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FAMILIAL SOCIAL SUPPORT SCALE FOR BREAST CANCER PATIENTS: DEVELOPMENT AND VALIDATION[#]

Bina Nausheen
School of Psychology
University of Southampton,
Southampton, England.

&

Anila Kamal
National Institute of Psychology
Centre of Excellence, Quaid-i-Azam University
Islamabad, Pakistan

The article describes the development of the 38-item Familial Social Support Scale (FSSS) which measures social support of the family as perceived by the women breast cancer patients. To generate items for the scale, a series of steps including literature review, interviews, and focus group discussion were carried out. For the selection of final items, judges' opinions were obtained and item total correlations were calculated. For item total correlation, 41-item Familial Social Support Scale was administered on a sample of 60 breast cancer patients (mean age: 43.21 years). The 38 items finally selected fell in the range of correlation coefficients of .53 to .89 ($p<.000$). The scale shows satisfactory alpha coefficient, split-half reliability, and content validity. The significantly negative value of the Pearson correlation coefficient indicated the discriminant validity of the scale. It was determined by investigating the relationship of familial social support with depression in breast cancer patients in a separate study with independent sample.

Breast cancer in women is one of the most frequently occurred and reported types of cancer in Pakistan and in the World. With advances in treatment and high survival rate, the patients live longer with the disease than ever before. In result, it has now become even more important to improve the quality of life of these patients.

[#] Correspondence concerning this article should be addressed to Bina Nausheen, School of Psychology, University of Southampton, Highfield, Southampton SO 17 1BJ, United Kingdom. <bina_n@hotmail.com & bn1@soton.ac.uk>

Despite the fact that an early diagnosis or detection will mean a higher operative cure rate, cancer has remained, however, a disease equated with hopelessness, pain, fear, and death. Its diagnosis and treatment often produce psychological stresses resulting from the actual symptoms of the disease, as well as the patient's and family's perceptions of the disease and its stigma.

In the various stages, cancer patients can experience a sequence of symptoms and psychosocial problems (Broeckel, Jacobsen, Balducci, Horton, & Lyman, 2000; Knobf, 1990; Schag, Heinrich, Aadland, & Ganz, 1990; Stone, Richards, A'Hern, & Hardy, 2000; Weisman, 1977). With regard to psychosocial problems cancer is a disease, which more than most other diseases, disorders the psychic balance from the beginning of the disease. The patient can be overwhelmed by feelings of despair, panic, and other emotions and in the other instances experience severe feelings of depression and apathy (Cassileth, et al., 1984). Bodily symptoms related to the disease or the treatments of the disease are an important aspect of the disease burden of cancer patients. They sometimes undergo stressful medical treatments like chemotherapy or radiotherapy, which can have severe side effects (Holland & Lesko, 1988; Silberfarb, Mauser, & Crouthamel, 1980).

Social support is one of the foremost contributions of the life quality along with satisfactory treatment course and it plays an important role in terminal illness (Carey, 1974; Lewis, et al., 2001; Seow, Huang, & Straughan, 2000; Weisman & Worden, 1975). Social support has been claimed to have positive effects on a variety of outcomes, including physical health, mental well being, and social functioning; while external locus of control, low social support, abnormal illness behavior, emotional stress, and poor coping mechanisms were associated with psychological symptoms and maladjustment to cancer (Klemm, 1994; Krishnasamy, 1996). Researches also suggest that cognitive behavioral therapy and social support may buffer patients against psychological distress in newly diagnosed cancer patients (Bottomley, Hunton, Roberts, & Jones, 1996; Marble, 1999) and the latter also been an important predictor of coping with mastectomy (Bloom, 1979; Jamison, Wellisch, & Pasnau, 1978).

An important issue that should be addressed by people in the care of cancer patients is the pattern of family and its ability to maintain cohesion and retain adequate social support during this period. The

social and emotional support of the family contributes to the psychosocial impact of illness on the family and the patient (Sales, Schulz, & Biegel, 1992). This in turn influences patient's perception of the illness and his/her coping strategies hence, determining his/her quality of life. In Pakistan, familial bonds are considered very essential in an individual's life and are the main source of social support for them.

