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Lived Experience of Adult Female Cancer Survivors to Discover Common Protective Resilience Factors to Cope with Cancer Experience and to Identify Potential Barriers to Resilience

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ABSTRACT

Objectives: Primary objective – Phase I: The primary objective of this study was as follows: (1) To identify common protective resilient factors that enabled the adult female cancer survivors to cope with the cancer experience. (2) To identify potential barriers to the resilience of adult female cancer survivors. Secondary objective – Phase II: The secondary objective of this study was to develop and validate a resilience tool for cancer survivorship.

Material and Methods: A mixed approach using sequential exploratory design was used in the study. A qualitative approach using phenomenology design was used in the first phase followed by a quantitative approach in the second phase. In the first phase, in-depth interviews were conducted until data saturation with 14 female breast cancer survivors chosen by purposive and maximum variation sampling methods based on inclusion criteria. The researcher used Colaizzi's data analysis framework to analyse the transcripts. Findings were configured as protective resilience factors and barriers to resilience. Based on the analysis of the qualitative phase, the researcher developed a 35-item resilience tool for cancer survivorship. Content validity, criterion validity and reliability of the newly developed instrument were assessed.

Results: In the qualitative phase, the mean age of the participants was 57.07 years and the mean age at diagnosis was 55.5 years. The majority 11 (78.57%) of them were homemakers. All 14 (100%) of them had undergone surgery. The majority 11 (78.57%) of them had all three modes of therapy, that is, surgery, chemotherapy and radiation therapy. The categories of themes identified are presented under two main headings, that is, protective resilience factors and barriers to resilience. The theme categories identified under protective resilience factors were personal, social, spiritual, physical, economic and psychological factors. The barriers to resilience identified were lack of awareness, medical/biological barriers, social, financial and psychological barriers. The developed resilience tool had a content validity index of 0.98, a criterion validity of 0.67, internal consistency of 0.88 and stability of 0.99 at a 95% confidence interval. Principle component analysis (PCA) was used to validate the domains. PCA of protective resilience factors (Q1–Q23) and barriers to resilience (Q24–Q35) had Eigenvalues of 7.65 and 4.49, respectively. The resilience tool for cancer survivorship was found to have good construct validity.

Conclusion: The present study has identified the protective resilience factors and barriers to resilience among adult female cancer survivors. The developed resilience tool for cancer survivorship was found to have good validity and reliability. It will be useful for nurses and all other healthcare professionals to assess the resilience needs of cancer survivors and to provide need-based quality cancer care

Keywords: Resilience, Protective factors, Barriers, Cancer survivorship

INTRODUCTION

Resilience is an individual's ability to bounce back from a negative experience. Resilient people are like *emotional rubber bands as they are stretched to the limit by life, without breaking, they eventually bounce back into something that resembled their previous shape*. The American Psychological Association defines resilience as the process of adapting well

in the face of adversity, trauma, tragedy, threats, or even significant sources of stress.^[1] Resilience is considered a process, rather than a trait in an individual. In other words, people who demonstrate resilience are people with positive emotions and attitudes; they are keen to effectively balance negative emotions with positive ones.^[2] Resilience is a dynamic process, in which psychological, social, environmental and

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biological factors interact to make an individual, at any stage of life, develop, maintain, or regain their mental health despite exposure to adversity.^[3] Resilient people approach difficult tasks, as challenges to be mastered rather than threats to be avoided. Hence, it is important to study resilience among cancer survivors as it will be an eye opener for both the caregiver and the health-care team to function in a better way. Resilience has both facilitators and barriers.

