



Research Article

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Health Related Quality of Life Perceived Among Caregivers and Breast Cancer Patients in Pakistan: Time to Ponder

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Abstract

Introduction: Breast cancer has been considered as an emerging non-communicable threat in Pakistan. Limited access to health care facilities, a smaller number of qualified oncologists, lack of technical equipment for diagnosis are the major factors effecting adequate control and prevention of breast cancer in Pakistan.

Objective: The present study was designed to assess health related quality of life among patients of breast cancer in Pakistan.

Methodology: A descriptive cross sectional study design was used to assess health related quality of life among 382 breast cancer patients and 71 care givers using EORTC QLQ C 30. Data was collected and statistically analyzed.

Results: Out of 453 respondents 84.3%, (n=382) were patients while 15.7%, (n=71) were care givers. Out of all the patients, 11.3% (n=43) had stage 1 of breast cancer and 70.9%, (n=271) had no co morbidity. Of all the patients, 47.4% (n=181) were treated through chemotherapy while 5.5% (n=21) through radiotherapy and 67.8% (n=259) underwent mastectomy. The results highlighted that the lowest scores for HRQoL were observed in the domain of symptom scale i.e., constipation (21.64, ±31.86) followed by domain of emotional functioning (24.17, ±22.40) whereas highest scores were observed in the domains of fatigue (68.79, ±21.05) and financial difficulties (68.67, ±24.69).

Conclusion: Breast cancer patients had poor HRQoL despite self-examination awareness campaigns and advanced therapeutic strategies. The current study concluded that breast cancer had a negative impact on health-related quality of life across all domains in Pakistan. Highest scores were observed in domains of fatigue and financial difficulties whereas, lowest scores for HRQoL were observed in the domain of symptom scale followed by domain of emotional functioning. On the other side, in view of care givers the highest scores perceived were observed in dyspnoea followed by pain.

Keywords: Breast cancer, Health related quality of life, Care givers, Patients, Pakistan, Dyspnoea, Multidimensional, Depression, Therapeutic, Nutritional

Introduction

Breast cancer has been ranked fifth as the most common cause of mortality with nearly 1.7 million new cases diagnosed in 2012 worldwide [1]. The mean prevalence of breast cancer is about 66.7 cases per 100 000 women [2]. In many countries with cutting edge therapeutic care the 5-year survival rate of early diagnosed

breast cancer is 80-90% which might get reduced to 24% in case of late diagnosis, resulting in more focus on possible treatment and quality of life of breast cancer patients [1]. Health related quality of life is a subjective and multidimensional concept that is made of expansive areas, by and large including physical, social, emotional,



and functional well-being as well as symptoms from breast cancer disease and its treatment. The major issues effecting patient's quality of life includes mental and emotional effects of illness, diagnostic and therapeutic measures, stress, pain, depression, disease outcomes on family, marital and social relations, additional economic burdens, nutritional issues, and treatment complications [3].

One of the most widely used tool for measuring HRQoL among cancer patients is European organization for research and treatment of cancer quality of life (EORTC QLQ-C30) questionnaire which is specifically designed to measure four key domains of patients namely physical functioning, emotional functioning, fatigue, and pain. EORTC QLQ-C30 questionnaire (English Version) is reliable and valid instrument to determine health related quality of life among breast cancer patients [4]. A study from Netherlands confirmed the importance and benefits of using EORTC QLQ-C30 questionnaire in identifying patients with clinically important problems which could be later intervened by health care professionals [5]. Breast cancer has been considered as an emerging non-communicable threat in Pakistan. One out of every nine women is most likely at the risk to suffer from breast cancer at any stage of their life mainly due to lack of access to screening facilities & specialty hospitals.

Poor Socio-economic status, lower educational background, socially stigmatized situation, and paucity of early detection programs are also responsible for adding towards cancer burden in Pakistan. Most of the breast cancer patients experience depression. Limited access to health care facilities, a smaller number of qualified oncologists, lack of technical equipment for diagnosis are the major factors effecting adequate control and prevention of breast cancer in Pakistan. The importance of health-related quality of life and its determinants including physical, emotional, and functional domains among breast cancer women has long been recognized in developed world but in developing countries including Pakistan, this concept is still in infancy, although its rate has been increasing at an alarming rate in Pakistan. Limited studies have assessed health related quality of life among breast cancer patients in Pakistan. Therefore, the present study was designed to assess health related quality of life among patients of breast cancer in Pakistan.