As positive attitude can help people in tolerating therapies and recovery, external resources in the form of social support can also facilitate the process of adaptation. Studies have found that social support serves as an ameliorating function during time of psychological distress in medical populations in general (Hammer, 1983; Kugaya, Akechi, Okamura, Mikami, & Uchitomi, 2000; Quinn, Fontana, & Reznikoff, 1986) and in breast cancer patients specifically (Ell, 1984; Funch & Mettlin, 1982; Hughes, 1982) emphasizing that certain aspects of the post diagnostic environment can influence the degree of upset the patient feels in response to breast cancer, particularly the accessibility of supportive interpersonal relationships among family members. In addition, studies have found that physically ill patients who perceive themselves as having more available social support experience less depression and helplessness (Zich & Temoshok, 1987). Aapro and Cull (1999) found depression to be uniformly present in the dying. A substantial weight of evidence demonstrates that the individuals suffer from high levels of anxiety and depression before they reach the terminal phase of their illness. Some studies suggest that treatments such as radiotherapy and chemotherapy, which often precede the terminal phase, actually cause this emotional disturbance (Palmer, Walsh, McKinna, & Greening, 1980; Peck & Boland, 1977).

Some of the scales used in the past researches on the topic are Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983), the anxiety and depression subscales of Symptom Checklist-90 (Derogatis & Cleary, 1977) and Social Support Questionnaire (SSQ, Northouse, 1988).

In Pakistan, the state of health psychology has emerged only quite recently as compared to the western world. On the basis of the role played by the psyche in the physiological problems, it is said that emotional support can help to improve the psychological well being and hence the quality of life of the physically ill patients, if not

completely alleviate the disease. Naheed (2000) identified that family support as a crucial factor in the improvement of stroke patients. According to an approximate estimate, in Pakistan, reported women cancer patients are 50.5% of the total out of which 42.84% are diagnosed as cases of breast cancer-which is at the top among women (data from Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore, for the year 1995-99). Despite being the most frequently reported type of cancer, little attention has been paid in the country to the psychological aspects of these patients.

The following sections will detail the instrument's development, results of psychometric analyses undertaken (including reliability and validity), and the result of the application of the instrument to a sample of breast cancer patients in which the relationship of familial social support with depression has been studied in order to determine its discriminant validity.

METHOD

Development of Familial Social Support Scale (FSSS) for Women Breast Cancer Patients

The details about the development of an indigenous Familial Social Support Scale for women breast cancer patients has been described in the following section.

Generation of Item Pool

In order to generate items for the scale, certain areas were derived from the available literature and researches in this domain (see for example, Bolger, 1996; Taylor, 1986). The eight identified areas included (i) treatment, (ii) nutrition/food, (iii) physical/health care, (iv) transportation, (v) cooperation (domestic help, emotional support, and financial support), (vi) child care assistance, (vii) sexuality/sex life, and (viii) attitude of the family because of social/community pressures.

The interviews with the breast cancer patients were carried out to generate items in the already derived areas through literature review of familial social support. Sample consisted of 25 women breast cancer patients with age range of 26-61 years (mean age: 45.6 years), visiting

the Out Patient Department (Oncology) at Nuclear Medicine, Oncology, and Radiotherapy Institute (N.O.R.I.), Islamabad (n = 10), and Combined Military Hospital (C.M.H.), Rawalpindi (n = 15). A total of 31 patients were approached but 6 patients were not interviewed because of their unfamiliarity with the Urdu language.

On the basis of these interviews, the already identified areas were confirmed, in which patients were facing problems with reference to their family. According to the identified areas of familial social support, 80 statements/items were formulated.

Since on the basis of interviews, in some areas of social support fewer items were generated as compared to others, therefore, focus group discussion was carried out with 8 students doing Master's in Psychology. As a result, 21 items were added (making a total of 101 items). Those 101 items were evaluated for overlapping and repetitive content by the researchers themselves. The redundant items were dropped and remaining items were checked for their appropriate wording and were improved through rephrasing. Sixty-one items were retained and listed in random sequence.

In order to further check the items, judges opinion was sought. Seven M.Phil. degree holders in Psychology were taken as judges to gauge any possible overlapping of the items and to identify inappropriate and unclear items. Out of 61 short-listed items, 41 items were selected on the basis of the consensus among the judges and 20 items were dropped.

Final Selection of Items

An independent sample of 60 breast cancer patients with age range of 20-70 years (mean age: 43.21 years) was taken. The data was collected from N.O.R.I., Islamabad (n = 16), and C.M.H., Rawalpindi (n = 44). 41 selected items were arranged on a 4-point Likert type scale. The categories of this scale were "never" (1), "sometimes" (2), "most of the time" (3), and "all the time" (4). The minimum possible score on the scale was 38 and the maximum score can be as high as 152 suggesting that the higher the score obtained by subjects, higher will be the familial social support. Out of 41 items, 38 items were found to be significantly correlated at p<.000 (Table 1).

