

Qualitative versus quantitative study of distress in a sample of young age breast cancer survivors

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Context

Breast cancer survivors suffer from distress that extends along a continuum: from common normal feelings of vulnerability to disabling psychiatric symptoms.

Aim

The aim of this study is to describe the 'lived' experience of distress in a sample of young breast cancer survivors using a person-centered approach, determine the coping mechanisms used, and the prevalence of anxiety and depression in these patients.

Patients and methods

This is a cross-sectional descriptive study in which 30 Egyptian female breast cancer survivors diagnosed between the age of 20 and 40 years were selected among the patients attending the outpatient clinic of the Oncology Department, Cairo University Hospitals. The Hospital Anxiety and Depression Scale was used to assess the prevalence of anxiety and depression among a sample of survivors and the Coping Processes Scale was used to determine the coping processes that they use in the face of their distress. A person-centered approach was used to determine the extent of their distress and gain a better knowledge of each survivor's experience with cancer.

Results

The prevalence of anxiety was 70.0% and that of depression was 63.3%. There was a statistically significant negative association between acceptance and depression and a negative association between seeking information and social support and anxiety.

Conclusion

Each patient had different experiences and different stress-related cancer effects and management. Each patient is unique in her experience so we must listen to each patient.

Keywords:

breast cancer, coping, distress, person-centered approach, survivors

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Introduction

Breast cancer is the world's most common cancer among women, and the most likely cancer that a woman will die from worldwide [International Agency for Research on Cancer (IARC), 2012]. It is estimated that female breast cancer is common in China and Egypt, despite a marked difference in incidence rates, being much higher among Egyptian women compared with Chinese women (Ibrahim *et al.*, 2014; Zeng *et al.*, 2014). The incidence of breast cancer differs considerably among rural and urban populations in both countries, with the higher urban incidence being consistent across all women older than 45 years of age (Zeng *et al.*, 2014; Dey *et al.*, 2010).

Distress in cancer patients has been defined as 'an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment.' It extends along

a continuum, from common normal feelings of vulnerability, sadness, grief, and fears, to syndromes that are disabling, such as depression, anxiety, and panic disorders (National Comprehensive Cancer Network, 1999).

The purposes of the Person-Centered Medicine may be summarized as promoting a medicine of the person (of the totality of the person's health, including its negative and positive aspects). The concept of diagnosis in the Person-Centered Integrative Diagnosis is to provide a broader understanding of the person's health status, describing both positive and ill health and to also include an innovative focus on

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positive aspects of health such as adaptive functioning, protective factors, and quality of life, deemed crucial for enhancing recovery and health restoration; each individual has his or her own way of experiencing and coping with health problems within their specific life circumstances (Starfield *et al.*, 2005). Individuals wish to know that their health worker understands them and their suffering. As a start, simply asking patients how they feel about their illness and how it affects their lives, rather than focusing only on the disease, results in measurably increased trust and compliance (Fiscella *et al.*, 2004) that allows the patient and the provider to find a common ground on clinical management, and facilitates the integration of prevention and health promotion in the therapeutic response (Mead and Bower, 2000; Stewart, 2001).

The aim of our study is to describe the 'lived' experience of distress in a sample of young breast cancer survivors using a person-centered approach (Miles and Mezzich, 2011) and to determine the prevalence of anxiety and depression using questionnaires testing depression and anxiety in the usual symptom format.

Patients and methods

This is a cross-sectional descriptive study in which a sample of 30 Egyptian female breast cancer survivors diagnosed between the age of 20 and 40 years was interviewed. They were selected from among the patients who were attending the outpatient clinic of the Oncology Department, Cairo University Hospitals. We included the patients who fulfilled the following criteria: diagnosed with breast cancer within the age of 20–40 years and their age did not exceed 45 years at the time of assessment because we intended to study a sample of young survivors, and under follow-up (after completing all the required treatment regimens: surgery, chemotherapy, and/or radiotherapy). Breast cancer is very rare among individuals younger than 20 years of age, and after the age of 40 years, the patients are not considered young breast cancer survivors. Moreover, patients, who were older than 45 years at the time of assessment were probably suffering from recurrence or metastasis. Thus, those patients were exposed to different stressors and had different fears and concerns than the patients who were not suffering from recurrence or metastasis. Patients who were still taking hormone therapy or receiving targeted therapy were included in the study. Patients were selected irrespective of their social, marital, or demographic characteristics to allow for a variety in personal experiences while

using the person-centered approach. In practice, the term 'survivor' is used when referring to the breast cancer patient since the time of diagnosis or after completion of the treatment regimen and is under follow-up. In our study, we needed to focus on patients who had completed the treatment regimen because their issues and concerns are different from those who are still receiving treatment.

