Original Article

Caregiving Burden and Psychological Distress of Breast Cancer Patients' Husbands after Mastectomy

Konstantina Chronopoulou, MSc
Psychologist-Psychotherapist, General Hospital of Preveza, Greece

Dionissios Sakkas, MD, PhD, E.C.P
Psychiatrist-Psychotherapist, President of the Greek Society of Systemic Family Therapy Groups and Individuals (HEL.A.SY.TH), Member of Consultative-Scientific team of Athenian Institute of Anthropos (AIA), Athens, Greece

Dimitrios Damigos, PhD
Assistant Professor, Medical School, University of Ioannina – Department of Social Medicine and Mental Health, Ioannina, Greece

Correspondence: Konstantina Chronopoulou, Psychologist-Psychotherapist, General Hospital of Preveza, Greece e- mail: k_chronopoulou@yahoo.gr

Abstract

Background: Mastectomized women suffer significant psychological burden. Besides women, the burden of her husband is an important parameter for the couple's well being.
Aims: The purpose of this study was to investigate the caregiver's burden of mastectomized women.
Methodology: Thirty three couples participated in this quantitative longitudinal study. The selection was made among women who during the previous two days had undergone mastectomy and were still hospitalized. Three months later, couples were re-evaluated. The HADS (for anxierty and depression in hospitalized patients) and the Zarit (for caregiver's burden)questionnaires were used.
Results: Right after the mastectomy, 45.5% of women presented with mild anxiety, 27.3% with moderate and 27.3% severe. As for depression, 12.1% of women appeared with normal levels, 24.2% mild and 21.2% moderate and 42.4% severe depression.Couple's anxiety and depression tend to resolve over time,although husbands experience greater burden three months after spouse's mastectomy.
Conclusion: The findings of the present study support the view that women and their husbands suffer significant psychological stress after mastectomy, while husbands continue to experience significant strain three months after spouse's mastectomy which was related to their role as caregivers.

Key words: Mastectomy, women, husbands, caregiver, burden

Introduction

Breast cancer remains the most common type of cancer in women in Greece, with mortality rates estimated at 2,000 women per year. Of course there is a significant progress in the patients' survival (i.e the average survival of patients with metastatic breast cancer doubled, rising from 1.2 years during 1991-1994 to 2.7 years during 2003-2006) (National Action against Cancer 2011-2015).

Factors, such as early diagnosis and use of systematic treatment, have increased the chance of survival from the disease. Given these, it has given particular importance to the psychological nature of the illness, which causes elevated stress levels and depression to patients, reduces their quality of life and hinders relationships within the family (Bard & Sutnerland 1955, Chropa & Kamal 2012).

A woman's quality of life with breast cancer, however, like all multidimensional and subjective concepts, can only be set within the major family and social systems in which she participates (Girgis et al 2013).

Each system and subsystem interacts with each other so that they influence and co-determine one another. In that context, the relationships between members affect the characteristics of the members and change the properties of the system; the environment can alter the properties and may also affect the relationships or alter the relationships between the members of the system and so on (Paritsis, 2003)

The couple, then, a member of which is the woman with breast cancer, is also a persons' system, and for this reason in the present research, besides the woman's psychological burden, the burden of her husband is researched as one important parameter for the couple's well being.

Material and methods

This quantitative longitudinal study was conducted at the following three hospitals in Athens during the years 2013 and 2014 (initial assessment and reassessment respectively): Agios Savvas Cancer Hospital, General Hospital of Athens Hippocrates and Metaxa Cancer Hospital of Piraeus. Permission for the study was obtained by the Scientific Committee of the hospitals.

Study sample

Thirty three couples participated, wife being mastectomized. Women who were unmarried or had no permanent partner were excluded from the sample.

A prerequisite for the participation in the study was the couple's consent. Both the objectives and the research process were explained, while their voluntary participation was also outlined. Their signed consent to the study was requested as well. Moreover, the refusal of one spouse to participate meant no participation for the other.

Sample selection method

A convenience sample was used. The selection was made among women who during the previous two days had undergone mastectomy and were still hospitalized. The study took place in two phases: A contact number was assigned to each couple to schedule the reassessment three months later.

Questionnaires were simultaneously filled in by the two spouses. For the couple's convenience, this appointment took place either at the short stay department where the woman went for her chemotherapy/radiotherapy, or at a scheduled appointment with the doctor in the hospital or in their practice.

Questionnaires

Two questionnaires were used: The HADS questionnaire and the Zarit Questionnaire. Mood disorders (anxiety and depression) were traced using the Hospital, Anxiety and Depression Scale Questionnaire (HADS) (Mystakidou et al 2004).

