lopez et al (6) selected photovoice to gain insight into how 13 African-American women breast cancer survivors defined quality of life. The researchers set tasks for the participants, thus shaping the photos participants took. There was a lack of opportunity for the participants individually to reflect and write down their interpretation of each photo before discussing them with other participants.

Breast cancer is the most frequently occurring cancer in women in England and the latest figures suggest 1-year survival to be about 96% and 5-year rates at approximately 83% (7). These higher levels of survival require better understanding of how women experience diagnosis and treatment to inform best practice in the short-term and what support would benefit them longer-term. Initially, this research was to develop training materials for health care professionals attending a module on caring for oncology patients at the researchers' university to gain greater insight into the patient experience and influence their practice. The findings from this research were further shared in various ways. The key themes with images and quotes from the women involved have been exhibited in university and local libraries in the Midlands of the United Kingdom. The same images and words have been shared with Macmillan Cancer Support, who endorsed the exhibition and provided THEIR leaflets and additional material and a Maggie's Centre; a presentation was made to Christies' researchers in Manchester; and conference presentations are planned, along with other journal articles, for both academic and nonacademic audiences.

The research aim was: to gain insight into how women perceived their experiences of diagnosis and treatment of breast cancer to better inform health care professionals. The research questions are:

1. What were the women's experience of diagnosis and treatment?
2. What was perceived positively?
3. What was perceived negatively?
4. What recommendations would the women make to improve their experience?

Method

Wallerstein and Duran (8) and Wang and Burris (9,10) identified the benefits of using participatory methods in health research as they recognize the expertise and knowledge people have about their circumstances. The photovoice

methodology is usually used with existing communities as a way of involving them in both the identification and resolution of a health care issue through implementation at the local community level (5,6,9–11). It has been used with individuals to explore the individual's experience of health conditions in a more holistic ways (2,12). However, in this research project, the participants were members of a community with a health care issue through their shared experience of a diagnosis and treatment of primary breast cancer. Thus, photovoice was adapted by bringing together participants who shared an experience with the researchers setting the aims and questions. The knowledge of the experience came from the participants.

To retain the ethos of photovoice whereby the participants generate the data using both images and words (2,5,6,9–12), while meeting the requirements of the research aims and questions, the question was deliberately wide and non-directive, "What is your experience of diagnosis and treatment of breast cancer." Participants were asked to create images and captions. The photovoice methodology provides for greater collaboration between researchers and participants, encouraging participants to take a lead in data generation. Ethical consent was gained from the university's ethics committee prior to the start of the research.

Recruitment was through a snowballing technique using the researchers' social networks. The selection criteria were women with a primary diagnosis of breast cancer. No time-frame was set for when the breast cancer was diagnosed. This is in recognition that primary breast cancer is curable and that survivorship can extend over a long period of time with the impact of diagnosis and treatment not necessarily limited to the period when monitored by health care professionals. Twenty white women were recruited from 2 locations in England. No personal data was collected, although this did emerge during their discussions. In keeping with the photovoice methodology, participants were asked to come together as a group. Ten of the women were part of an established Breast Cancer support group. Two further groups of 5 women were formed on the basis of when individuals could attend a meeting with the researchers. Some participants knew each other previously and others did not.

Two meetings were held with each group. At an initial meeting, the researchers briefed participants on the aim of the study, including discussing ethical issues. Participants were asked to create images of their experience and to write a short explanation of what the image represented to them (the photo and voice—words—elements of photovoice). Questions by the participants about the task led to examples being generated by them, such as, "Do you mean how I found out I had breast cancer and my feelings when the letter arrived?" An image of a letter was considered along with words to explain it. Unlike other photovoice projects, the participants were not provided with disposable cameras nor were specific questions set neither was the type and number of images/words proscribed. This was part of the adaptation of exploring the experience and trying to demonstrate the



Figure 1. Sheila's Waiting Collage.

participant-led nature of the data generation. As the participants were from affluent backgrounds, they had the resources to produce their images and were used to seeing television and internet images to be informed. The format participants produced of images/words was varied. Some chose to create a narrative of their experience illustrated with images, either hand-drawn or downloaded from the internet. Others provided a few pictures cut out of magazines or newspapers to which they gave captions.

There was a time lag of 2 weeks before a second meeting was held with the same 3 groups. This was to provide the women with the opportunity to reflect on their experience of diagnosis and treatment and to create their images and words. It also allowed for a “cooling off” period whereby they could withdraw should they wish. The women brought only those images they wished to share. This was important due to the sensitive nature of the topic. Pseudonyms were used to protect participants' identity. Researchers did not see the images until this time.