Methodology

A descriptive cross-sectional study design was used to determine the health-related quality of life among patients of breast cancer in Pakistan. Study approval was taken from the Ethical Committee of Hamdard University (Ref ERBHUIIC 00178). Approval was also taken from Medical superintendents of different public and private healthcare facilities located in Islamabad (Federal Capital) and Rawalpindi (Twin city). Patients were briefed regarding nature and objectives of the study and verbal and written consent were

obtained prior to data collection. Respondents were assured of the confidentiality of their responses and their right to withdraw from the study at any time. Study respondents included patients diagnosed with breast cancer and their caregivers. Patients having age 20 years and older, diagnosed with breast cancer and who could speak & understand Urdu or English were included, while all other cancer patients other than breast cancer and patients not willing to participate were excluded.

Sample Size & Sampling Procedure

Sample size was calculated using Raosoft® sample size calculator. Sample size was calculated to be 382 patients to achieve 95% confidence level with 5% margin of error, while amongst the care givers of patients, 71 caregivers filled HRQoL questionnaire. As no updated list of number of breast cancer patients in twin cities is available, convenient sampling technique was used. According to convenient sampling technique all the available respondents that were present at the time of data collection were included in study.

Data Collection Tool

A pre-validated EORTC QLQ C 30 was used to measure Health Related Quality of Life for patients and their caregivers and written permission had been obtained from the Quality-of-Life Group. Pilot testing was performed on 10% of sample size to confirm reliability of tool. The value of Cronbach's alpha was 0.71 for European Organization for Research and Treatment of Cancer Quality-of-life Questionnaire Core 30 (EORTC QLQ C30). EORTC QLQ-C30 is most widely used health related quality of life questionnaire in cancer research. It consisted of five functional scales (physical, role, emotional, cognitive, and social), three symptom scales (fatigue, nausea & vomiting and pain) and a global health status/QoL scale. Furthermore, it contains six single items (dyspnoea, insomnia, appetite loss, constipation, diarrhoea and financial difficulties).

Scoring of the Tool

Items response data was entered. Scoring of the EORTC QLQ C 30 was begun with ensuring that the questionnaire was complete. The 'n' item response values were recorded. After item recording, estimated the average of the items that contribute to the scale; this is the raw score. And afterwards through linear transformation to standardize the raw score. All the scales and single-item measures ranged in score from 0 to 100. Higher score for the functioning scales and global health status denoted a better level of functioning (i.e., a better state of the patient), while higher scores on the symptom and single-item scales indicated a higher level of symptoms (i.e., a worse state of the patient). For all scales, the Raw Score, RS, is the mean of the component items: $Raw\ Score = RS = (I_1 + I_2 + \dots + I_n) / n$. Then for Functional scales: $Score = 1 - (RS - 1) / range \times 100$ and for Symptom scales/items and Global health status/QoL: $Score = \{(RS - 1) / range\} \times 100$. "Item range" is the difference between the possible maximum and the minimum response to individual items.

Data Collection and Analysis

Data was collected by the principal investigator trained by the supervisor. The questionnaire was self-administered to the respondents and collected back on the same day to avoid biasness. Response rate of data collection in patients of breast cancer were 100% (382/382 ×100) and among care givers of patients were recorded as 18.5% (71/382 ×100). After data collection, data was cleaned, coded, and entered in SPSS version-21. Descriptive statistics comprising of frequency and percentages were calculated. The nonparametric tests including Mann-Whitney and Kruskal-Wallis ($p \geq 0.05$) were performed to find out the difference among different variables.

Results

Out of 453 respondents 84.3%, (n=382) were patients while 15.7%, (n=71) were care givers. Out of 382 patients, 11.5% (n=44) were in age range 20-29 while 14.1%, (n=54) were greater than sixty years old. Of the total patients, 87.7% (n =335) got treatment from public sector while 12% (n=46) from private sector. Out of all the patients, 20.2% (n=77) were illiterate, while 44.8% (n=171) were matric. Out of all the patients 11.3% (n=43) had stage 1 of breast cancer and 70.9%, (n=271) had no co morbidity. Of all the patients 47.4% (n=181) were treated through chemotherapy while 5.5% (n=21) through radiotherapy and 67.8% (n=259) underwent

mastectomy (Table 1). The results highlighted that the lowest scores for HRQoL were observed in the domain of symptom scale i.e., constipation (21.64, ±31.86) followed by domain of emotional functioning (24.17, ±22.40) whereas highest scores were observed in the domains of fatigue (68.79, ±21.05) and financial difficulties (68.67, ±24.69).

