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Quality of Life of Spouses of Breast Cancer patients

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ABSTRACT

Spouses play an important role, both physically and emotionally when it comes to the life events of a couple. The impact of a cancer diagnosis in particular, would affect the lives of both the patient and their spouse in various aspects. The study uses a quantitative method to understand the impact of the illness on male spouses of patients with breast cancer. The tools used for the study include the Caregiver Oncology Quality of Life tool and a semi-structured questionnaire. The data obtained from the sample ($n=30$) is analyzed using Descriptive statistics to study overall Quality of Life of spouses. Paired 't' test is used to compare Quality of life of spouses according to Place of residence (Rural and Urban), Age (Above 50 years and Below 50 years) and Number of years of marriage (Above 25 years and Below 25 years). The study found that spouses of breast cancer patients have a good quality of life.

Keywords: Breast Cancer, Quality of Life, Spouses.

BACKGROUND

Breast cancer is a leading cancer and the incidence is increasing at an alarming rate. The diagnosis of cancer impacts various domains of an individual's life: physical, emotional, family, social and financial. While Health care professionals offer medical care to facilitate physical well-being, the psychological and emotional support is generally provided by family and friends. Very often in married patients the spouse provides care. Cancer can change the family identity, roles and activities of daily living. This change has serious implications for both the patient and the caregivers and very often takes away quality parenting, communication and interpersonal relationship. As the course of the cancer changes from acute to chronic, patients need continuous care: they need physical assistance, emotional support, their roles and responsibilities in the family have to

be fulfilled, all of which will have a direct impact on the spouse. While extending support to the patient, sometimes caregivers may not give enough attention to their own needs; compromising their well-being and daily functioning. While spouses offer care, at times they find it challenging and some even perceive it as a burden. They often experience sleep disturbances and eating disorders, heightened anxiety and depression, a pervasive sense of helplessness, and fears about cancer and its treatment. Thus caregiver or spouse will face existential concerns, they re-evaluate the past, future and they change life goals.[1] Thus various aspects of the patients' and caregivers' lives are affected, which impacts their Quality of Life. Quality of life is seen to be an important prognostic factor in survival of cancer patient. [2] According to WHO, Quality of Life is 'an individual's perception of their position in life in the

context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment. Several studies have focused on quality of life issues of caregivers. Spouses of women with cancer face many challenges like taking care of women's emotional life, lack of social support, finance and administration and so on. Above all, there is fear of losing a loved one. On the contrary, women as caregivers are seen to experience more psychological distress while caring for their partners. When the individual is identified with cancer, it affects their lifestyle, communication and behavioral factors leading to loss of control over the life. However, couples with high marital satisfaction have better adjustment than those who have are in dysfunctional relationship due to lack of understanding, incongruent views and perspective between the partners. [2] The life partners who assume the sole responsibility in dealing with patients may experience dissatisfaction and burden of care. It deprives the physical, psychological, emotional and functional health of spouses. As obligations and demands increase, they become worried about their capacity to adapt and meet the demands of care giving. The burden of care and lack of adaptive coping mechanism alters quality of Life. [3] Alongside, the administration and financial burden also make it tough for caregivers and patients to focus on recovery. [4] Spouses who have more positive coping styles have reduced level of care giving burden; they use different coping strategies like keeping busy, thinking positively and learning more about how to manage [5,6] conducted an open survey to understand the psychosexual problems of cancer patients and their spouses. The results showed high psychosexual morbidity. The reason was physical barriers such as financial crisis. What impact cancer has on caregivers and how caring affects their quality of life? Questions of the kind have not been systematically and scientifically explored in the Indian context. The present study was undertaken to explore and answer these fundamental questions.