With permission of the participants, the second meeting was audio recorded. Each group began by participants being asked if anyone would like to share any of their images and captions. Usually 1 participant showed the others an image explaining why she had given it a particular caption. The combination of visuals and words helped group members discuss their own contributions. Figure 1 shows Sheila's Waiting Collage typified this as other participants added comments about similar or different experiences, sparking new topics which may not have originally had an image or comment. The women's words led to the theme with a quote used which best articulated its concept. In this case, the discussion focused on Waiting in its various forms. This adaptation of photovoice with a participant-led discussion meant the topics covered were those of importance and relevance to them. They tended to facilitate the group and include everyone with the researchers only asking for clarification, usually around treatment aspects and drug names.

Wang and Burris (8,9) use a structured approach to facilitate the discussion of participants' images and their words with an emphasis on solving a specific health community issue. As the participants were unlikely to take on a central role directly in informing health care professionals of the issues raised, it was decided to take a thematic approach based on using the data generated to answer the research questions. Analysis of the images/words and the transcripts

of the group conversation was based on the theoretical underpinning of community-based participatory research (8,13). The photovoice path (2) was covered with all participants being involved in individual image/narrative construction then sharing and reflecting.

The 3 researchers independently read the group discussion transcripts, in conjunction with looking at the images/words of the participants. One of the researchers went through the transcripts to identify which image/words were being discussed and used an identifying number for use by the other researchers. Each researcher annotated the transcript and related images to identify key themes and met together to discuss their individual findings, grouped quotations into themes then agreed theme titles. Seven themes were agreed upon: Waiting; Fear/Shock; Lack of Control; Communication/Practicalities; Body image changes; Specialist versus nonspecialist Centers/Staff; and Ongoing Support. Those participants, who were willing to do so, reviewed the themes and relevant images. They endorsed the themes as relating to their experience and that the specific image related to their group discussion. The original caption of the image reflected their experience.

Results

Table 1 presents linking the themes to the research questions, provides examples from the discussion of the images/narratives to the themes. The fourth research question concerning recommendations is summarized in the Discussion section.

Themes

Waiting (Research Question 1). There were many references about how time passed in waiting at various points in the diagnosis and treatment stages: the initial diagnosis in specialist centers generally occurred within a day. Between each stage time was describes as passing very slowly, leading to increased anxiety. Sheila's image (Figure 1) showed different chairs using various fonts around the concept of “waiting.” Her caption listed all the times when she found herself waiting. In discussion, the women echoed this sentiment, sharing different images. Time is distorted by the waiting, going beyond the treatment process. Some spoke of the potential wait for the cancer to return.

Table 1. Linking the Themes to the Research Questions.

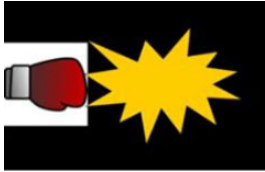





Research question	Theme	Comment	Image
1. What were the women's experience of diagnosis and treatment?	Waiting	See Figure 1.	
	Fear/Shock	Wham, I wasn't expecting that.	
	Body image changes	I'd just wake up in the morning and the pillow would be full of hair. Or any gust of wind and your hair floats away	
2. What was perceived positively?	Communication/ Practicalities	The nurse held my hand and explained the procedure in detail. I'm so glad she did!!!'	
	Support with body changes/advice	Advice about wigs and scarves was helpful	
	Specialist Centers	Having the same nurses who were knowledgeable	
3. What was perceived negatively?	Ongoing support	I think that you need to talk to someone that's had it more than anything else . . . because they give you the tips	No image due to anonymity (Organization leaflet)
	Lack of control	The chair reclined, tipped you forward, you had nothing to do. I felt smothered and mothered throughout the whole process.	
	Communication GPs Nonspecialist centers	I was in a general ward, the nurse asked if I was in for breast reduction	No image due to anonymity (Hospital ward)



Figure 2. Liz's picture of drain bag with a tube, contrasting with her caption.

Fear/Shock (Research Question 2). Some women described shock and fear on receiving a recall letter or on finding a lump. Part of this came from not having considered that they would get cancer. One woman explained it was like being punched in the stomach or the emotions of being on a rollercoaster: shock, disbelief, and relief.

The diagnosis led to consideration of their mortality. Pat's response was: "And the first thing out of my mouth was, 'Am I going to die?'" This led to solidarity among participants as they acknowledged their shared experiences and emotions. They felt uncertainty about the future, leading to hesitation about any forward planning. Ivy said, "I wouldn't book anything because I thought that I might not live to do it." They lived in the present, facing life day by day. The shock of the diagnosis became part of who they are, continuing in their thoughts and behaviors.