Among cancer survivors, resilience facilitators are those factors that enabled them to cope successfully with adversity and have been categorised as individual and societal protective factors by many researchers. The key individual resilience facilitators in their journey with breast cancer were acceptance of the situation, setting goals, focusing on potential solutions, taking responsibility for their own life, and escaping from the role of a victim of circumstance.^[4,5] Complementary and alternative medicine (CAM) practice included qigong, an exercise and healing movement that strengthens one's qi, or life energy and massage.^[4] CAM has been mentioned in many studies among cancer survivors for mind and spirituality healing.^[6-10]

The societal protective factors identified among cancer survivors are perceived social support associated with positive adjustment to illness.^[5] Barriers to resilience, faced by cancer survivors, identified in the literature include a fragmented and poorly coordinated cancer care system; the absence of a locus of responsibility for follow-up care; poor mechanisms for communication; a lack of guidance on the specific tests, examinations and advice; inadequate reimbursement from insurers for some aspects of care and limited experience on the best way to deliver care.^[4,5]

The topic of resilience in general and specifically among female cancer is a relatively new area of study in the nursing community. Resilience tools available are commonly used for resilience in the general population and for psychological disorders, but not specifically for cancer. The tools that exist do not address resilience issues specific to cancer. Hence, there is a need to develop a resilience scale for cancer survivorship.

Aim

The study aims to explore the experiences of adult female cancer survivors, to discover and describe common protective resilience factors that helped them to cope with the cancer experience and to identify the barriers to resilience. Based on the findings, a resilience tool for cancer survivorship will be developed and validated and tested for its reliability.

Objectives of the study

Primary objective

Phase I

The primary objectives of this study are as follows:

1. To identify common protective resilient factors that enabled the adult female cancer survivors to cope with

the cancer experience

2. To identify potential barriers to the resilience of adult female cancer survivors.

Secondary objective

Phase II

1. The secondary objective of this study was to develop and validate a resilience tool for cancer survivorship.

MATERIAL AND METHODS

Phase I

Design

The research approach adopted for this study was a mixed approach using a sequential exploratory design. A qualitative approach with phenomenological was used in the first phase followed by a quantitative approach in the second phase.

Setting and participants

In the first phase, the population consisted of all adult female breast cancer survivors who took treatment at the hospital. The setting was the home of the participants. Sample and sampling technique – adult female breast cancer survivors who satisfied the following inclusion criteria using purposive and maximum variation sampling were chosen for the study. Inclusion criteria were as follows – adult female breast cancer survivors who were between 18 and 70 years of age had completed treatment and were symptom free for the past 3 months and not exceeding 3 years. Exclusion criteria were as follows – Adult female breast cancer survivors who were with metastasis, terminally ill and with comorbidities like renal, cardiac and neurological conditions. Data were collected from the participants until data saturation was achieved, and 14 participants were interviewed.

Data collection procedure

A mix of participants, which included, women from different age groups, of varying educational status, working women as well as housewives. Women were selected from different states and cultural backgrounds in India and different socioeconomic statuses. Rapport was developed and the purpose of the study was further explained to them in detail and consent was obtained. Initially, the demographic and clinical characteristics of the participants were collected with demographic proforma. An interview guide with semi-structured and open-ended questions were used for an in-depth interview. The type of questions included experience questions; feeling questions and knowledge questions. As the conversation progressed, prompting questions were used when there was silence or a break in the conversation. Besides audio-taped data, observations were noted regarding the environment, emotions and artefacts displayed during the interview. Information was also collected from the medical records of the participants, for

which prior permission was sought. A log was maintained by the researcher regarding the interviews.

The recorded in-depth interviews were transferred to a laptop, pen drive and e-mail and stored on the same evening of the interview. The verbatim was transcribed in their original languages, that is Tamil, Hindi or English and was translated to English and back to the original language. This was verified by language experts.

Data management strategies

Data were managed manually. Data validation was done by returning the transcripts to five of the participants, who read the transcripts and acknowledged that it was a true reflection of their experience that they shared. The researcher read through the transcripts repeatedly to acquire a feeling of their ideas and to understand them. Meanings were formulated and codes were created. Themes were identified from the codes. Grouping of themes led to tentative theme categories or clusters; continual referring back to formulated meanings, significant statements and original transcripts were done repeatedly to ensure accuracy. Following this, final theme categories were formed. Peer review was done and suggestions were taken.

Ethical consideration

Permission from the Institutional Ethical Committee and concerned hospital authorities was obtained. Informed consent was taken from participants for both phases of the study. The confidentiality of participants and data was maintained.