HADS questionnaire consists of 14 items (sentences-questions) with answers in four-point Likert scale. It has seven questions regarding anxiety and seven for depression. Each item had four possible answers and results range from 0 to 3. HADS measures the level of symptoms within the last 10 days. HADS uses >8 as a "cut –off" score, that is in accordance with the suggestions of its creators. A score below 8 means that the individual is free of symptoms and a score beyond 8 that symptomatology of anxiety or depression is present.

The Zarit Burden Interview, a popular caregiver self-report measure used by many aging agencies, originated as a 29-item questionnaire (Zarit, Reever & Bach-Peterson, 1980). The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). Higher scores mean higher burden. The scale has been validated in Greek and four factor have been emerged, explaining 63,92% of the total variance, while a total a Cronbach coefficient has been found high (0.93). The four factors are as follows: " "personal strain", " role strain", "relationship deprivation" and "care management" .

Statistics

Descriptive and inferential statistics was performed. The paired samples t-test and Pearson correlations were used. Statistical significance was set at p=0.05. SPSS 22.0 was used.

Results

Thirty three couples were finally enrolled in the study (patient-caregiver dyads). Women's age was 51.61±9.06, while husbands' age was 55.82±10.25 years old.

.

Table 1.Paired differences for anxiety and depression levels in women

		Paired Differences					T	df	P
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower	Upper			
Pair 1	Patients' anxiety A- Patients' anxiety B	2.323	3.229	.580	1.138	3.507	4.005	30	**<0.001**
Pair 2	Patients' depression A- Patients' depression B	1.742	5.092	.915	-.126	3.610	1.905	30	*0.066*
Pair 3	Total patients' anxiety score A- Total patients' anxiety score B	4.065	5.933	1.066	1.888	6.241	3.815	30	**0.001**

Table 2. Paired differences for anxiety and depression levels in women and caregivers' burden

Paired Samples Test									
men		Paired Differences					T	df	P
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower	Upper			
Pair 1	Score caregivers anxiety A -Score caregivers anxiety B	3.435	4.944	1.031	1.297	5.573	3.332	22	**.003**
Pair 2	Score caregivers depression A – Score caregivers depression B	2.783	4.101	.855	1.009	4.556	3.254	22	**.004**
Pair 3	Caregivers' total score A - Caregivers' total score B	6.217	8.404	1.752	2.583	9.852	3.548	22	**.002**
Pair 4	Score ZARIT A - Score ZARIT B	-1.000	9.203	1.771	-4.641	2.641	-.565	26	.577
Pair 5	Score ZARIT 1 A - Score ZARIT 1 B	-2.481	5.508	1.060	-4.660	-.303	-2.341	26	**.027**
Pair 6	Score ZARIT 2 A - Score ZARIT 2 B	-1.852	8.960	1.724	-5.396	1.693	-1.074	26	.293
Pair 7	Score ZARIT 3 A - Score E ZARIT 3 B	.296	1.514	.291	-.303	.895	1.017	26	.319
Pair 8	Score ZARIT 4 A - Score ZARIT 4 B	-.852	3.022	.582	-2.047	.344	-1.465	26	.155

Table 3. Correlations between caregiver's burden dimensions between the two phases of the study.

N=33		Score ZARIT 2 A	Score ZARIT 3 A	Score ZARIT 4 A	Score ZARIT 1 B	Score ZARIT 2 B	Score ZARIT 3 B	Score ZARIT 4 B
Score ZARIT 1 A	r	**.578****	.144	.300	**.718****	.095	-.355	.192
	p	<0.001	.423	.089	<0.001	.639	.070	.336
Score ZARIT 2 A	r		.313	.316	.302	.046	.145	.539**
	p		.076	.073	.126	.821	.470	.004
Score ZARIT 3 A	r			.204	-.085	.090	.609**	.351
	p			.255	.674	.654	.001	.073
Score ZARIT 4 A	r				.117	-.021	.032	.455*
	p				.560	.918	.874	.017
Score ZARIT 1 B	r					**.635****	-.387*	.335
	p					<0.001	.046	.088
Score ZARIT 2 B	r						-.016	.293
	p						.937	.138
Score ZARIT 3 B	r							.297
	p							.132

Most women (84.4%) were High School graduates, while 45.5% of men did so. Right after the mastectomy, 45.5% of women presented with mild anxiety, 27.3% with moderate and 27.3% severe. As for depression, 12.1% of women appeared with normal levels, 24.2% mild and 21.2% moderate and 42.4% severe depression.

Women's anxiety and depression tend to resolve over time, the difference being statistically significant in the case of anxiety (p<0.001) and marginally in the case of depression (p=0.066) (Table 1).

Regarding husbands, anxiety and depression ameliorate over time (p<0,05). However, husbands experience greater burden three months after spouse's mastectomy in all three dimensions but 3rd, while statistically significant difference occurred in factor 1 (p=0.027). Personal strain and role strain correlated to one another between the two phases (p<0.001), while personal strain in phase A correlated significantly with personal strain in phase B (p<0.001)and the same happened with role strain (Table 2).