On the other side, in view of caregivers the highest scores perceived for the patients were observed in Dyspnoea (76, ±25) followed by pain (69, ±21). A detailed description is given (Table 2). Comparison of HRQoL domains in different age groups demonstrated a relatively significant difference ($p=0.001$) with breast cancer patients aged more than 60 years having worst HRQoL scores. Analyzing the scores of the respondents with different marital status reported better functioning ($p=0.08$) among married breast cancer patients. Significant difference ($p=0.001$) was observed among different stages of breast cancer with stage 3 patients reported increased symptoms. Furthermore, comparison of HRQoL domains across different types of surgery revealed a comparatively significant difference ($p=0.001$) with worst symptom scale reported among patients who underwent both chemotherapy and radiotherapy. Moreover, significant difference ($p=0.001$) was found in breast cancer patients receiving radiotherapy. A detailed description is given (Table 3).

Table 1: Demographic Characteristics of Respondents

Indicator	n (%)	Patient	Care Giver
		n (%)	
Age	20-29Y	44 (11.5)	13 (18.3)
	30-39Y	117 (30.6)	24 (33.8)
	40-49Y	109 (28.5)	19 (26.8)
	50-59Y	58(15.2)	7 (9.9)
	>60Y	54(14.1)	8 (11.3)
Hospital Sector	Public	335 (87.7)	60 (84.5)
	Private	46 (12)	9 (12.7)
Status of Respondent	Patient	382 (84.3)	71 (15.7)
Marital Status	Single	42 (11)	5 (7)
	Married	267 (69.9)	46 (64.8)
	Widow	23 (6)	8 (11.3)
	Separate	39 (10.2)	10 (14.1)
	Divorce	11 (2.9)	2 (2.8)
Level of Education	Illiterate	77 (20.2)	9 (12.7)
	Primary	171 (44.8)	21 (29.6)
	Secondary	89 (23.3)	24 (33.8)
	Bachelors	34(8.9)	11 (15.5)
	Masters	9(2.4)	6 (8.5)
	Postgraduate	2(0.5)	0

No of Children	None	132 (34.6)	16 (22.5)
	1	23 (6)	4 (5.6)
	2	46 (12)	16 (22.5)
	3	73(19.1)	16 (22.5)
	4	50(13.1)	13 (18.3)
	>4	58(15.2)	6 (8.5)
Monthly Income	<20,000PKR	136 (35.6)	26 (36.6)
	21,000-40,000PKR	164 (42.9)	30 (42.3)
	41,000-60,000PKR	58 (15.2)	7 (9.9)
	61,000-80,000PKR	17(4.5)	5 (7)
	81,000-100,000PKR	6(1.6)	2 (2.8)
	>100,000PKR	1(0.3)	1 (1.4)
Settings	Urban	177(46.3)	33 (46.5)
	Rural	205(53.7)	37 (52.1)
Stages of Breast Cancer	Stage 1	43 (11.3)	6 (8.5)
	Stage 2	264 (69.1)	51 (71.8)
	Stage 3	68 (17.8)	12 (16.9)
	Stage 4	1(3)	1 (1.4)
	Not Known	6 (1.6)	1 (1.4)
Type of Co morbidities	None	271 (70.9)	51 (71.8)
	Hypertension	81 (21.2)	11 (15.5)
	Diabetes mellitus	10 (2.6)	6 (8.5)
	Others	1(0.3)	0
	Hypertension & Diabetes	19 (5)	3 (4.2)
Type of Therapy	Chemotherapy	181 (47.4)	35 (49.3)
	Radiotherapy	21 (5.5)	3 (4.2)
	None	112 (29.3)	14 (19.7)
	Both	68(17.8)	19 (26.8)
Type of Surgery	Mastectomy	259 (67.8)	47 (66.2)
	Lumpectomy	17 (4.5)	5 (7)
	None	99 (25.9)	14 (19.7)
	Both	7(1.8)	19 (26.8)
Family History	Known	83(21.7)	19 (26.8)
	Not known	299(78.3)	52 (73.2)
Gender of Care giver	Male	N. A	30 (42.3)
	Female		41 (57.7)
Relation of Care giver with patient	Husband	N. A	22 (31)
	Daughter	N. A	15 (21.1)
	Mother	N. A	4 (5.6)
	Brother	N. A	4 (5.6)
	Sister	N. A	8 (11.3)
	Son	N. A	4 (5.6)
	Others	N. A	14 (19.7)

