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SOCIAL SUPPORT NEEDS AND ADJUSTMENT OF CANCER PATIENTS

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ABSTRACT

Background: Given the limited health care funds and increasing survival from cancer, services should be targeted to meet patients' post-treatment need.

Objectives: To identify which of the needs that patients consider important; examine how they compare the role of the family, nurses and friends in meeting these needs; and assess the relationship between social support and adjustment to cancer.

Setting: Radiotherapy clinic, University College Hospital, Ibadan, Nigeria.

Design: Cross-sectional study.

Measurements: A 29-item needs questionnaire for assessing patients' expressed and perceived informational, physical (relief of pain), emotional and instrumental (economic) needs/support from family, friends and nurses; and indices of social adjustment (self-esteem, coping, acceptance).

Subjects: Seventy two (20 males and 52 females) consecutive attendees mean age, 41.1, SD 12.7.

Results: The highest needs expressed were physical (95.8%) and informational (81.7%), while emotional support was the most perceived as provided. Nurses and families were similarly perceived as significant providers of total social support, with nurses being identified as best providers of physical and instrumental support. Over 75% felt socially adjusted. Informational support was the most important predictor of social adjustment, while total social support predicted self-esteem.

Conclusion: The findings support previous work indicating that clinicians should drop their reticence and provide adequate information to cancer patients and their relatives. Staff social support is appreciated by patients and is predictive of social adjustment. Policy makers should consider social welfare measures to relieve the burden of cancer on families.

INTRODUCTION

Cancer is a major cause of morbidity and mortality throughout the world, with nine million people newly diagnosed each year and 5 million people dying from the disease(1). In sub-Saharan Africa, the validity of estimated incidence rates is plagued by under-ascertainment of cases. However, recent estimates from national cancer registries in West Africa indicate an age-standardised incidence rate for all sites, ranging from 55.7-110.5 per 100,000 population, compared with USA: 272.6 per 100,000(2).

Improvement in treatment and detection has led to more patients living with the disease for longer years. Learning about survivors' post-treatment needs and adjustment has therefore become an increasingly important issue. In a search of the literature, we found that most African studies estimating the adequacy of health care services and post-treatment needs of cancer patients have focused primarily on the physical aspects of the disease and on improvements in length of survival. There is

paucity of African studies that have explored the extent to which cancer patients' perceived needs are being met across a range of issues, such as information provision, physical and daily living support and emotional well being(3,4). In developed countries, the post-treatment needs of cancer patients have gained increasing attention(5-8), within the emerging sub-specialty of psycho-oncology. Given the limited health care funds, it is imperative that services are targeted to meet patients' needs; and to make these services relevant, the patients should participate in outlining the needs. Needs assessment enables individuals and sub-groups of patients with higher levels of need to be identified and targeted with appropriate early interventions, and also makes it possible for aspects of health services that need improvement to be identified and prioritised.

Whatever these needs may be, it is important that caregivers, especially nurses and family members, be conversant with them, in order to enhance their care giving roles. Of all health care workers, nurses spend the longest hours with the patients. Nursing should utilise this golden

opportunity to assess the needs of patients and ensure that these needs are being met as much as possible. This will help to improve the quality of care and the coping ability of patients. The objectives of this study were: (i) to identify which of the social support needs that cancer patients consider important for their adjustment to the disease; (ii) to examine how they compared the role of the family, nurses and friends in meeting these social support needs and; (iii) highlight how the patients were adjusting to the disease; and assess the relationship between social support and indices of adjustment to cancer.

MATERIALS AND METHODS

Operational definitions: Social support: These is support given by health care workers and significant others, which meet the perceived needs of patients and maintain their self-esteem. Such support includes, information on cancer and its management, help with physical care and relief of pain, economic support, companionship, good interpersonal relationship and job security(9,10).

Needs: In this context, "needs" can be defined as the requirement of some action or resource that is necessary, desirable or useful to attain optimal well being(7). The needs of the patient determine the types of social support that he/she values or requires; and hence the use of the terms, 'social support' and 'needs' depends on whether we are referring to the provider (i.e. care giver- nurse, family, friends) or the patient. The caregiver provides a specific social support to meet the relevant need of the patient. The needs/ social support assessed in this study were, health informational, physical (i.e. help with relief of pain and physical care), emotional (i.e. love/ relationship) and instrumental (i.e. economic) support.