The first Zarit scale factor correlated significantly with the second one in both phases (r=0.578 for Phase A και 0.635 for phase B (Table 3).

Discussion

The findings of the present study support the view that women and their husbands suffer significant psychological stress after mastectomy, while husbands continue to experience significant strain three months after spouse's mastectomy which was related to their role as caregivers.

Indeed, anxiety and depression in women after mastectomy range from moderate to severe levels. The level of anxiety and depression among women with breast cancer was influenced by the type of the applied surgical procedure and adjuvant chemotherapy.

It was concluded that going through mastectomy leads to moderate to severe levels of depression and anxiety, primarily because the females feel

incomplete and insecure after losing a part of themselves (Kemeny et al., 1998, Wellish et al., 1989, Kemeny et al., 1998, Alicikus et al 2009). A recent study conducted in Greece found that women who underwent radical mastectomy felt less attractive and avoided social contact (Anagnostopoulos & Myrgianni 2009). Despite the fact that less invasive techniques have been established in relation to the past, the effects of surgery on a woman's body image and sexuality are still significant (Chropa & Kamal 2012)).

The life-threatening nature of breast cancer and its strenuous treatment, place great strain on patients and their families. In the present study this was obvious in the field of care management and personal and role strain. Given their course in time, it is clear that men seem to experience a greater burden of care three months after their partner's mastectomy. It seems that it takes time to experience the burden inherent in the concept of care.

Research supports the view husbands may be especially vulnerable as the main source of support to their spouses. Husbands are the primary care providers for women with breast cancer. They experience significant burden and role strain, but may also perceive positive aspects to the caregiving (Wagner et al, 2006, Wagner et al., 2011). It has been suggested that the higher the caregiver burden, the higher the caregiver's strain and the lower the caregiver's quality of life.

Husbands perform a variety of caregiving tasks for wives during and after breast cancer treatment (Obaidi et al 2013). In a longitudinal perspective, it seems that husbands' role strains improve in the social domain but worsen in the domestic domain.

Husbands reporting persistent domestic role strain are at high risk for continued psychological distress following their wives' breast cancer treatment. Health care providers should monitor husbands' caregiver burden regularly (Wagner et al., 2011).

The couples should be counselled to take advantage of any available resources to reduce domestic role strain (such as social support and communication training). Counselling along with other appropriate psychological intervention may alleviate the psychological distress in husbands.

References

Alicikus ZA, Gorken IB, Sen RC, Kentli S, et al (2009) Psychosexual and body image aspects of quality of life in Turkish breast cancer patients: a comparison of breast conserving treatment and mastectomy. Tumori 95:212-218.

Anagnostopoulos F, Myrgianni S (2009) Body image of Greek breast cancer patients treated with mastectomy or breast conserving surgery. J Clin Psychol Med Settings 16:311-321.

Bard M, Sutnerland AM (1955) Psychological impact of cancer and its treatment. IV. Adaptation to radical mastectomy. Cancer 8:656-672.

Chopra I, Kamal KM (2012) A systematic review of quality of life instruments in long-term breast cancer survivors. Health Qual Life Outcomes 10:14

Girgis A, Lambert S, Johnson C, Waller A, Currow D (2013). Physical, psychosocial, relationship, and economic burden of caring for people with cancer: a review. J Oncol Pract. 9:197-202.

Kemeny MM, Wellisch DK, Schain WS (1998) Psychosocial outcome in a randomized surgical trial for treatment of primary breast cancer. Cancer 62:1231-1237.

Mystakidou K, Tsilika A, Galanos A, Vlachos L. (2004). The hospital anxiety and depression scale in Greek cancer patient:Psychometric analysis and applicability. Support Care Cancer 12.821-825.

National Action against Cancer.
http://www.anticancer.gov.gr/catalogue/SxedioDrasis_24selido.pdf, retrieved 3.9.16

Obaidi J & Al-Atiyyat N (2013). Quality of Life among Primary Caregivers of Women with Breast Cancer: A Review. Middle East J Cancer 4:45-49

Paritsis N, (2003). The intelligence of life, Athens, BETA - Medical Publications

Wagner CD, Bigatti SM, Storniolo AM (2006) .Quality of life of husbands of women with breast cancer. Psychooncology. 15:109-20.

Wagner CD, Tanmoy Das L, Bigatti SM, Storniolo AM (2011). Characterizing burden, caregiving benefits, and psychological distress of husbands of breast cancer patients during treatment and beyond. Cancer Nurs 34: 21-30.

Wellisch DK, DiMatteo R, Silverstein M, Landsverk J, Hoffman R, et al (1989).Psychosocial outcomes of breast cancer therapies: lumpectomy versus mastectomy. Psychosomatics 30:365-373.

Zarit SH, Reever KE, Back-Peterson J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. The Gerontologist 20: 649-655