Table 2: Domains of HRQoL using EORTC QLQ-C30

Indicator	Mean		Median		Standard Deviation	
	Patient	Caregiver	Patient	Caregiver	Patient	Caregiver
Global Health Status	37.19	38	33.33	33	11.78	13
Functional Scale						
Physical Functioning	46.72	44	53.33	47	26.48	21
Role Functioning	35.65	31	33.33	33	24.26	23
Emotional Functioning	24.17	19	33.33	17	22.4	19
Cognitive Functioning	54.36	34	50	33	21.23	19
Social Functioning	37.22	35	33.33	33	18.29	17
Symptom Scale						
Fatigue	68.79	67	66.67	67	21.05	22
Nausea & Vomiting	33.99	30	33.33	33	28.36	28
Pain	65.23	69	66.67	67	20.82	21
Dyspnoea	64.75	76	66.67	67	33.45	25
Insomnia	43.63	54	33.33	67	35.67	33
Appetite Loss	34.38	0	33.33	0	34.77	0
Constipation	21.64	18	0	0	31.86	28
Diarrhea	34.29	31	16.67	0	40.53	35
Financial Difficulties	68.67	33	66.67	33	24.69	0

Table 3: Comparison of HRQoL Domains among Breast Cancer Patients by Demographic Characteristics Mann-Whitney Test ($p \geq 0.05$); Kruskal Wallis Test ($p \geq 0.05$)

Demographics					EORTC QLQ-C30							
GHS					Functional Scale				Symptom Scale			
	n	Mean rank	Test Stats	P-value	n	Mean rank	Test stats	P-value	n	Mean rank	Test stats	P-value
Marital Status	Single=42	159.12	5434	0.74	Single=42	163.6	5246.0 ^a	0.5	Single=42	132.4	4658.00 ^a	0.08
	Married=267	154.35			Married=267	153.6			Married=267	158.5		
Settings	Urban=177	218.92	13289.00 ^a		Urban=177	202.69	16161.0 ^a		Urban=177	182.19	16495.0 ^a	
	Rural=205	167.82		0.001	Rural=205	181.83		0.06	Rural=205	199.54		0.12
Age	20-29Y=44	212.56			20-29Y=44	251.38			20-29Y=44	148.2		
	30-39Y=117	222.21	24.113 ^b	0.001	30-39Y=117	207.46	47.96 ^b	0.001	30-39Y=117	163.2	36.51 ^b	0.001
	40-49Y=109	185.93			40-49Y=109	201.9			40-49Y=109	191.5		
	50-59Y=58	161.86			50-59Y=58	170.28			50-59Y=58	222.8		
	>60Y=54	150.87			>60Y=54	109.94			>60Y=54	254.2		
Level of Education	Illiterate=77	139.86			Illiterate=77	137.12			Illiterate=77	223.6		
	Primary=171	186.66			Primary=171	172.77			Primary=171	204.1		
	Secondary=89	214.61	39.45 ^b	0.001	Secondary=89	239.66	60.68 ^b	0.001	Secondary=89	160.2	23.19 ^b	0.001
	Bachelors=34	244.91			Bachelors=34	274.15			Bachelors=34	141.7		
	Masters=9	293.33			Masters=9	228.13			Masters=9	170.4		
	Postgraduate=2	198.25			Postgraduate=2	170			Postgraduate=2	204		

Stages of Breast Cancer	Stage 1=43	241.93			Stage 1=43	233.7			Stage 1=43	129.7		
	Stage 2=264	186.46	15.14 ^b	0.04	Stage 2=264	192.8	16.12 ^b	0.002	Stage 2=264	191.8	22.58 ^b	0.001
	Stage 3=68	174.92			Stage 3=68	153.8			Stage 3=68	230.5		
	Stage 4=1	379			Stage 4=1	240.5			Stage 4=1	252		
	Not known=6	208.5			Not known=6	2501			Not known=6	167.25		
Type of Comorbidity	None=271	202.78			None=271	204.7			None=271	179.9		
	Hypertension=81	153.14			Hypertension=81	157.5			Hypertension=81	214.9		
	Diabetes mellitus=11	260.4	21.32 ^b	0.001	Diabetes mellitus=11	232	19.68 ^b	0.001	Diabetes mellitus=11	154.9	18.8 ^b	0.001
	Both=19	166.7			Both=19	132.4			Both= 19	269.4		
Type of Therapy	Chemotherapy=181	197.46			Chemotherapy=181	199.3			Chemotherapy=181	193.9		
	Radiotherapy=21	198.33			Radiotherapy=21	177.4			Radiotherapy=21	220.5		
	None=112	169.59	7.36 ^b	0.06	None=112	194.7	4.01 ^b	0.26	None= 112	158.3	20.27 ^b	0.001
	Both=68	209.6			Both=68	169.6			Both= 68	230.8		
Type of Surgery	Mastectomy=259	182.85			Mastectomy=259	175.14			Mastectomy= 259	209.9		
	Lumpectomy=17	215	5.83 ^b	0.1	Lumpectomy=17	243.15	18.7 ^b	0.001	Lumpectomy= 17	184.7	30.9 ^b	0.001
	None=99	206.9			None=99	225.4			None= 99	140		
	Both=7	235.7			Both=7	191.93			Both=7	251.5		
Family History	Known=83	205.61	11237.5 ^a	0.1	Known=83	187.42	12070.0 ^a	0.7	Known=83	190.5	12326.0 ^a	0.9
	Not Known=299	187.58			Not Known= 299	192.63			Not Known=299	191.8		