RATIONALE

In 1970-80s there were some descriptive studies on cancer related stress among family members and not specifically related to spouses. Studies on cancer related stress are more focused on patient adjustment and few studies are available on the distress of spouses. In this study, the target population is male spouses of women with breast cancer. This is a group that is deeply affected by cancer and its treatment, yet there is little research to highlight what they go through in caring for their loved one. The research that is available focuses on mostly the psycho-social impact of cancer on spouses. Other domains, which may have a role to play, are not always represented thereby distorting the range of problems experienced by spouses. This study aims to look at the impact in a more comprehensive manner by exploring the quality of life of spouses of women with breast cancer. This study would enable us to understand the spouses' quality of life and would certainly facilitate in planning intervention programs to address their issues. In addition, this study would undoubtedly contribute to scientific data base.

MATERIALS AND METHODS

Sample

Patients with breast cancer who were diagnosed between October 2014 and January 2015 were included in the study. By way of convenient sampling Male spouses of women with breast cancer (N=30) were accrued into the study with the following defined criteria.

Inclusion Criteria:

- Male spouses of breast cancer patients,
- Age: 30 years -75 years
- Both in and outpatient setting
- Consented to participate in the study

Exclusion Criteria:

- Spouses of Non-Breast cancer
- Other family members and caregivers
- Past history of Psychiatric and other neurological disorders.

Research Instruments

1. Semi-structured Interview Schedule: Designed and developed by the researcher to gather Socio-demographic, Medical and personal details
2. Care giver Oncology Quality of Life (CarGOQol) [7]

It is a self-report questionnaire, consisting of 29 items measured on a 5 point Likert scale. (1– Not at all, 2- A little, 3- Moderately, 4 – A lot, 5- Enormously) The scale has 10 functional domains: (i) Physical well-being (ii) Psychological wellbeing, (iii) Burden, (iv) Administration, (v) Finance, (vi) Coping, (vii) Self-esteem, (viii) Social support, (ix) Relationship with health care, (x) Leisure time and private life. It has a Cronbach's alpha coefficient of 0.7. The obtained scores were compared to the scores of a population validated by the authors of the scale

Procedure

This study was conducted after obtaining scientific and clearance from ethical committee. Consent of the spouse to participate was obtained prior to the study. They were assured of confidentiality and privacy of the information revealed during the session. The medical details of the patient were noted down before interviewing their spouse. All

participants were seen on a one-on-one basis, under the supervision of a senior psycho-oncologist. Both the semi-structured interview schedule and the Caregivers Oncology Quality of Life Questionnaire were administered by interview method. The researcher read out the questions and the responses were noted down verbatim.

Data Analysis

Quantitative and qualitative data was entered in the master chart. The data was analyzed using the SPSS 16 for Windows; the researcher used descriptive statistics and quantitative content analysis. The descriptive statistics (CarGOQol Syntax file) was used to check mean, standard deviation and normality. Quality of life was compared with age, and years of marriage using *t*-test (graph pad t test calculator).

RESULTS

The aim of the study was to assess quality of life of male spouses of women with breast cancer. The tabulated data was quantitatively analyzed. The quantitative data was analyzed using the SPSS 16 for Windows.

Table 1 *The characteristics of demographic variables*

Demographic Variables	Characteristics	Frequency	Percentage
Age (Years)	30 – 45	8	26.67
	46 – 60	13	43.33
	61 – 75	19	63.33
Educational Qualification	Below PU	3	10.00
	Graduate	19	63.33
	Post Graduate	8	26.67
Residential Place	Rural	11	36.67
	Urban	19	63.33

Working Status	Working	20	66.67
	Not Working	10	33.33
Number of Married Years	Below 25	15	50.00
	Above 25	15	50.00
Family Type	Joint	3	10.00
	Nuclear	27	90.00
Quality of Life	Poor	3	10.00
	Average	13	43.33
	Good	14	46.67
Dietary Habits	Vegetarian	7	23.33
	Non Vegetarian	23	76.67
Mode of Treatment	Surgery	8	26.67
	Chemotherapy	17	56.67
	Radiation Therapy	5	16.67

Table 2 Showing the CarGOQol domain and index scores

	PWB	B	RHC	AF	COP	PhWB	SE	LEI	SS	PL	Index CarGOQoL
N	30	30	30	30	30	30	30	30	30	30	30
Mean	58.95	71.45	74.44	77.5	70.83	77.5	78.75	67.5	75	63.33	71.5278
Std. Deviation	24.49	19.74	21.43	22.22	20.02	22.54	18.02	25.76	22.97	22.48	13.94394