Adjustment/adaptation: The ability of the patient to adapt to the condition. It is associated with such factors as, ability to freely discuss the disease, its management and prognosis, perceive and utilise available social support, have positive self-esteem, engage in meaningful interactions with the family, friends and health workers and contribute as much as possible to family resources. It was measured by items on self-esteem, coping and acceptance. Coping is the process of taking active steps to try to remove stress or reduce its effects. It includes such measures as, initiating direct action or increasing one's effort in a positive manner. Acceptance is the willingness to live with the condition with a positive attitude, thus engaging in activities to deal with the situation.

Adequate social support: Any item of perceived social support, which at least 55% of patients agreed that care givers/ providers had met it.

Setting and the patients: The study was carried out at the radiotherapy unit of the University College Hospital, Ibadan, Nigeria. The target population consisted of all adult cancer patients (>18 years) attending the radiotherapy clinic. The inclusion criteria were that the patient had been attending the clinic for at least one year after diagnosis of cancer, and was accompanied to the clinic by a first degree relative. This was to ensure the inclusion of patients who had adequate social and clinical experience of the disease and caregivers(11). In addition, the patient had to be ambulant, fully conscious and alert, in good physical condition and able to participate in a 45-minute interview. Consecutive attendees who met these criteria over a 3-week period were interviewed privately by one of us (BMO).

Questionnaire: We articulated a 29-item needs questionnaire with items on self-esteem and coping adapted from previous work(12,13). Each item was rated on a 4-point scale of: strongly disagree (score of 1), disagree (score of 2), agree (score of 3), and strongly agree (score of 4). The first seven items (on expressed need) related to how much the patient valued (i.e. agreed with) various types of social support needs, including information on the illness, help with relief of pain, desire for confiding relationship, financial support and job security. The next 12 items explored the role of family members, friends and nurses in providing information, physical, emotional and instrumental support. The last 10 items on adjustment consisted of 4 items on patient's feelings of self esteem; 4 items explored how far the patient was taking steps to cope with the illness; while the remaining 2 items related to how much the patient had accepted the condition. In the preliminary stage of the study, the original version of the questionnaire was subjected to face and content validity. Face validity refers to the clarity of the items, while content validity refers to the extent to which the instrument samples the variables or situation. To do this, the questionnaire was given to four specialists in the field, namely, a consultant oncologist, a clinical psychologist, a social worker and a senior nurse in oncology. They examined the items for clarity and relationship to the objectives of the study on a 4-point scale of: very important (score of 4), important but needs minor correction (score of 3), ambiguous and needs revision (score of 2), and unimportant (score of 1). The test-retest reliability of the questionnaire was tested by administering it twice to each of the four articulate cancer patients in the surgical ward in a one-week interval. Using Spearman's rank order correlation, the reliability coefficient was 0.7.

Procedure and study design: The study was a cross-sectional study approved by the hospital authorities. The objectives of the study were explained to the patients and accompanying family members and their consent was sought. The questionnaire was translated into the local Yoruba language by the method of back-translation. Subjects literate in only Yoruba were interviewed by one of us (BMO), with the assistance of a translator. Subjects literate in English completed the questionnaire with the assistance of BMO.

Data were analysed by the Statistical Package for Social Sciences (SPSS) at 5% level of statistical significance. Frequency counts were used to highlight the types of social support needs expressed by the patients and the perceived adequacy of social supports provided by care-givers. All the observations were deemed to have been independent of each other, because the perception or expression of one form of need/support did not have to affect the others. Accordingly, the hypotheses were tested by Zee test of proportions, Pearson's correlation, and one-way analysis of variance (with Bonferroni method of multiple comparison). In view of the numerous significant correlations, step-wise regression analysis was used to assess the components of social support (as independent variables) that could predict indices of adjustment (each as dependent variable). Since the various needs/support, were represented by unequal number of items, the total scores and percentages for needs/social support that had more than one item were weighed in order to make them comparable.