Discussion

Breast cancer has become one of the most prevailing cancer among the women worldwide bringing about expanded morbidity and mortality. Due to prolonged therapy and recurrence of breast cancer, patients suffer from physical, emotional, social, and sexual discomfort leading towards poor disease outcomes. Estimation of HRQoL is important in breast cancer, as it helps both patients and physicians in choosing better treatment option and in return improving health outcomes of patients. The results of the current study featured a consequential impact on several domains of HRQoL among breast cancer patients and their caregivers. Lowest scores for HRQoL were observed in the domain of symptom scale i.e., constipation followed by domain of emotional functioning whereas highest scores were observed in the domains of fatigue and financial difficulties. These findings are in concordance with a study from Germany in which mean score in domain of financial difficulties was reported as highest [6].

EORTC QLQ C30 has been most widely used tool consisting of GHS, functional and symptom scales and the scores provide useful information of disease on various dimensions of affected

individuals. Most of the breast cancer patients enrolled in this study considered their health and QoL as poor which might be due to poor Socio-economic status and psychological crisis among breast cancer patients, on contrary to another study findings from Pakistan where breast cancer patients reported their GHS as clinically poor [7]. About functional scale, the results of the current study revealed that most of breast cancer patients had difficulty in remembering things and their physical condition interfered with their family life and social activities and except cognitive functioning (moderate) all of the other domains including physical, role, emotional and social functioning were reported poor. Similarly, these findings are in accordance with a study from Kuwait where most of the patients also stated their emotional, social, role and physical functioning poor [8].

On symptom scale, the results of the present study unveiled that most of the breast cancer patients reported pain, dyspnoea, fatigue and financial difficulties and among all of the breast cancer patients, very few of them reported appetite loss, constipation and diarrhea. Moreover, the results of the present study revealed that breast cancer patients in stage three, who had mastectomy and

on chemotherapy had relatively low health related quality of life. Illiterate breast patients reported worst HRQoL across all domains except in domains of insomnia, appetite loss and constipation. These findings are consistent with a study conducted in Sweden where majority of the breast cancer patients suffered from pain, dyspnoea, fatigue and financial difficulties [9].

Caregivers play an important role in determining quality of life of patients as they have more keen observation of their patients under variety of circumstances. The results of the current study revealed that most of the care givers considered their patient's quality of life and health as mediocre. In their view, breast cancer patients had trouble doing strenuous activities, in taking a long and short walk and pursuing their hobbies. They felt worried, irritable, and depressed and have difficulty in concentrating on things like reading a newspaper or watching television. Similarly, poor health related quality of life was reported among the patients in Ethiopia which highlighted that physical condition interfered with the family life and social activities of breast cancer patients [10-15].

Limitations of the Study

The main issues faced during the study were time and financial constraints and cross-sectional study design which does not show cause and effect relationships. Furthermore, the results of this study were limited to two cities of Pakistan and should not be generalized to other parts of country.

Conclusion

Breast cancer patients had poor HRQoL despite self-examination awareness campaigns and advanced therapeutic strategies. The current study concluded that breast cancer had a negative impact on health-related quality of life across all domains in Pakistan. Highest scores were observed in domains of fatigue and financial difficulties whereas, lowest scores for HRQoL were observed in the domain of symptom scale followed by domain of emotional functioning. On the other side, in view of caregivers the highest scores were observed in dyspnoea followed by pain. Necessary health educational and psychological interventional programs targeting patients as well as care givers with lower educational programs should be initiated to improve awareness and to reduce depression among breast cancer patients as well as their caregivers.

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The study received no funding.

Conflict of Interest

The authors declare no conflict of interest.

Ethics

Not applicable.

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