Table 1

Item Total Correlation for the 41-item Familial Social Support Scale (FSSS) (N = 60)

Item Nos.	*r*	Item Nos.	*r*
1	.87*	22	.57*
2	.60*	23	.66*
3	.87*	24	.62*
4	.72*	25	.64*
5	.80*	26	.76*
6	.45	27	.81*
7	.67*	28	.86*
8	.78*	29	.78*
9	.83*	30	.73*
10	.75*	31	.80*
11	.70*	32	.84*
12	.80*	33	.85*
13	.56*	34	.80*
14	.75*	35	.76*
15	.75*	36	.73*
16	.66*	37	.12
17	.56*	38	.89*
18	.68*	39	.75*
19	.67*	40	.53*
20	.88*	41	.76*
21	.28		

*$p < .000$

The final number of items falling in each area of the 38-item Familial Social Support Scale were: (i) treatment: 4; (ii) nutrition/ food: 1; (iii) physical/health care: 4; (iv) transportation: 1; (v) cooperation in domestic help: 2; emotional support 18; financial support 2; (vi) child care assistance: 1; (vii) sexuality/sex life: 3; and (viii) attitude of the family because of social/community pressures: 2. Among these 38

items, 23 items were positively and 15 were negatively phrased, to which reverse scoring was assigned.

Reliability

The reliability analysis were also carried out on the same sample of 60 women breast cancer patients.

Cronbach's Alpha Coefficient

Initial psychometric analysis, using Cronbach's alpha coefficient yielded an internal consistency coefficient of .97 ($N = 60$) for the entire 38-item Familial Social Support Scale.

Split-half Reliability

The split-half reliability of FSSS was found to be .93 ($N = 60$). The alpha reliability coefficients of Part I and Part II of the FSSS were .95 and .96, respectively, having 19 items in each part.

Validity

As the items of FSSS have been empirically determined on the basis of interviews done with the women breast cancer patients and judges' opinion has also been sought, therefore, its content validity has been established.

For further validation of this scale, the discriminant validity with Siddiqui-Shah Depression Scale (SSDS, Siddiqui, 1992) has been established, by finding the relationship between familial social support and depression in women breast cancer patients. Siddiqui-Shah Depression Scale was used to gauge depression. It was hypothesized that the higher the depression in the patients, the lower would be their perception of the familial social support. This also established the discriminant validity of the FSSS along with finding the relationship between these two variables i.e., there would be a negative correlation between familial social support and depression.

An independent study was carried out in which FSSS and SSDS were administered on a sample of 80 women breast cancer patients with mean age 42.53, from Combined Military Hospital (CMH), Rawalpindi. The correlation was calculated between FSSS and SSDS.

The value of the Pearson correlation coefficient was significantly negative, indicating discriminant validity of the FSSS (Table 2).

Table 2

Correlation between Familial Social Support Scale and Siddiqui-Shah Depression Scale (N= 80)

Variables	Familial Social Support
Depression	-.85*

*$p < .000$

DISCUSSION

The breast cancer patients was a difficult sample to deal with because of their vulnerability to be depressed due to the disease and anxiety about the reaction of their family members in case of disclosure of their responses to their families. Although they were assured by the researcher about the confidentiality of their responses. It was observed during data collection that many patients were in a highly suggestible and uncooperative physical and psychological state. In some cases, family members of the patients felt that it was not fair with the patients to remind them about the nature of their disease.

The sample was quite homogeneous as only married (and not widowed or unmarried) breast cancer patients were taken so its findings can be generalized to this population only. Also only those women were included in the sample, who could at least understand proper Urdu language since the researcher was unable to communicate in any regional language, in this case Punjabi, which is the most frequently spoken language in Rawalpindi/Islamabad.

This Familial Social Support Scale developed in this study may prove to be useful in measuring breast cancer patients' perception of familial social support, keeping in view the Pakistani social system. As the increase in rates of incidence, prevalence, and survivorship of breast cancer, growing numbers of women are faced with the need to adapt to its diagnosis and treatments. Increased understanding of the role of social support in this adaptation process is of value to those

who are involved with these patients like social workers, doctors, family members in particular and to the society in general.

RECOMMENDATIONS

Keeping in view the limitations of the present research, a few recommendations for future research are: (i) bigger sample size should be taken; (ii) sample should be selected randomly for proper representation of the population; and (iii) nation-wide data should be collected.

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