PWB= Psychological Well-being, B= Burden, RHC= Relationship with Health care, AF= Administration & Finances, COP= Coping, PhWB= Physical Well-being, SE= Self-esteem LEI= Leisure time, SS= Social Support, PL= Private Life

The CarGOQol index is a measure which provides a score for overall quality of life across various domain of the tool. This sample obtained a score of 71.52 with a standard deviation of 13.94, which indicates a

good Quality of life. On comparing the score obtained from the sample with score provided by validation population (66.2 ± 12.9), the present population has good Quality of life. Additionally, it was found that the sample scored lowest on

psychological well –being (58.98) and highest on Self-esteem (78.75).

QUALITY OF LIFE AND AGE

Table 3 Showing the quality of life according to age

	Below 50 (n=11)		Above 50 (n=19)		Df	t	Sig
	Mean	S deviation	Mean	S deviation			
PSW	48.29	23.40	65.35	24.25	28	1.85	0.0737
B	69.31	14.90	69.73	23.12	28	0.05	0.9574
RHC	62.87	23.08	60.08	16.56	28	0.38	0.7034
AF	71.96	25.62	67.98	18.27	28	0.49	0.6239
COP	56.81	17.00	80.26	17.61	28	3.55	0.0014
PhWB	67.04	24.54	82.89	19.07	28	1.97	0.0582
SE	76.13	14.20	47.36	17.46	28	4.63	0.0001
LEI	51.13	27.64	82.23	11.26	28	4.36	0.0002
SS	76.13	16.25	81.57	20.56	28	0.75	0.4592
PL	55.68	25.22	20.39	24.72	28	3.74	0.0008
Index	63.54	11.41	65.78	7.58	28	0.64	0.5227
CarGOQol							

To understand how the age is related to Quality of life, the researcher divided the age group into two; i.e. below 50 years and above 50 years. The mean of the group's age is 53.83. On the Coping subscale, a significant difference was noted in the means of the sample below 50 years (56.81) and the sample above 50 years (80.26) indicating better coping in the latter. Similarly, in the Leisure component the sample

above 50 years scored better than the sample below 50 years i.e. 82.23 and 51.13 respectively. However the group below 50 years scored better on Self-esteem (76.13) than the group above 50 years (47.36). In Private life too, the former group (55.68) scored more than the group above 50 years (24.72). Overall, there was no significant difference between the two groups on the CarGOQol Index.

URBAN AND RURAL POPULATION

Table 4 Showing the quality of life according to place of residence

	Place of Residence (Rural) n=11		Place of Residence (Urban) n=19		Df	t	Sig
	Mean	S deviation	Mean	S deviation			
PSW	63.06	22.43	56.57	25.89	28	0.69	0.4939
B	72.72	22.75	71.05	18.88	28	0.21	0.8301
RHC	85.60	11.83	67.98	23.28	28	2.33	0.0272
AF	76.51	22.61	78.07	22.60	28	0.18	0.8568
COP	71.96	17.97	70.17	21.57	28	0.23	0.8181
PhWB	80.11	21.43	75.98	23.59	28	0.47	0.6369
SE	75.00	22.36	80.92	15.23	28	0.86	0.3954
LEI	76.13	22.67	62.50	26.67	28	1.42	0.1663
SS	64.77	31.53	80.92	14.04	28	1.94	0.0623
PL	68.18	21.91	60.52	22.92	28	0.89	0.3779
Index	73.40	14.24	70.47	14.07	28	5.05	0.0001
CarGOQol							

By referring to the table, a significant difference was noted in the CarGOQol index of the rural population (73.40) versus the urban population (70.47) indicating a better quality of life the former. Also, a significant difference noted between rural and urban

population in the domain of relationship with the health care. The former had a mean of 85.60 in the rural population and a mean of 67.98 in the urban population.