..RESULTS

Out of seventy five respondents interviewed, three questionnaires were discarded because of incomplete data,

leaving 72 which form the study group. There were no statistically significant gender differences in the reporting of expressed needs and perceived support. The subjects were predominantly female (52 or 72.2%), middle aged (mean age, 41.1, SD 12.7 years), married (77.8%), with some education (51.4% had at least secondary school education), and ill for less than two years (88.9%). The majority (43 or 51.7%) were either in low level occupations or unemployed (Table 1).

Table 1

Socio-demographic characteristics

Variable			Frequency: N = 72 (%)	
			N	%
1.	Sex:	Female	52	72.2
		Male	20	27.8
2.	Age:	18-27 (yrs)	11	15.3
		28-37	16	22.2
		38-47	25	34.7
		48-57	10	13.9
		58-67	7	9.7
		68-77	3	4.2
	-Mean 41.1,SD12.7; Mode 40;Median40			
3.	Marital status	- married	56	77.8
		- single	6	8.3
4.	Educational status: no formal education		12	16.7
		primary school	23	31.9
		secondary school	20	27.8
		tertiary education	17	23.6
5.	Occupational status: unemployed		6	8.3
		petty trader	22	30.6
		junior worker	15	20.8
		middle level officer	7	9.7
		senior civil servant	3	4.2
		business man/woman	19	26.4
6.	Duration of illness (yrs)			
		1-2	64	88.9
		3-4	7	9.7
		5 years and above	1	1.4

The findings with regard to expressed valued needs and perception of social support provided by care-givers are presented in Table 2. Physical need for relief of pain (95.8%) and informational need about the nature of the illness (81.9%), were much more valued than emotional (67.7%) and instrumental (54.8%) needs. Family members (65.3% agreed) and nurses (68% agreed), were similarly perceived as providing adequate informational support, while only 31% agreed that friends provided informational support ($Z = 2$; $Z = 2.29$, respectively, compared with friends, $p < 0.05$). Over 80% agreed that family members and nurses provided emotional support, while 69.5% agreed that friends provided such support ($p > 0.05$). Nurses (80.6% agreed) were more highly perceived as providing physical support, while the family (48.6% agreed) ($Z = 3.26$, $p = 0.001$) and friends (31.9% agreed) ($Z = 4.05$, $P = 0.0001$) were not perceived as providing adequate support in this regard. The family (75% agreed) was the only group that was perceived as providing adequate instrumental support, significantly more than nurses ($Z = 4.5$, $P = 0.0001$) and friends ($Z = 3.9$, $P = 0.0001$). Overall, the family (68.4% agreed, mean 2.72, SD 0.64) and nurses (61.7% agreed, mean 2.62, SD 0.5) were perceived as providing adequate total social support, while friends (40.9%, mean 2.2, SD 0.58) were comparatively poorly perceived ($F = 7.9$, df= 2/213, $P = 0.0001$). Subjects significantly perceived provision of emotional support (79.2% agreed, mean 2.9), more than informational (52.7% agreed, mean 2.48), physical (53.7% agreed, mean 2.48) and instrumental (42.6% agreed, mean 2.21) support ($F = 9.9$, df= 3/284, $P = 0.0001$). At least 75% of subjects were positive on the indices of social adjustment (Table 3).

Table 2

Frequency of expressed needs, perception of supports by caregivers and perception of total available social supports