Lack of Control (Research Question 3). There was consensus of relinquishing decision-making power to others. The appointments system for treatments meant their lives were on-hold "... it's like being in limbo, because you've lost control. You've lost control, that's what I felt. That really for twelve months I'd lost control." In the women's normal role, they are directing their families and households, thus they felt their self-identity was challenged. Taking control away from them added to their anxiety with potential implications for their response to treatment.

Communication/Practicalities (Research Questions 2 and 3). Communication channels was a very strong theme and mentioned by everyone. The women explained how information they were provided, small gestures by others or learning through experience, helped them to feel more at ease. Fay explained that she felt better once she knew the system and had some knowledge: "such as the best place to park, whether I would need to take a drink or to make sure I had a book to read." Lucy summarized this, "It's the periphery things really, until you get into the swing of it." Ivy identified that, "information is what gives you control." Iris highlighted that, "The information in the booklets is sometimes out of date and not always right." They wanted up-to-date information about practicalities, such as parking, and what to expect in treatment.

Effective support from clinicians was valued. Marg's example was the nurse who prepared her for a biopsy: "You will hear a loud noise, it's not going to hurt but it will feel uncomfortable and it will make a loud noise." She emphasized the explanation was *all information, not patronising, not trying to beat around the bush but explaining what was going to happen*. Other women agreed that the people who did their biopsies were kind and gentle, checking if they had had one before.

A big issue for the women was the lack of explanation about the drain put in after surgery (Figure 2).

Iris explained she was quite clueless as I came out of hospital with about 3 yards of tubing and a bottle. This was shared by another woman: It was for 10 days I think that it was that I had the thing in. It was on a vacuum thing and the vacuum failed, and I had to go back and they put another bottle on and I did not like that at all, I hated that. The difference between participants' expectations of a "tube" and their experience could have been much improved by a clearer explanation.

Body Image changes (Research Questions 1 and 2). Previous awareness of others with breast cancer brought anxiety in itself, particularly when not discussed or explained in advance. The strong association between breast cancer and hair loss was reflected by the women. Their hair fell out gradually. It was insidious: "in the plughole after showering, on the pillow when waking and blown out in windy conditions when in the street" (Lucy). The women appreciated advice on appropriate wigs, makeup, and the use of scarves. Having the opportunity to share their experiences and their emotional impact gave them a sense of community. Although hair may grow back, the longer term implications of changing the body shape due to surgery is not often mentioned in the literature. The tattoos, given during radiotherapy, remain even after a cure is achieved. They described feelings of a shadow, representing the cancer's potential return.

Specialist versus nonspecialist Centers/Staff (Research Questions 2 and 3). Some went to specialist centers where staff were knowledgeable, trained, and experienced with treatments and had time to provide reassurance, reducing anxiety. Specialist Breast Cancer nurses were particularly valued: "She

would write things on the front of leaflets and make it personal” (Faye). This contrasted with, “in the local hospital there is not a breast cancer ward, so you go onto a mixed ward. I got most upset because some nurses they thought I was in for a breast reduction” (Lucy).

General Practitioners (GPs) in the United Kingdom have responsibility for monitoring, apart from an annual hospital mammogram. The support offered by GPs varied enormously. Their lack of understanding resulted in dissatisfaction. Jude experienced depression as a side-effect of medication. The GP’s nurse lacked confidence to change the tablets as prescribed by the hospital, resulting in Jude waiting for her annual breast cancer nurse check before action occurred. However, Jennifer received a supportive phone call from her GP, after he received the hospital letter about her diagnosis, but when Ivy went to her GP, “he took the letter, logged on to his computer, avoided eye-contact and gave me a prescription for anti-sickness tablets.” This left her feeling dismissed and isolated.

On-Going Support (Research Question 2).

Talking to others who had experienced a diagnosis and treatment of breast cancer was valued, there was a lady who used to ring me up. She had had breast cancer and it was like peer support . . . and she had had some training on how to talk to people that was really amazing and so supportive (Ivy).

Opportunities provided by the hospital to meet with other patients and engage in activities such as art and crafts were beneficial.