QUALITY OF LIFE AND NUMBER OF MARRIED YEARS

Table 5 Showing the quality of life according to the number of married years

	Number of years after marriage (below 25) (n=15)		Number of years after marriage (above 25) (n=15)		Df	t	Sig
	Mean	S deviation	Mean	S deviation			
PSW	52.91	26.50	66.25	23.00	28	1.47	0.1521

B	71.66	16.34	72.91	24.73	28	1.42	0.1648
RHC	70.00	20.36	81.11	19.78	28	1.51	0.1408
AF	76.11	23.95	79.44	21.56	28	0.40	0.6920
COP	62.22	22.01	78.88	13.31	28	2.50	0.0182
PhWB	73.75	24.11	81.25	20.99	28	0.90	0.3713
SE	77.50	13.52	80.00	22.05	28	0.37	0.7110
LEI	62.50	27.54	73.33	24.02	28	1.14	0.26.8
SS	78.33	14.53	75.00	29.50	28	0.39	0.6979
PL	59.16	23.36	67.50	21.54	28	1.01	0.3181
Index	68.41	13.33	75.56	14.67	28	1.39	0.1734
CarGOQol							

There is a significant difference between in the people with married life below 25 (62.22) and above 25 (78.88) in the domain of coping.

DISCUSSION

The present study explored the quality of life of male spouses of women with breast cancer. The spouses in this study appeared to have good quality of life, thus refuting the findings of several studies that have shown spouses as caregivers of cancer patients experience poor quality of life.[8] This is perhaps due to the fact that in the Indian context the family and social support provide adequate buffer against stress. Majority of the participant in this study indicated good family support. The data also revealed the fact that majority of the patients were diagnosed and undergoing treatment for several months. This perhaps enabled spouses of these patients to make their adjustments and also with acceptance of their altered situation; their quality of life was not impacted. Research has revealed that factors like older age, number of married years [9], and type of hospital facilities provided (corporate) have an impact on the quality of life of spouses of cancer patients. In this study, three variables- age, place of residence and years of marriage seem to influence coping, self-esteem leisure time and private life. The sample data was divided and analysed and it shows a significant difference in the domains of Coping, Self-esteem, leisure time and private life. Studies show

partner and patient had a significant negative impact on the coping process. [10] But in this study they had good coping mechanisms. The other reasons were they were financially stable and their children are taking care of them. The people who had been married more than 25 years have better coping than younger couples. The spouses reported that with time they are adjusted to this situation. When comparing the private life between the age group, the people below 50 were satisfied with the sexual life. When comparing urban and rural population, the latter keeps a better relationship with health care professionals. The rural population had better quality of life than urban population. [11] Conducted a study on quality of life in rural and urban populations by using SF-36 health survey. The people who are living in the rural area scored more in vitality than people in the urban area. Also the older people are more satisfied than younger people except physical functioning.

SUMMARY AND CONCLUSION

Caregivers are often known as the 'unpaid' loved ones, who support the patient both emotionally and physically. They are often the lifeline of the person suffering from the disease. Anyone can be a caregiver; a partner, a family member, a friend and soon. The spouses however, provide love, care, compassion and most importantly, their invaluable time. Even as the patients suffer, the spouses bear

their agony in silence. The study aims to assess the Quality of life of spouses of the breast cancer patients. By using the Caregiver Oncology Quality of Life, the investigator conducted the study on 30 husbands of the breast cancer patients. The results indicated that the spouses had a good quality of life. There was a significant difference in the quality of life of spouses of the breast cancer patients based on the place of residence (Urban or Rural).

LIMITATION

- The small sample size has reduced the studies statistical strength
- Quality of Life is better understood as a longitudinal study
- The study only considers certain variables such as adjustment, depression, anxiety, that may have an effect

IMPLICATION

- To understand the impact of cancer on male spouses of patient.
- To understand if the findings would aid

intervention

- The findings would contribute to both world and Indian literature.
- The findings of this study could lay the foundation for future research in this area.

RECOMMENDATION FOR FUTURE RESEARCH

This is a one point study; in future the researcher could look different point of the quality of the spouses of the breast cancer patients. Also the researcher can check the quality of life in different stages and during different mode of treatment.

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