Experiences of Breast Cancer Survivors with Oncology Settings in Urban India: Qualitative Findings

Michelle S. Barthakur^{1,2} · Mahendra P. Sharma² ·
Santosh K. Chaturvedi³ · Suraj K. Manjunath⁴

Received: 21 June 2015 / Accepted: 19 April 2016 / Published online: 27 April 2016
© Indian Association of Surgical Oncology 2016

Abstract The experience of diagnosis and treatment of cancer leads to significant changes within an individual. In the course of survivorship trajectory, very often cancer survivors are left with the sense, improvements could be done to enhance the quality of cancer care. This article focuses on experiences of breast cancer survivors with oncology setting in urban India. Data was collected from 15 women in South and East India using in-depth interview method. Qualitative interview data was analysed using descriptive phenomenology method. Areas of importance that emerged broadly included informational and emotional categories. Findings reveal quality of cancer care in India can be improved through developing an orientation towards patient-centred style rather than doctor/disease centred approach which has major influence on physical and mental health outcomes. This would require further research and increased emphasis on training of medical as well as paramedical professionals.

Keywords Breast cancer · Survivors · Informational Needs · Emotional Needs · Qualitative

Introduction

The diagnosis of breast cancer tends to evoke a series of distressful emotional responses starting from the time of discovery of lump or any of its other symptoms. As treatment protocol starts, it also requires the patient to participate in decisions about the place of treatment, the choice of doctors and the treatment protocol. This is further complicated by the need to understand huge amounts of information under time pressure, the consequences of these decisions on life trajectory, the perpetual anxiety in the background and the overall emotional stress [1, 2].

In a systematic review of research done on understanding cancer patients' needs, information sources during diagnosis and treatment, information needs about the stage of the disease, treatment options and side-effects of treatment were most required. However, there was also need for information related to post-treatment issues during recovery process [3, 4].

In the Indian context, research on breast cancer has focused primarily on research focused on its epidemiological trends, identifying beliefs about breast cancer screening, its awareness and policies about cost-effective ways of making it available. Studies have also been done focusing on genetic correlates of different kinds of breast cancer and its prognosis. Lastly, it has focused on the medical treatments and ways of improvising on it. However, when it comes to the domain of psycho-oncology, studies have focused on Quality of Life [5] and handful of studies has focused on the psychosocial aspects of it [6, 7]. It directly hints at the great dearth and the need for further research in psycho-oncology in India.

The aim of the larger study was to understand body image, sexuality and quality of life in women survivors of breast cancer from an Indian perspective. It was a mixed method design wherein in-depth qualitative data covering a broader area of experiences was gathered from a sub-section of the

✉ Michelle S. Barthakur
m.s.barthakur@gmail.com

¹ Manukau Community Mental Health Centre, Counties Manukau District Health Board, Auckland, New Zealand
² Department of Clinical Psychology, NIMHANS, Bangalore, India
³ Department of Psychiatry, NIMHANS, Bangalore, India
⁴ Department of Surgical Oncology, St. Johns Medical College and Hospital, Bangalore, India

larger quantitative sample. In this context, the following article focuses on perspectives of breast cancer survivors in urban India in dealing with oncology health professionals and the system as a whole.

Method

Sample consisted of 15 Indian women from urban communities of Southern and Eastern India. Socio-demographic characteristics and clinical characteristics are depicted in Tables 1 and 2 respectively.

Inclusion criteria of the study were a) Women who have undergone mastectomy/lumpectomy and those currently undergoing hormonal treatment as adjuvant therapy, b) Women in age group of 18 and above, c) Married women, d) English or Hindi speaking, e) Minimum education up to Class X and f) At least 6 months post radiation therapy and chemotherapy. Exclusion criteria were a) Women currently undergoing chemotherapy or radiation treatment, b) Women with cognitive impairments, c) Women with active or distant metastases.

Interview data was collected from survivors associated with two non-governmental organisations (NGO), a) Connect to Heal based in Bangalore, and b) Hitaishini based in Kolkata, St. John's Medical College and Hospital, Bangalore, a private oncology clinic in Bangalore and through snowball sampling. Approval for the research study was taken from the Institute's Ethical Committee Board of NIMHANS, Bangalore in January, 2012 and St. John's Medical College and Hospital, Bangalore in August, 2013.