RESULTS AND DISCUSSION

Participant's demographic characteristics

The mean age of the participants was 57.07 years and the mean age at diagnosis was 55.5 years. The majority 11 (78.57%) of them were homemakers. All 14 (100%) of them had undergone surgery. The majority 11 (78.57%) of them had all three modes of therapy, that is, surgery, chemotherapy and radiation therapy.

Categories and themes

The findings are presented under two main headings, that is, protective resilience factors and barriers to resilience. Colaizzi's data analysis framework was used to analyse the transcripts.

Protective resilience factors

Personal factors

The themes identified under personal factors were – optimism and strong determination, avoiding panic, self-awareness and self-empowerment, self-advocacy and motivating forces.

Optimism and strong determination

Most of the study participants endorsed an optimistic attitude after being diagnosed. A strong mind with positive

thoughts assisted them to face the illness with its challenges. Their optimistic attitude is evident in the following verbatim. *'I guess it's the attitude that matters, if there is a problem you've got to solve it, you cannot let it be heavy on your system, what's got to be done has got to be done.'* (Age: 57, Homemaker; mother of two children).

Avoiding panic

All the participants declared that they were scared at some point of time. Getting rid of cancer from their body was a priority. *'I did not get scared. We have to move on and we have to face life.'*

Self-awareness and self-empowerment

Participants appeared to have self-awareness and were seemingly self-empowered. The majority of them were aware of breast cancer, and four of them had performed breast self-examination, did mammograms and screening for cancer regularly before the diagnosis, as clearly seen in their statements. *'For the past 5 years I've been going for my check up regularly, I do mammograms and USG of the pelvis as part of the screening, I was not expecting something like this would happen to me.'* (Age: 57, Homemaker).

Self-advocacy

All participants expressed that the decision regarding breast conservation surgery or mastectomy was clearly explained to them. Adequate time was given for them to decide. This is evident from their responses. *'The doctor said that I had to undergo surgery. I told him to remove the whole breast, if it recurs, I will have to undergo surgery again. I told him to remove both breasts. But he told me to go home and think about it and the next time we would discuss and decide.'* (Age: 46, Teacher).

Motivating forces

For the younger women, it was their children, the main concern was the children's education. *'I cried a lot initially, and then I remembered that I have two children, the older one was in college and the younger one in school. They were also very supportive.'* (Age: 42, Home maker) The older women were worried about marriage and settling their children, especially the daughters as mentioned in the statement below. *'One of my daughters was studying CA. I have to get her married, so I was worried inside.'* (Age: 63, Homemaker with two daughters).

Social factors

Social support was displayed through family, friends, workplace and religious community.

Support from family

It was the immediate family members that helped them through the physical, psychological and emotional problems as seen in the verbatim. *'Psychologically, I had no problem as I had the full support of my family and friends.'* Most of the

married women expressed that their spouse were a great source of strength and support and for some, it was their in-laws. *'My husband is an awesome man, he took care of me and my son and he was a great source of strength. I had good support, we grew to love each other more and we became very close.'* (Age: 55, Pharmacist) *'My mother-in-law was very supportive. She gave me strength to fight day by day and to move on.'* (Age: 42, homemaker).

Support from friends and peers

'I got lots of support from my friends from abroad.' (Age: 46, Teacher; Divorcee)

Support at work

Many of them mentioned that they had seen God through people. *'My department colleagues were very helpful and supportive, we have never seen God, but through people we see God.'* (Age: 50, Technician).

Support from Healthcare personnel

All participants expressed that the health care personnel at the tertiary care hospital were very approachable, explained about the treatment, clarified their doubts and counselled them. The surgeons were appreciated for their empathy. As seen in this narration by a surgeon. *'For me it is a matter of 2 hours of work, for you it is life, so take your time, discuss with your friends and community.'* Participants also expressed that the nurses were also very caring, compassionate, knowledgeable, and skillful.

Support from the religious community

The religious community was seen as a great sense of strength and support for some of the survivors. *'For me, I have a community behind me, I have security, I have sisters coming with me to the hospital.'* (Age: 55, Religious nun).