Discussion

Photovoice encouraged individual reflection of the experience, particularly as they had time between the initial briefing meeting, the construction of their images then discussing and sharing them with others which add to the patient’s definition of quality improvement as described by Lorenz and Chilingirian (2). In contrast with Lopez et al (6), the women in this research identified their own issues and articulated their meanings without researcher direction. In this research, the participants were not required to produce their images/comments using researcher-provided cameras. Such flexibility meant they used a range of formats relevant to what they wished to express. The different formats were discussed among the participants as they shared their images and meanings.

The aim of this research was to gain insight into how the women experienced diagnosis and treatment of breast cancer so that they can be better supported and health care professionals have access to their thinking (1–4). From the themes, which were common across the 3 groups with similar words and images produced, there are some key learning points for health care professionals and policy makers (4).

The first research question was concerned with the women’s experience of diagnosis and treatment. The themes

of Waiting and Fear/Shock are clearly expressed through the images and words of the picture captions and discussions. It is likely that if health care professionals openly acknowledge this then the transition through diagnosis and treatment is likely to be easier for newly diagnosed patients.

Participants felt positive when health care professionals recognized their unfamiliarity with the cancer experience and explained procedures in advance, for example, the nurse explaining the biopsy procedure. Providing practical suggestions for how to manage the changes in body image were welcomed and reduced anxiety. The negative aspects were when clinical practices and procedures, familiar to staff, were not explained to patients (drainage bags and tubes). Different images were used by participants to describe the drainage bag which is an example of how photovoice with its use of image and words can generate discussion among participants who may not have brought such as image themselves, but the discussion generates wider insight into an issue of relevance to all. Recognizing such potential points, when assumptions can lead to misunderstanding and alleviating these, helps to ease the path through cancer diagnosis and treatment. Frustration resulted over short-notice of appointments. This compromised the women’s need to plan; their desire to meet ongoing caring duties during treatment; and retain a sense of control over their lives. The photovoice methodology (2,12) with its use of images and words provides clinicians with insight into the wider world of the patient and their environment.

Research question 4: What recommendations would the woman make to improve their experience, provided insight into how understanding the patient’s context can improve the delivery of service (2). The recommendations by the women in this research are that knowledgeable and experienced staff helped the women to feel they could ask questions and develop relationships (specialist centers). The highest priority identified is for training in interpersonal communication, specifically developing empathy and listening skills, for all health care staff, especially GP practices about how to respond to a diagnosis of cancer. GP practice staff would benefit from increased knowledge about how to monitor patients with cancer long term which would result in better patient care and avoidance of inappropriate medication. The women valued the continuity with their GP surgeries. Effective, ongoing, and available support is likely to increase in importance as the survival rate and length of time women living with it increases.

An unexpected outcome of this research was the women found the research group helped them to process their experience. The women identified that there is an ongoing concern that the cancer could return and that there are real benefits from being provided with the opportunity to have support from others. In the established breast cancer support group, some of the women had continued membership for over 10 years. The women who were not members of a support group commented on therapeutic aspects of the group and how it gave them space to understand their

experience and ongoing concerns, which reflects Baker and Wang's findings (12). Two sisters who participated had been diagnosed with breast cancer about the same time. They felt the research allowed them to share things not previously discussed or shared with each other. The opportunities to participate in activities and conversations with others who had had the same diagnosis were seen to be valuable and important. Talking to others, who had been in their situation early in the diagnosis, was valued as giving insight into the patient experience. Self-help groups may provide effective psychological support both during and after the end of medical intervention.

The concerns raised by Ocloo and Matthews (4) as to how patients can be actively involved in the implementation of PPI policies may in part be answered by the use of the photovoice methodology. In dissemination activities with cancer support organizations (Macmillan) and specialist centers (Christies' Researchers, Maggies), as the material produced for the exhibition was both visual and verbal, provided access to the participants expressing themselves and giving insight to professionals. A further paper relating to the way in which the photovoice materials were used and received by oncology students is in preparation.

Limitations

This was a small scale study with only white women who had experienced breast cancer. There would be benefits in extending the range of gender, types of cancer, and ethnic/social diversity of participants to further explore the effectiveness of the photovoice methodology (5,6,11,12).

Although participants identified the topics, they were not directly involved in the data analysis. It would be worthwhile exploring this in future research to identify whether there would be a further depth of insight from additional participant reflection of the data and better inform practice (1–3).

Conclusions

Previous research (1,2,12) emphasized the benefits from involving patients and sharing the knowledge. The difficulty is how to achieve this (3,4). This research showed that using photovoice helped the women articulate what they wanted and needed. The photovoice methodology used provided the means to achieve participation. This is potentially a low-cost and easy to implement process to both involve and support patients through their experience of diagnosis, treatment and long-term survival.

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