Table 1 Socio-demographic characteristics

Variable	Range of age (in years)	Mean
Current age	45–72	57 years
	<i>n</i> (%)	
Education level		
- Class X	1 (6)	
- UG	4 (27)	
- PG	10 (67)	
Occupational status		
- Employed	6 (40)	
- Home makers	3 (20)	
- Volunteers	6 (40)	
Religion		
- Hindu	11 (73)	
- Islam	2 (13)	
- Christian	1 (7)	
- Zoroastrian	1 (7)	

Table 2 Clinical characteristics

Variable	Range of age (in years)	Mean
Age of onset	29–65 years	42.86 years
Duration of illness	3–28 years	9.3 years
	<i>n</i> (%)	
Kind of surgery	Lumpectomy	5 (33)
	Mastectomy	10 (67)
Adjuvant Therapy	Chemotherapy	11 (73)
	Radiation Therapy	12 (80)
	Hormonal	9 (60)
	Herceptin	2 (13)

Semi-structured interview schedules were developed by researchers based on review of literature and the draft was given to 7 experts whose feedbacks were incorporated. Before interviews were done, participant information leaflet was provided and informed consent was taken from survivors. They were informed there would be one-on-one interviews which would occur over 2–3 sessions, each lasting 1.5–2 h. Interviews were carried out at homes and offices of participants and audio recorded after their permissions were obtained. One participant refused consent for audio recording and therefore, detailed notes were made through the interview. After providing consent, filling out demographic and clinical data sheet and quantitative measures, interviews were started. All participants spoke English.

Data Management and Analysis

Descriptive phenomenological approach was utilised to analyse interview data. Husserl [8] explained it as “the science of essence of consciousness” and tried to explain the concept of *intentionality* and meaning of lived experiences from first person point of view. Neutrality was maintained using a memo for *bracketing* which focused on eliminating researcher's personal biases.

To analyse the data, following steps were followed [9]:

1. Transcription (using InQ Scribe), proof-reading of interview and re-reading to acquire understanding of experiences
2. Line by line reading to identify broad area of phenomena being captured
3. Statements assigned meanings to enable recognition of intricate details pertaining to phenomena
4. Codes grouped into cluster of themes and categories
5. Findings integrated into exhaustive description of phenomena and provided to supervisors for review
6. Feedback of supervisors incorporated to reflect universal features of phenomena

Results

Informational Needs & Experiences

Illness, Treatment and Side-Effects

Common theme regarding information about illness symptoms was everyone tends to have general understanding about it. However, one survivor indicated “...there should be more awareness created about the symptoms. ... I mean the lump is not the only symptom” (1). Common sources of information for survivors included the internet, newspapers or magazines and doctors. One survivor indicated about myth of cancer illness in equating it to death: “I think the reason why cancer is such a myth and there is so much of fear about it is because the ones who got well don’t speak of it. The ones who didn’t are speaking louder than anything” (5).

With regard to being provided with information about the illness and its treatment as a whole, themes suggested a mixed picture: “I think the doctor should explain in detail what exactly is that disease and what are the advantages of different treatment also... here the doctor made it very clear to us, he clarified all our doubts...” (11) In contrast to another response: “Talking to him is like pulling teeth. Impossible! ‘Why this?’ ‘I’ll give it to you. You’ll become okay.’ I say, ‘But why this? Why are you giving me this drug versus this drug?’” (5)

In decision making process related to treatment, the most common theme was letting the doctor decide as it was their profession to do so. However, few survivors were equally involved in their treatment based on research or through consultations with oncologists in the USA through Internet. One survivor indicated choice of treatment should not be based on fear: “Come to a stage of calm before you take your decisions. You know the tendency will be you’ve got cancer. Fast, fast, do..., take the treatment... But please calm down. Find out. Participate in your treatment. Don’t let the doctors’ just take over. It’s not meant to be like that.” (1).