Spiritual factors

The participants had faith in God throughout their experience, trusting God at every step. Religious rituals, prayers, music, yoga, and meditation played a key role in their journey of faith.

Faith in god

All the women said that they trusted God and had this unshakeable faith in his mighty power. They believed that "God is the Healer" and "He" is the one that works through people especially the doctors and all involved in their treatment. *'It has made me closer to God. I have strengthened my prayer life, the first thing I thought was my Jesus, you are my God and you are in full control and you are going to heal me now.'*

Prayers and rituals

Participants stressed the importance of rituals and prayers during their recovery. Prayers helped to relieve a lot of tension

and worries and helped them to feel relaxed. Prayers brought a sense of peace and positive energy to many of them. They acknowledged the grace of God in their lives, one example of such prayer is *'Lord give me the grace to journey with it (cancer) and the strength to bear it.'* *'Prayer, and listening to motivational songs and speeches encouraged me. I liked it when people prayed. There was this verse that I read from the Bible: 'It is wiped by the Blood of Jesus' It was awesome, He has wiped me with His Blood, nothing was there, 'I felt like jumping, and I started writing bible verses in my diary and from that verse, I became very strong.'*

Music

Participants listened to spiritual music both at home and at the hospital. It had a soothing effect on their mind and body. *'I used to listen to music every day; it helped me and gave me strength.'* (Age: 46, Teacher).

Physical factors

Physical factors of resilience were in terms of tolerance toward the side effects of chemotherapy. Silent endurance of suffering was expressed by many of them.

Tolerating chemotherapy

Side effects were seen as a major area of fear and concern. All of them mentioned having experienced severe fatigue. Many of them had nausea, mouth ulcers, and loss of appetite as seen in the statement below. *'I was very tired, it was the main problem, I had weight loss, no energy in my body.'* Hair fall was also a major concern for those who received chemotherapy. They found it difficult to accept and coped in different ways. *'I found it difficult to see my hair fall, I had long hair and I did not know how to answer people.'* (Age: 42, Homemaker).

Silent endurance of suffering

Participants endured sufferings of chemotherapy side effects without complaining or expressing their feelings. *'I had lots of tiredness; I could not sleep at night. I used to avoid daytime sleep as I did not want to disturb others, it's a one bedroom house, my daughter needs to study and husband has to go to work, so I should not trouble anybody.'* (Age: 50, Technician).

Treatment adherence

Participants expressed that they were regular with follow-up and adhered to the medical advice. Fear of recurrence motivated them to adhere to treatment and be regular with follow up. *'As I am triple negative, the doctor said within 5 years, there are chances of recurrence, after that there are less chances. Because of this reason I wish to do my check up regularly.'* (Age: 42, Homemaker).

Lifestyle modification

'I participate in yoga classes every day; I try to exercise as much as possible. It makes me relaxed and I hope that it helps to prevent cancer recurrence.' (Age: 55, Homemaker).

Economic factors

Financial security

Not having to worry about financial issues was one of the major protective resilience factors which would have otherwise been a major barrier for some of them. Many of the participants were able to arrange finances for treatment through savings, insurance, or help from family as seen in the verbatim below *'My daughter had insurance, 70% was paid through insurance and as my daughters were working and we had some savings, we managed'*. (Age: 63, Homemaker).

Financial assistance

Participants obtained financial assistance through various means to complete treatment. It is interesting to note that a participant who did not have money obtained help from friends by communicating with them through social media. *'I told one of my friends, she sent a message to the group and it went through to all the classmates, one friend said I will pay your bill, I managed with the money sent by friends'*.

Psychological factors

Acceptance that one has the disease, release of emotions, keeping one's self busy and complimentary therapy. They had a deeper appreciation for life and wanted to do good for others.

Acceptance

'I thought any way it is an illness, and there are possibilities to get it treated, science has improved a lot, yes when we hear the word 'cancer', people are so afraid, but it made me think that there are so many people who have had this illness, it is has come to me and I will accept it and get treated'.