Need/support	No. of patients expressing need		Comparative perception of supports by			Perception of total available supports		
			Family	Friends	Nurses			
	S/A (%)	Agree (%)	Mean (SD)* Mean (SD)	Mean (SD)	Mean (SD)*	S/A (%)	Agree (%)	Mean (SD)*
1. Informational Needs/supports**	32 (44.4)	27 (37.5)	3.2 (0.84) 2.6 (0.99)	2.1 (0.92)	2.7 (0.93)	34 (15.7)	80 (37)	2.48 (0.7)
2. Physical needs/supports**	27 (37.5)	42 (58.3)	3.3 (0.68) 2.4 (1.02)	2.04 (0.96)	3.01 (0.79)	35 (16.2)	81 (37.5)	2.48 (0.64)
3. Emotional needs/Supports**	43 (19.9)	103 (47.8)	2.7 (0.63) 3.04 (0.76)	2.75 (0.92)	2.96 (0.72)	44 (20.4)	127 (58.8)	2.92 (0.56)
4. Instrumental needs/Support**	33 (22.9)	46 (31.9)	2.6 (0.83) 2.79 (0.93)	2.04 (0.83)	1.8 (0.91)	20 (9.26)	72 (33.3)	2.21 (0.62)

Note: ** = weighted scores

S/A = strongly agree

* = maximum score is 4

Table 3

Frequency of indices of adjustment; and relation of adjustment to perceived social supports (Pearson's r)

A. Frequency of indices of adjustment (all scores are adjusted)			
	S/agree(%)	Agree (%)	Mean (SD)
1. Self-esteem	102 (35.4)	121 (42)	3.06 (0.61)
2. Coping	77 (26.7)	151 (52.4)	3.0 (0.52)
3. Acceptance	68 (47.2)	41 (28.5)	3.1 (0.62)
4. Total adjustment	247 (34.3)	313 (43.5)	3.05 (1.4).
B.Relation of adjustment to perceived social supports (Pearson's r)			
Relation between perceived			
informational support and:	Pearson's r	t	P-value
Total adjustment score	0.43	4	0.001
Self-esteem	0.28	2.44	0.02
Coping	0.36	3.2	0.002
Acceptance	0.29	2.44	0.02
Relation between perceived			
physical support and:			
Total adjustment score	0.03		NS
Self-esteem	0.12		NS
Coping	0.08		NS
Acceptance	0.03		NS
Relation between perceived			
emotional support and:			
Total adjustment score	0.32	2.82	0.001
Self-esteem	0.29	2.53	0.015
Coping	0.21	-	NS
Acceptance	0.17	-	NS
Relation between perceived			
instrumental support and:			
Total adjustment score	0.42	3.85	0.01
Self-esteem	0.27	2.35	0.01
Coping	0.31	2.74	0.01
Acceptance	0.32	2.82	0.01

Table 4

Step-wise regression analysis for assessment of predictors of indices of social adjustment

Dependent variable	Significant predictors	Variance (%)	T	P-value
1. Total (social) adjustment	Perceived informational support	18	4.0	0.001
2. Self-esteem	Total perceived social support	9	2.8	0.006
3. Coping	Perceived informational support		3.3	0.002
	Perceived physical support		3.0	0.03
	Perceived instrumental support	4.8	2.2	0.03
4. Acceptance	Perceived instrumental support		2.8	0.006
	Age		2.1	0.03
	Perceived physical support	38	2.1	0.04

Overall, the indices of social adjustment were more closely related to perceived provided informational support than the emotional and instrumental support, while not being significantly correlated with physical support. Of the expressed needs, only the emotional need had significant (inverse) correlation with perceived provision of emotional support (r = - 0.24, t = 2.01, p = 0.04). That is, the more emotional support there was available from caregivers, the less the patient expressed the need for it. There was significant correlation between feeling of self- satisfaction and provision of social support by the family (r = 0.28,

p = 0.01), friends (r = 0.32, p = 0.01) and nurses (r = 0.25, p = 0.04).

In view of these multiple significant correlations, the data were subjected to multivariate statistics. In step-wise regression analysis, each of the indices of social adjustment was treated as a dependent variable, while the following were entered as independent (predictor) variables: total perceived social support, age, and each of the domains of expressed needs and perceived social support. As Table 4 shows, perceived informational support was the most frequent and important significant predictor of indices of social adjustment, being the only significant predictor of total adjustment (accounting for 18% of the variance). It is noteworthy that total perceived social support was the only significant predictor of self-esteem; that perceived physical support was one of the significant predictors of coping and acceptance; while age was also a significant predictor of acceptance.