Themes also suggested strong and mixed reactions to allopathic modality of treatment versus alternative medicine. Allopathic treatment included views of being made a “victim” of allopathy, it is “corporatized,” “you are a disease” and “surgery” is what works best. However, at other end of the spectrum themes suggested: “Only allopathic treatment is available that works for cancer, no other form of treatment works for the time-being” and “it has some side effects because I have not tried other methods, I am sure those also will have side effects...” (3) One view about cancer treatment was, “the treatment is harsher than the disease.” (2).

Finances regarding treatment were a major concern amongst most survivors, especially Herceptin. Few survivors indicated need for information about ways of decreasing treatment costs: “when I went to chemotherapy ... he told me, ‘We

also sell here ... If you buy drugs from there, that’s also is good,’ But then we started buying from there which turned out quite cheaper for us....So that way like you know they can give an option...” (7).

With regard to nature of side effects associated with adjuvant therapies, the common theme was need for more information in preparation for it: “But even the side effects of chemo, you don’t know...It is far more insidious and it has far worse effects than people tell...” (3) In relation to this, as narrated by a survivor, an oncologist had indicated to her the need to downplay side effects: “You don’t understand. If I had told you then you would have said, ‘I do not want treatment,’ If I had listed to you all the side-effects which are possible then you wouldn’t be here for treatment.” (12).

A common issue was regarding nutrition during chemotherapy: “They never tell you what to eat. They never even tell you, eat well...Probed and all, what should I eat? Eat a balanced diet. That’s the best you’ll get.” (15).

Few survivors experienced difficulties due to lack of information about access to prosthesis: “You go to a Bra company; they don’t know what a prosthetic bra is? They are in that trade so I mean Indian women they have to suffer, they don’t have a choice... it is a pity that there is not enough information even in hospitals about prosthesis.” (8)

Lastly, issue of collusion also emerged wherein patients are not informed about their diagnosis: “Please don’t tell the patient that she has cancer because we haven’t told her.” Doctors go ahead with that because it’s too complex to kind of enter into all that... so when patient ignorance is bliss so thank God for that in our country.” (9)

Need for Counselling

Few survivors reported having received counselling prior to surgery and during treatment. It was of benefit to them in following ways: “She used to come and meet all the patients downstairs at the OPD and... answer all our queries... how to dress up and those type of things because some of these questions we can’t ask the doctor because they don’t have time for all these things... how to, where to buy the wig and what type of food to take, when to get any nutrient supplements or what type of fruits...” (10).

However, general concern was that such services are by far and large unavailable and much in need to address ‘softer issues.’ These included issues about handling side effects of treatment, gaining access to prosthesis, getting information about clothes to be worn, how to handle changed sexuality and as an outlet of emotional expression. One survivor expressed that availing counselling was “a sign of weakness” for her while another survivor expressed: “at that time, even counsellors didn’t work... I didn’t want...” (3).

Emotional Needs & Experiences

Quality of Interactions

Several survivors' reported the belief that treating team hold a 'casual' attitude towards the illness as breast cancer has become like 'ordinary cold and cough for the doctors' (9). Similarly, a theme also emerged that a 'dismissive' or 'matter of fact' attitude is held towards managing side-effects.

As a whole, kind and level of information received by survivors was related to perceived quality of interaction: "You are just a clinical status. You're not a person when you enter the doctor's room which is really sad. In our country we tend to treat a disease as just a disease and a disease is separate from the individual. But they come as package even doctors don't realise this..." (2) However, such themes were mentioned in context of time constraints of treating teams: "They are only concerned about the fifty other patients waiting outside. You are another tick.... It's not so much about money; it's just about getting through the day." (8) As a result, most survivors voiced a lack of "personal touch" or "some doctors are very in the name of honesty and being very frank, they are very rude and blunt." (7) However, few survivors reported being able to contact their treating team whenever required and one survivor went on to say that: "Behaviour was just like my family." (6).

One survivor's account illustrated the difference in treatment agenda held by the treatment team versus the survivor: "I couldn't bring myself to ask the doctor such a trivial ordinary cosmetic vanity question... the doctor doesn't really care... his focus is to get you well. He doesn't care how you look but he doesn't realise that for you how you look is more important than whether you get you get well or not." (14).