Release of emotions

All participants expressed that they did cry at some point of time during the illness. *'I cried when I got the news and I prayed. I asked God to give me the strength and grace to bear it. I got lots of support and energy'*. A few of them spoke about humour. They expressed that laughing and joking helped them to get rid of the negative feelings and created a positive energy in them. Avoiding negative thoughts and keeping oneself happy all the time was one of the ways to overcome the disease.

Keep oneself busy

'I keep myself busy with household work, I go and see my grandchildren and take care of them too'. (Age: 55, Homemaker)

Complementary therapy

The majority of the participants used various types of complementary therapy such as yoga, meditation and listening to music. *'I do yoga and meditation; I have been doing yoga for the past 20 years. I do it for 1½ hours every day. I wake up at 4.30 am. I like music, now I concentrate on dancing too'*. (Age: 55, Homemaker).

Deeper appreciation for life

Many of them expressed a deep sense of gratitude to God and had a deep appreciation for having a second chance to live. They felt a renewed strength to move on with life. *'I am celebrating life, I wish to get back to work, be prayerful and enjoy life, it's not by my merit but by God's grace that I am alive'*.

Wanting to do good for others

Many of them were interested and motivated to do good for others in various ways. They felt that they have been blessed to live and wanted to give back to others by doing something for people, especially those suffering from cancer. They were prepared to share their story through magazines, to motivate others. *'It would be good if we can start a magazine for sharing our experience. I am prepared to share my story, you can put my picture too no problem'*.

Barriers to resilience

The barriers to resilience were the factors that delayed or prevented their recovery in the journey with cancer.

Lack of awareness

A few women expressed that they were not aware about the signs and symptoms of breast cancer. This resulted in a delay in seeking medical help. *'I thought it is a small growth and just neglected it. I saw a TV program about cancer, and then I went to the doctor, had I known earlier I would have got myself treated'*. (Age: 68, Homemaker).

Ignorance and myths

A few of them demonstrated ignorance and had myths regarding the causes of cancer which was a cause for delay in treatment. *'I thought it is because of my past sins, it's a punishment from God'*.

Stigma towards cancer

'I did not tell anyone. Even if neighbours asked me, I used to just say I had some leg pain and was going to the hospital to treat it'. (Age: 68, Homemaker).

Biological/medical barriers

The biological or medical barriers identified were the insensitiveness of the medical professionals which led to late diagnosis and in some cases miscued diagnosis.

Insensitiveness of medical professionals

Most of the participants said that once they identified the lump, they immediately went to their family doctor. Some of the family doctors did not advise for immediate referrals to tertiary hospitals. Their casual attitude and insensitiveness resulted in incorrect advice, delay in diagnosis and referrals to tertiary hospitals. Lack of clear communication from the doctors resulted in a delay in initiating treatment. This is

highlighted in the following statements. *'I showed my family doctor, she said there was no major problem. She asked me to take vitamin E and it would be okay. After 10 days, it did not reduce, I went again to the same doctor then she told me to do all the tests. The result came positive, and then she advised me to go to Hospital'. (Age: 42, Home maker).*

Miscued/late diagnosis

Some of the participants stated that diagnosis of breast cancer, in the early stages, was missed, even after visiting a physician. They received confusing information. Miscued diagnoses and contradicting pathology reports were mentioned by some participants that caused stress and delay in treatment.

Physical barriers

Physical barriers were related to the inability to tolerate and manage the side effects of chemotherapy.

Side effects of chemotherapy

One of the common complaints experienced by the participants was fatigue. They expressed that fatigue decreased their energy level, made them feel drained and this prevented them from carrying out their daily tasks. *'I became very tired, in the evenings. I could not eat. I had severe mouth ulcers, even when I used to drink water it used to burn like fire in my mouth, it was very painful'. (Age: 68, Homemaker).*

Social barrier

Social barriers were lack of family support and social support.