We excluded the following patients: those who were newly diagnosed with breast cancer; those who claimed to have a previously diagnosed chronic disease as this would confound and bias the study; patients who had been interviewed before; and uncooperative patients refusing to participate in the study.

Informed written consent was obtained from every patient before distributing the questionnaires or interviewing them. The study design was approved by the Ethical and Scientific Committees of the Psychiatry Department, Faculty of Medicine, Cairo University.

Data tools and collection

A mixed-method study was used. The study included two rounds: a quantitative data collection phase where psychometric tests were applied for all patients, followed by a qualitative study of only 12 patients.

Quantitative data collection phase

We preferred to use the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) to other scales because its depression subscale items focus on the anhedonic state (loss of pleasure) as the cardinal symptom of depression, and is the most likely to respond to antidepressant drug therapy. Care was taken to avoid items that could be attributed to physical illness, such as headache or dizziness. The score for each subscale (anxiety and depression) can range from 0 to 21, with scores categorized as follows: normal (0–7), mild (8–10), moderate (11–14), and severe (15–21). Scores for the entire scale (emotional distress) range from 0 to 42, with higher scores indicating more distress. Then, the Coping Processes Scale (Ibrahim, 1994) was applied to assess different coping mechanisms that could be used to deal with stressful situations. It is classified into five categories: I, mechanisms dealing with the source of a problem (active coping and exercising restraint); II, behavioral strategy to decrease emotional reactions to stress (helplessness and emotional discharge); III, cognitive activities dealing with the problem in an attempt to solve it (positive reinterpretation and denial); IV, cognitive processes

dealing with the emotional side of a problem (acceptance, mental disengagement, and wishful thinking); and V, mixed behavioral and cognitive mechanisms (information, social support, and turning to religion). It is a self-rated scale. Each one of the 11 coping processes has certain phrases and each phrase has a score from 1 to 4, and then the total score for each process is calculated. The normal cut-off value ranges from 35 to 65, where a low score is less than 35 and a high score is more than 65.

Qualitative data collection phase

Twelve out of the 30 patients were interviewed using in-depth interviews to determine how their quality of life has been affected by the cancer experience from each patient's own perspective. In-depth interviews used the person-centered approach to explore in detail the respondent's own perceptions and accounts (Green and Thorogood, 2004). They were one-to-one nonstructured interviews. Each patient was interviewed once and each interview lasted from 75 to 90 min. The interviews were recorded using pen and paper documentation of the entire interview. We used open-ended questions such as the following: 'Could you please describe for us how your cancer experience affected you?' and 'What's the difference between your life before the cancer experience and after it?' According to the patient's response to the questions, further questions were asked to gain as much insight as possible into her unique experience. We attempted to explore feelings, emotions, and circumstances in great detail. We attempted to understand what 'cancer' meant for each patient and how it affected her life.

Quantitative data analysis

Data were coded and entered using the statistical package SPSS statistics program (Version 17, SPSS Inc., Chicago, IL, USA). Data were summarized using mean, minimum, and maximum for quantitative variables and frequencies (number of cases) and relative frequencies (percentages) for categorical variables. Comparisons between quantitative variables were performed using the nonparametric Mann-Whitney *U*-test when comparing two categories. *P*-values less than 0.05 were considered statistically significant.

Results

Quantitative data results

Demographic and clinical data

(1) The mean age of the patients was 36.8 years; the minimum age was 24 years and the maximum age was 45 years at the time of assessment.