Cultural Norms

Several survivors' experiences were related to norms about privacy that become relevant especially in the Indian context: "Whole body the way it is treated you'll feel that it doesn't belong to you... we are older generation, our body is not

exposed to other people. All the doctors are touching those places which you are so protected and so taken care of... first few days, it was difficult for me particularly when men surgeons are doing... they are not doing it for any other sensation when they press your breast... way they do it is more clinical than anything else." (7).

Another survivor indicated about differences in levels of faith in doctors by patients from rural versus urban contexts and its possible effect: "Today most of the rural based patients tend to have immense faith in the doctors... faith is beyond belief... faith is the ultimate. They say, "If the doctor says, I have to do this, I have to do this..." "they don't even question... He's God... that faith cures people more than other stuff but yet if you see amongst the general populace especially the urban, without counselling, they're suffering a huge lot." (12).

Discussion

Aim of current study was to understand breast cancer survivorship trajectory from an Indian perspective. In the current article, an attempt was to understand experiences of breast cancer survivorship in dealing with medical health professionals and the system as a whole.

Strengths of the study included: a) it was the first in-depth study trying to understand breast cancer survivorship experience in Indian context, b) it highlighted experiences of cancer patients as they negotiated their way through the medical system, c) Majority of survivors had been diagnosed in early stages of the disease, were primarily from urban backgrounds, middle category income families with at least 12 years of formal education thus representing a homogeneous sample, d) it also provided an understanding about attitude towards use of alternative medicine in oncology-related conditions, e) The concept of 'breast navigators' or 'peers' already exists in certain pockets of the country that have come into focus through the study.

Limitations included: a) Since it included survivors primarily from an urban background, felt needs of those from rural context could be different; b) It was a cross-sectional study

Table 3 Informational and emotional needs of survivors of breast cancer

Categories	Themes	Codes
Informational	Illness, treatment and side effects	Awareness about symptoms, decision making,
	Need for Counselling	'Treatment harsher than disease' Time constraints of treating professionals Address 'softer issues'
Emotional	Quality of Interactions	"You are just a clinical status."
	Cultural Norms	"Behaviour was just like my family." Norms about privacy Difference between rural versus urban patient

design with purposive sampling therefore, self-selection bias could have been present in the study, c) it did not include those with active metastatic illness or terminal illness.

Table 3 shows that in category of informational needs, awareness of the lump as a symptom was the most commonly known symptom. Therefore, awareness campaigns need to focus on various other symptoms associated with the disease to enable its earlier detection. With reference to treatment procedures, often survivors were unaware about treatment procedures and therefore unable to participate in decision making process either. Studies have shown that provision of information to patients about their illness enables them to make informed decision about their treatments [10]. However, studies have also shown that there is a need to maintain a balance about the provision of right amount and type of information [11]. In the Indian context, as reported in another study as well, patients tend to leave the choice of treatment with the treating team [12]. In such situations, a counsellor/breast navigator can play an effective role in handling the informational and emotional needs of the patients and the family thereby, reducing time-related pressure on the treating team [13, 14]. Moreover, as reported in another study, the issue of collusion also affects the decision making process in treatment process [15, 16].

With these lacunae, it contributes to development of *doctor-centred style* (or *disease centred approach*): physician is task-focused, concentrates on one's own agenda and attempts to reach a diagnosis through textbook descriptions [17]. This is in contrast to *patient-centred style* consists of affective behaviours (empathy, openness and reassurance), egalitarian and involvement of patients in decision making process which is significantly associated with increased levels of satisfaction of patients with medical care [18] which in turns influences range of positive and psychological health outcomes [19].

The clinical implications of the study include a) need to address doctor patient communication styles, b) need to understand differences about informational and emotional needs between urban versus rural patients, c) Need for focus on education about illness, the treatment procedures and the associated side effects, d) Inclusion of patients in decision making process about treatment related procedures and regarding its cost-effectiveness ways, e) Breast- cancer peers/navigators or trained counsellors can contribute towards management of patients.