Lack of family support

Lack of support from spouse and children resulted in insecure feelings. Some expressed loneliness and wished that they had their relatives or someone to talk to when alone at home. *'I have cried every day. Up until the children get married, they will care for their parents. Once wives come, sons will listen only to them. I like to mind my business, but if someone says some hurtful words I get very upset and start to cry, for small misunderstandings'. (Age: 68, Homemaker).*

Lack of social support

Pity and non-acceptance by coworkers after recovery was expressed by participants. *'I am a senior technician, after I re-joined work; my co-workers ignore me, give back answers and hurt my feelings'. (Age: 47, Technician).*

Financial barrier

Finance was a major concern for some of them as they did not get financial support from their spouse or children. The inability to arrange finance for treatment deepened their stress and anxiety. *'My son takes care of me, he takes me to the hospital but I have to pay the bill. I did not get any support from my husband or children; I still have credit to pay back'. (Age: 68, Homemaker).*

Psychological barriers

The psychological barriers identified in the initial phases were anxiety, panic, and non-acceptance. As the treatment progressed, they expressed an inability to ventilate feelings, loneliness, depression and emotional changes. In the recovery phase, they expressed fear of recurrence, worry, uncertainty and avoidance as many of them did not want to remember the bitter experience.

Anxiety and panic

'I had fear, I had no idea what would happen, I heard one will die if it is cancer'. (Age: 63, Homemaker).

Non-acceptance

The participants were shocked, afraid and surprised when confirmed of having cancer. Some of them found it very difficult to accept the fact that they got the disease as they did screen themselves on a regular basis. *'I was not expecting something like this to happen to me. Actually, for the past 5 years I've been doing my check up, I do mammograms and USG of pelvis as part a screening'.*

Inability to ventilate feelings

Some participants expressed that they preferred not to talk to close family members for fear of further tension or burden to them. They sometimes felt that family members did not understand what they were going through.

Loneliness and depression

Many of them conveyed feelings about loneliness at some point of time. Depression was seen in a few of them. *'In the evenings I used to get depressed'. (Age: 68, Homemaker).*

Emotional changes

Many participants went through a series of emotional changes throughout the cancer experience. Some expressed mood swings, felt sad, lonely and cried when alone. The following statement is evident of mood swings. *'I got very upset and cried, even for small misunderstandings'.*

Fear of recurrence

Fear of recurrence was a great concern for all the participants. *'I am triple negative, there is no preventive treatment, there is every likelihood of me getting cancer in the first 5 years'.*

Worry and uncertainty

The most common reasons were fear of side effects of chemotherapy, fear of recurrence and fear of death. As the date for follow-up or the time for scans approached, the participants experienced a lot of apprehension and anxiety not knowing what the result would be like. *'Every time we go for tests, we have so much fear whether it will come as positive'. (Age: 42, Homemaker, mother of two children).*

Avoidance

Not wanting to talk or think about the event or recall anything related to it was what some of them expressed. They wished to forget about the whole episode. *'I do not want to think about it or talk about it. It will upset my mind. I don't want to recall. I don't want to discuss about the bitterness I want to forget it'*. (Age: 55, Homemaker).

Phase II

Secondary objective of the study

The secondary objective is to develop and validate a resilience tool for cancer survivorship.

Methodology

Based on the analysis of the qualitative phase, the researcher extracted significant statements from the verbatim, codes and themes and developed a resilience tool for cancer survivorship. The tool comprised two parts – protective resilience factors and barriers to resilience. Preliminary tool testing was done. The tool was administered to 30 adult females with cancer for reliability and criterion validity. Once found reliable that the tool was administered to 100 females with cancer for factor analysis.

Content validity

A panel of experts was asked to evaluate the content validity of the new instrument. The content Validity Index (CVI) was calculated for individual items based on 15 experts' agreement.

Reliability of the tool

For reliability testing, 30 adult females with cancer and on treatment were administered the tool. The purpose of the study was explained with patient information sheet and a written consent was taken. The newly developed resilience tool was administered followed by the Connor Davidson Resilience Scale (for criterion validity). After a gap of 6–8 days, the newly developed resilience tool was administered again to the same subjects. The statistical analysis was calculated for internal consistency, stability and criterion validity.

Results

Content validity

The content validity of the tool was found to have a CVI of 0.98.

Internal consistency

For internal consistency split-half technique was used. The internal consistency of the total scale was 0.88.