- (2) In terms of the patients' marital status, 24 (80%) were married, three (10%) were single, two (6.7%) were divorced, and one (3.3%) was widowed.
- (3) In terms of the patients' occupational status, 25 (83.3%) were unemployed and five (16.7%) were employed. One was a secretary, one was a hairdresser, one was a lawyer, and two were teachers.
- (4) In terms of the patients' educational status, 17 (56.7%) were illiterate, nine (30%) had an institutional or faculty education, and four (13.3%) hadn't gone beyond high school education.
- (5) In terms of the patients' time since diagnosis, 11 (36.7%) were surviving their first year following diagnosis, 10 (33.3%) were surviving their first 2 years following diagnosis, and nine (30%) were surviving their first 5 years following the diagnosis of breast cancer.
- (6) In terms of breast reconstruction, 28 (93.3%) did not undergo breast reconstruction and two (6.7%) underwent breast reconstruction.

Psychometric data

We found that the prevalence of anxiety among our sample was 70%, where 47.6% of them had mild anxiety. The prevalence of depression was 63.3%, where 52.6% had moderate depression (Table 1). All the 30 patients showed average use of active coping, exercising restraint, mental disengagement, and wishful thinking. There was average usage of helplessness among 90%. The use of emotional discharge was average among 80%. The use of positive reinterpretation was average among 76.7%. The use of denial was average among 93.3%. The use of acceptance was average among 56.7%. The use of seeking information and social support was average among 90%. The use of turning to religion was average among 76.7% (Table 2).

Table 1 Percentage of patients with different grades of anxiety and/or depression

Hospital anxiety and depression (HADS) scale	Count (Percentage)
Anxiety	
Present	21 (70.0)
Not present	9 (30.0)
Anxiety grades	
Mild	10 (47.6)
Moderate	3 (14.3)
Severe	8 (38.1)
Depression	
Present	19 (63.3)
Not present	11 (36.7)
Depression grades	
Mild	8 (42.1)
Moderate	10 (52.6)
Severe	1 (5.3)

Table 2 Percentage of patients using different coping mechanisms and whether their usage of each coping process is low, high, or average

Coping processes scale items	Degree of usage	Count (Percentage)
Active coping	Average	30 (100.0)
Exercising restraint	Average	30 (100.0)
Helplessness	Average	27 (90.0)
	High	2 (6.7)
	Low	1 (3.3)
Emotional discharge	Average	24 (80.0)
	High	5 (16.7)
	Low	1 (3.3)
Positive reinterpretation	Average	23 (76.7)
	High	6 (20.0)
	Low	1 (3.3)
Denial	Average	28 (93.3)
	High	2 (6.7)
Acceptance	Average	17 (56.7)
	High	13 (43.3)
Mental disengagement	Average	30 (100.0)
Wishful thinking	Average	30 (100.0)
Seeking information and social support	Average	27 (90.0)
	Low	3 (10.0)
Turning to religion	Average	23 (76.7)
	Low	7 (23.3)

There was a statistically significant negative association between the presence of anxiety (by HADS) and the item of seeking information and social support of the Coping Processes Scale ($P=0.039$). Also, there was a statistically significant negative association between the presence of depression (by HADS) and the item of acceptance of the Coping Processes Scale ($P=0.032$).

Qualitative data results (phenomenological analysis)

The 12 patients had in common their high spirituality as a source of power for them. This kept them going. This was the factor that helped them cope with their cancer experience. One survivor stated the following: 'I take God as a friend. I talk to him all the time now. I am grateful for my cancer experience because God always does what is best for us. I don't think much about recurrence because I believe what is destined is what will happen and it's all for the best.'

One patient also believed that cancer was brought upon her by God as a means of bringing her closer to Him, stating: 'God wanted me to get closer to Him, so He gave me this bliss. I wasn't that close to Him before my cancer experience. God gave me that experience because He is merciful.'

Two of the patients underwent breast reconstruction surgery and they reported that it meant a lot to them.

It made a considerable difference in their lives by improving their body image and self-esteem.

For some patients, social support was a very important factor in their fight with the disease; one patient stated the following: 'My husband is too good to be true. After the surgery, I was so shy, I didn't want my husband to see my body, but he was always there for me telling me that he loved me and that I was beautiful the way I was. I don't know what I would have done without him and his support. He stood by me and this helped me so much in getting back to normal and in viewing my body as whole again.'