The research implications include a) Replicability of the study to rural contexts, low-income and less education groups would help generalizability of findings, b) Focus on training of breast navigators or peer counsellors and understand its impact on quality of life outcomes.

In the light of the above mentioned implications, these concerns can play a significant role in promoting holistic cancer care.

References

1. Aitken-Swan J, Paterson R (1959) Reactions of cancer patients on being told their diagnosis. *Br Med J* 1:779–783
2. Kreitler S (2003) Psycho-oncology. In: Chen LM, McChargue DE, Collins FL (eds) *The Health Psychology Handbook: Practical Issues for the Behavioral Medicine Specialist*. Sage Publication, California, pp. 325–359
3. Rutten LJF, Arora NK, Bakos AD, Aziz N, Rowland J (2005) Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). *Patient Educ Couns* 57:250–261
4. Ashing-Giwa KT, Padilla G, Tejero J, Kraemer J, Wright K, Clayton S, Williams I, Hills D (2004) Understanding the breast cancer experience of women: a qualitative study of African-American, Asian American, Latina and Caucasian cancer survivors. *Psychooncology* 13:408–428
5. Dubashi B, Vidhubala E, Cyriac S, Sagar T (2010) Quality of life among young women with breast cancer. Study from a tertiary cancer institute in South India. *Indian J Cancer* 47:142–147
6. Mahapatro F, Parkar S (2005) A comparative study of coping skills and body image: Mastectomized vs lumpectomized patients with breast carcinoma. *Indian J Psychiatry* 47:198–204
7. Khan MA, Bahadur AK, Agarwal PN, Sehgal A, Das BC (2010) Psychosocial disorders in women undergoing post-operative radiation and chemotherapy for breast cancer in India. *Indian J Cancer* 47:296–303
8. Husserl E (1959) *Logical investigation*. Humanities Press, New York
9. Collaizzi PF (1978) Psychological research as the phenomenologist views it. In: Valle RS, King M (eds) *Existential phenomenological alternatives for psychology*. Plenum, New York, pp. 48–71
10. Luker KA, Beaver K, Leinster SJ, Owens RG, Degner LF, Sloan JA (1995) Information needs and sources of information for women with breast cancer: a follow-up study. *J Adv Nurs* 23:487–495
11. Northouse PG, Northouse LL (1987) Communication and cancer issues confronting patients, health professionals and family members. *J Psychosoc Oncol* 5:17–46
12. Agrawal S, Goel AK, Lal P (2012) Participation in decision making regarding type of surgery and treatment-related satisfaction in North Indian women with early breast cancer. *J Cancer Res Ther* 8:222–225
13. Carroll JK, Humiston SG, Meldrum SC, Salamone CM, Jean-Pierre P, Epstein RM, Fiscella K (2010) Patients' experiences with navigation for cancer care. *Patient Educ Couns* 80:241–247. doi:10.1016/j.pec.2009.10.024
14. Giese-Davis J, Bliss-Isberg C, Carson K, Star P, Donaghy J, Cordova MJ, et al. (2006) The effect of peer counseling on quality of life following diagnosis of breast cancer: an observational study. *Psycho-Oncology* 15:1014–1022
15. Chittam M, Norman P, Harris PR (2012) Relationships between perceived diagnostic disclosure, patient characteristics, psychological distress and illness perceptions in Indian cancer patients. *Psychooncology* 22:1375–1380. doi:10.1002/pon.3149
16. Chaturvedi SK, Loisel CG, Chandra PS (2009) Communication with relatives and collusion in palliative care: a cross-cultural perspective. *Indian J Palliat Care* 15:2–9
17. Williams S, Weinman J, Dale J (1998) Doctor-patient communication and patient satisfaction: a review. *Fam Pract* 15:480–492
18. Venetis MK, Robinson JD, Turkiewicz KL (2009) An evidence base for patient centred care: a meta-analysis of studies of observed communication between cancer specialists and their patients. *Patient Educ Couns* 77:379–383
19. Shillings V, Jenkins V, Fallowfield L (2003) Factors affecting patient and clinician satisfaction with the clinical consultation: can communication skills training for clinicians improve satisfaction? *Psychooncology* 12:599–611