Stability

For assessing stability, test-retest method was used, for which intraclass correlation coefficient model was used. Findings demonstrated a very good agreement with an intraclass reliability of 0.99 at 95% confidence interval.

Criterion validity

The scores of the developed instrument were examined with Connor-Davidson Resilience tool. The obtained criterion validity of the developed tool demonstrated an agreement of 0.67 at a 95% confidence interval with intraclass reliability.

Principal Component Analysis (PCA)

The tool was administered to a total of 100 subjects for factor analysis. As all the items of the tool are related to resilience, the tool was found to be uni-dimensional and factors could not be picked up. Hence, Principle Component Analysis (PCA) was used to validate the domains.

PCA of protective resilience factors (Q1–Q23), as shown in Table 1 and barriers to resilience (Q24–Q35), as shown in Table 2, had Eigenvalues 7.65 and 4.49, respectively. The resilience tool for cancer survivorship was found to have good construct validity.

Nursing implications

Nursing practice

The findings of the study enlighten nurses on the topic of resilience in cancer care. It helps nurses to understand and attend to the specific needs and provide individualised care addressing the barriers to resilience and utilising the protective factors and enhancing need-based care. The study has also thrown light on the need to encourage patients to use yoga, music, prayer, meditation and other CAM techniques which enhance healing.

Nursing education

The study highlights the need for staff nurses and student nurses to be aware of the topic of resilience in cancer care. Sensitisation programs can be conducted through CNE for nurses on the topic of protective resilience factors and barriers to resilience. The topic of resilience can be included in the nursing curriculum under the unit of oncology nursing.

Nursing administration

The nurse administrators can take initiative to discuss resilience as a part of daily care so that staff nurses equip themselves to understand resilience and provide quality care accordingly. They can encourage the health-care team to also discuss health-related needs based on resilience protective factors and barriers and address needs accordingly.

Nursing research

The study findings have added rich qualitative data to the limited literature on the topic of resilience, specifically in India. Nurses can be encouraged to do more research in the area of resilience.

Limitations of the study

The qualitative phase of the study was done only on breast cancer survivors. The qualitative phase included survivors

Table 1: Principle component analysis, Eigenvalues and proportion of variances of Q1–Q23 (protective resilience factors).

	Items of the resilience tool	Eigenvalue	Difference between consecutive Eigenvalue	Proportion of variance	Cumulative proportion of variance
1	Facing challenges	7.66	5.68	0.33	0.33
2	Taking responsibility for health	1.98	0.49	0.09	0.42
3	Adapting to changes	1.49	0.17	0.06	0.48
4	Fighting against illness	1.32	0.11	0.06	0.54
5	Expressing feelings/problems	1.21	0.08	0.05	0.59
6	Support from family	1.14	0.15	0.05	0.64
7	Support from HCP	0.98	0.11	0.04	0.69
8	Support from employer	0.88	0.10	0.04	0.72
9	Support from religious communities	0.77	0.04	0.03	0.76
10	Support from friends	0.73	0.04	0.03	0.79
11	Interaction with survivors	0.69	0.06	0.03	0.82
12	Finance	0.63	0.07	0.03	0.85
13	Physical symptoms	0.56	0.05	0.02	0.87
14	Information	0.51	0.05	0.02	0.89
15	Regret	0.46	0.04	0.02	0.91
16	Lifestyle changes	0.42	0.07	0.02	0.93
17	Follow up	0.35	0.01	0.02	0.95
18	Spirituality	0.33	0.06	0.01	0.96
19	Prayers	0.27	0.04	0.01	0.97
20	Music/Meditation/Yoga	0.23	0.04	0.01	0.98
21	Acceptance	0.19	0.06	0.01	0.99
22	Keeping busy	0.12	0.06	0.01	1.00
23	Sharing experiences	0.07	.	0.00	1.00

Table 2: Principle component analysis, Eigenvalues of Q24–Q35 (barriers to resilience).