For other patients, the cancer experience did not affect them that much and these were the patients who had a great deal of financial or social stressors or suffered from a greater loss. For example, one patient lost her father to heart failure and she stated the following: 'My cancer experience is nothing compared to the loss of my father. I am ready to face cancer and its pain a thousand times, but I still can't bare the idea that my father is gone. After my father's death, no experience is too painful and all I feel is indifference to everything.'

We could also observe the contradicting effects of chemotherapy on patients. For most patients, chemotherapy was a painful experience that entailed hair loss, fatigue, and aches all over the body. For most patients, chemotherapy was the worst part of the treatment regimen, but two patients had completely contradicting experiences involving chemotherapy. For one patient, chemotherapy was a great time. She stated the following: 'When I first went into the chemo room, I found patients sitting in misery with their hands on their cheeks and I just thought why can't we try and have fun instead of accepting chemo as a painful experience? I started singing and laughing and my fellow patients starting laughing along with me, and the next time, I got an audio cassette with me and we played songs and we were all singing together, and what was supposed to be one of the worst experiences for most women, was our fun time. We had fun, we made friends and for me, it was one of the best times of my life. I was happy and I made those around me happy.'

For another patient, chemotherapy represented the worst nightmare ever. She stated the following: 'I don't fear recurrence. I fear that if the disease recurs, I will have to go through the chemo experience again. I would do anything not to experience that pain and that ache again. During chemotherapy, I was trying to figure out which part of my body hurt the most and

I realized that the pain was all over. Everywhere is hurting. My hair was falling right in front of my eyes that I got my husband's razor and shaved it all in order to stop that pain. I looked at myself in the mirror and I was no different than a man. Whatever the consequences will be; even if recurrence will kill me if I don't take chemo again, I will never take it. I made that promise to myself.

For some patients, the stigma of cancer was too much to bear; one patient stated the following: 'When I was diagnosed with breast cancer and I had my surgery done, my mother-in-law started mocking me, she used to ask my husband to leave me, because I was no longer a whole woman. She blamed me for my cancer and she mocked on me after the surgery. I had to leave her house together with my husband because she was blaming me for a disease that I had no hands in'.

Most patients had fears of recurrence; some because they were afraid it would kill them and others because they wanted to live for their children. In most cases, patients attempted to neutralize these fears by fatalism and spirituality. One patient stated the following: 'I used to fear recurrence and think about it a lot, but not anymore because I believe that what is destined for us will happen and we have no hands in that. God will always do what is best for us, so I'm not worried anymore'.

For some patients' families, the end of cancer treatment meant that they got back to normal, although in most cases this was not true because most patients reported that they were slower than before and more easily fatigued after their cancer experience and cancer treatment. One patient stated the following: 'I have always been viewed by my family as a hard worker and reliable person. After my cancer experience and treatment, I realized I was a lot slower than before and I was easily fatigued. I don't know why this happened, but I know it's true. I try to push myself to get back to my old normal, but I can't. My mother thinks I'm just seeking attention and I'm acting sick. She asks me to do the house chores with the same speed and efficiency like before my sickness and I try to tell her that I can't. But she keeps telling me that I was done with my treatment and I was not suffering from anything now, so I was just supposed to get back to normal. She just doesn't want to understand that the end of treatment is not the end of the consequences of my disease and its treatment. I wish somebody could make her understand'.

For some patients, the psychological trauma affected their kids as well; one patient stated the following: 'When I took chemo, my son was 2 years old, and he used to witness my pain, my tears and my ache. Now he is 4 years old and whenever he sees me tired, he runs to me in extreme anxiety and fear and keeps asking me whether I was doing ok and whether I got tired again like I was 2 years ago. The problem now is with my son. He worries too much about me and I thought a lot about seeking psychiatric advice for him'.

Most of the patients stated that it would have been a lot better if there had been psychiatric and psychological counseling during their follow-up visits. They stated that it would differ a lot and it would help them a lot.

Discussion

This study found that the prevalence of anxiety in young breast cancer survivors was 70%; 38.1% had severe anxiety. The prevalence of depression was 63.3%; 52.6% had moderate depression. These results are in agreement to a great extent with a previous study showing that the percentage of breast cancer patients reporting anxiety ranges from 12 to 47% (Eskelinen and Ollonen, 2011). From previous studies, the prevalence of anxiety disorder in breast cancer patients ranged from 1 to 49% and that of depression in breast cancer ranged from 1.5 to 46%. The wide-range prevalence of anxiety and depression found in breast cancer was because of the different stages of disease, the different time points of evaluation, the different measurements, and the different populations studied (Morasso *et al.*, 2001; Massie, 2004).