	Items of the resilience tool	Eigenvalue	Difference between consecutive Eigenvalue	Proportion of variance	Cumulative proportion of variance
24	Delay in seeking medical help	4.50	2.64	0.37	0.37
25	Awareness	1.86	0.71	0.15	0.53
26	Delay in treatment	1.15	0.09	0.10	0.63
27	Feeling lonely	1.05	0.26	0.09	0.71
28	Anxious	0.79	0.12	0.07	0.78
29	Worried	0.67	0.16	0.06	0.83
30	Fear of death	0.51	0.07	0.04	0.88
31	Burden to family	0.45	0.06	0.04	0.91
32	Lost role	0.39	0.10	0.03	0.95
33	Indifferent treatment	0.29	0.07	0.02	0.97
34	Others coming to know	0.21	0.08	0.02	0.99
35	Financial support	0.14		0.01	1.00

who knew only one of the three languages of English, Hindi and Tamil. In the second phase, the preliminary tool that was developed was tested on women with all types of cancer and not only on breast cancer survivors. The preliminary tool testing was done only with the English version.

CONCLUSION

Protective resilience factors and barriers to resilience have been identified among Indian female breast cancer survivors. A resilience tool for cancer survivorship has been developed

and tested among adult female cancer survivors and was found to have good validity and reliability. It is a gender and culture specific resilience tool for cancer survivorship. It is a preliminary tool, which need to be tested on a larger sample. Once it is standardised it can be used by health-care personnel to assess resilience among cancer survivors and provide need-based quality care.

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Declaration of patient consent

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Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. American Psychological Association. *The Road to Resilience*. Washington, DC: American Psychological Association; 2014.
2. Richardson GE. The meta-theory of resilience and resiliency. *J Clin Psychol* 2002;58:307-21.
3. Carver CS, Connor-Smith J. Personality and coping. *Annu Rev Psychol* 2010;61:679-704.
4. Valenti MC. *A New Look at Survivorship: Female Cancer Survivors Experience of Resilience in the Face of Adversity*. [Dissertation]. Ohio: Wright State University; 2011.
5. Violett P. *The Experience of Cancer Survivors as they Transition from Chemotherapy Treatment to Life after Cancer*. [Dissertation]. South West of Western Australia: Edith Cowan University; 2012.
6. Bahrami M, Taleghani F, Loripoor M, Yousefy A. Positive changes after breast cancer: A qualitative study. *J Educ Health Promot* 2015;4:55.
7. Schneider MA, Fletcher PC, Snider H. Mind over matter: A qualitative examination of the coping resources used by women with cancer. *Indian J Palliat Care* 2008;14:56-70.
8. Chalon C, Howe K, Peirce B, O'Connor M, Woulfe C. *Enhancing the Quality of Life of Breast Cancer Survivors in the South West of Western Australia*. [Dissertation]. South West of Western Australia: Edith Cowan University; 2010.
9. Min JA, Yoon S, Lee CU, Chae JH, Lee C, Song KY. Psychological resilience contributes to low emotional distress in cancer patients. *Support Care Cancer* 2013;21:2469-76.
10. Chang HY, Chen SM, Lin WL. Experiences of healing yoga among breast cancer women with adjuvant chemotherapy. *J Nurs Care* 2017;6:2.
11. Connor KM, Davidson JR. Development of a new resilience scale: The Connor-Davidson Resilience Scale (CD-RISC). *Depress Anxiety* 2003;18:76-82.
12. Wagnild GM, Young HM. Development and psychometric evaluation of the Resilience Scale. *J Nurs Meas* 1993;1:165-78.
13. Friborg O, Hjemdal O, Rosenvinge JH, Martinussen M. A new rating scale for adult resilience: What are the central protective resources behind healthy adjustment? *Int J Methods Psychiatr Res* 2003;12:65-76.
14. Polit DF, Beck CT. *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. Philadelphia: Lippincott William and Wilkins; 2014. p. 309.
15. Anderson C. Presenting and evaluating qualitative research. *Am J Pharm Educ* 2010;74:141.
16. Zurc J. Integrating quantitative and qualitative methodology in health science research: A systematic review. *Slov J Public Health* 2013;52:221-35.

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