In terms of the coping process scale, there was a statistically significant association between the 'acceptance' item and the absence of depression. These results are in agreement with the results of a previous study showing that acceptance and positive reappraisal were associated with higher levels of positive affect, whereas self-blame was associated with a lower positive affect (Kvillemo and Bränström, 2014). There was also a statistically significant association between 'seeking information and social support' item and the absence of anxiety. These results are in agreement with a study showing that strong social support and good family relationships are positive person's resources and protective factors of psychiatric morbidities. Social support helps to buffer the impacts of stress on a person's life, especially when experiencing a life crisis such as a serious illness or cancer (Drageset and Lindstrom, 2005).

In-depth interviews

Our qualitative data-collection phase provided us with better insight into each patient's unique experiences and perspectives. We noted the following:

- (1) The depth of each patient's emotions and distress could not be determined using quantitative data-collection tools, such as questionnaires. In addition, the questionnaires did not provide us with a broader and more enlightened picture of the patients' sufferings and losses, their hopes, and expectations. The qualitative data-collection tools helped us become better doctors by being in touch with the patients' true feelings and needs, so that we could really help them. It is important to consider the person as a whole, where areas of 'vulnerability' are mutually identified with the therapist, rather than fragmented questionnaires focusing on symptomatic areas (body image, depression, sexuality, etc.).
- (2) In the literature on research methods, questionnaires and interviews are considered to have different and possibly complementary strengths and weaknesses, whereas questionnaires are usually viewed as a more objective research tool that can produce generalizable results because of large sample sizes. Questionnaire research can be considered to be over-reliant on instruments and thus disconnected from everyday life (Bryman, 2008). Interviews are not neutral tools; here, data are based on personal interactions that lead to negotiated and contextually based results (Fontana and Frey, 2000; Silverman, 2000; Silverman, 2006); because of the interpersonal nature of the interview context, participants may be more likely to respond in ways they deem socially desirable (Richman *et al.*, 1999; Yin, 2009). In addition, as most qualitative studies have relatively small sample sizes, the results can be difficult to replicate or generalize (Bryman, 2008).
- (3) Interviews with cancer survivors highlight the importance of the education of family members about cancer and its stigma and that was the case with one of the survivors whose mother-in-law blamed her for having cancer; the therapist can act as a case manager treating vulnerable family members and that was the case with one of the survivors, whose son was traumatized by his mother's traumatic chemotherapy experience.
- (4) Increased belief in religion was very evident during the interviews, especially with one of the survivors, who considered her cancer as a blissful experience and it got her a lot closer to God. Her fears of recurrence were washed away by her deep faith

that God would always do what was best for her and she could face anything as long as God was by her side. Studies found that prayer was positively related to psychological well-being (Meraviglia, 2006).

- (5) We also found positive aspects of the cancer experience; for example, some of the patients felt that they were truly loved and accepted by their husbands. One survivor provided us with insights into the importance of having centers where cancer survivors can talk about their experience with cancer to tell other survivors that they were not alone and that the fight against cancer could be won. Here, the importance of support groups that can help patients cope and provide patients with more knowledge and different perspectives about breast cancer is highlighted.

Limitations of the study

The sample size was relatively small as our inclusion criteria targeted a specific population. It is worth noting that just under 7% of all breast cancer cases occur in women younger than 40 years of age (Howlader *et al.*, 2015). In addition, we were studying young breast cancer survivors without recurrence or metastasis or any other chronic illness and this to the exclusion of breast cancer patients who did not fulfill the inclusion criteria. Another limitation was that breast cancer survivors attending the outpatient oncology clinic were usually in a hurry; they wanted to complete the follow-up appointment and go home. Also, our qualitative study using the person-centered approach had its limitation as we cannot neglect the bias of subjectivity during the interview. However, we attempted to use the patients' exact words and expressions in the analysis.

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Conflicts of interest

There are no conflicts of interest.

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