DISCUSSION

The findings cannot be generalised because the study has limitations, which include, its cross-sectional nature, the subjects were from one center, the sample size was rather small, and hence not representative of the general population of cancer patients. In addition, the questionnaire was limited in the range of items used to assess needs and perceived social support. The brevity of the questionnaire was tailored to meet the general level of education in the locality, and the constraints of reasonable time available to the patient to participate in a research interview in a busy clinic. However, the socio-demographic and clinical characteristics of the patients were similar to those involved in previous psychosocial studies of cancer in the hospital(3,14).

The over-representation of females in our psychosocial studies of cancer in this hospital has also been noted by workers in the developed countries(5,7). In the case of the Nigerian center, this finding may be related to the rising ascertainment rate of breast and cervical cancer in the country, which require radiotherapy(15). Although we did not analyse for differences in expressed needs and perception of support from the perspective of cancer site, the evidence in the needs literature is that these needs and perceptions of support cut across cancer diagnostic barriers(5-7,16). The high frequency of expressed physical (95.8%) and informational (81.9%) needs by respondents could be explained by the nature of the illness. Cancer is associated with a lot of physical pain, and the desire to know about their condition is related to the fear of the unknown associated with the diagnosis of cancer. In an Australian study(8), it was found that, of the highest moderate or high unmet needs, 10 related to health information. A Scottish study(6) found that 79% of 250 cancer patients wanted as much information as possible, and 96% had a need or an absolute need to know they had cancer. Foot *et al*(17) found the highest level of unmet needs to be in the information domain, while Sanson-

Fisher *et al*(7) found that patients' perceived needs were highest in the psychological, health system information and physical and daily living domains. We could not demonstrate the socio-demographic and clinical factors associated with unmet needs(7,8), perhaps as a result of the small sample size and the predominantly low socio-economic attainments of our patients.

Nurses had a comparatively high approval ratings for provision of informational, physical and emotional support; and not surprisingly, only the family members were perceived as providing adequate instrumental support. This result is logical because physical care (e.g. relief of pain) is a component of the care-giver role element of the nurse; while in the absence of national social welfare programmes, the burden of instrumental care rests largely on the family(11). Coupled with the high appreciation level of emotional support (over 80% agreed), nurses should feel encouraged by this finding to bring a positive attitude towards their long duty hours, so as to enhance the image of nursing and quality of care. Over three quarters of respondents felt positively adjusted to the condition, with a high frequency of positive responses on self-esteem, coping and acceptance. Care givers are therefore encouraged to continue to give their best to the patients, because the results of the correlation analysis is in line with previous reports, indicating that provision of social support is predictive of feelings of self-satisfaction among cancer patients(18).

Results of the correlation and multivariate analyses showed that provision of health information support was the most important predictor of indices of adjustment to cancer. This appears to be the consensus of opinion in the needs literature, and has given rise to the wide popularity of cancer psycho-educational programmes(19). It is reasonable to expect that if one is armed with information about such an enigmatic disease as cancer, then one is more likely to have a greater sense of self-esteem, is enabled to cope and is therefore more enlightened to accept the condition. The primacy of informational need and support among cancer patients in our locality was noted as an implication of the findings in our previous studies(15,20), and underscores the need for clinicians to be open and frank in a responsible manner in discussing diagnosis and management with cancer patients and their relatives. The high level of positive responses on indices of social adjustment evidenced by patients in this and our previous studies, indicates that cancer patients in our locality can be trusted with information about their condition. If we are reticent in providing the information that our cancer patients require from us, we expose them to the risk of obtaining inadequate and harmful information from unprofessional sources(14,20). However, informational support accounted for only 18% of variance in predicting total social support, while physical support was a significant predictor of coping and acceptance. This implies that psychosocial resources are only adjuncts to treatment in cancer and are only effective with adequacy of physical treatment.

In conclusion, in spite of the limitations of the study,

the findings are in support of the robust evidence in the needs literature linking patients' needs and perceptions of provision of social support with adjustment in cancer. If the results are replicated in larger studies, these findings indicate that workers in the field should find creative ways of providing adequate information to patients and families, pay attention to relief of pain and maintain tolerant, responsible hopeful attitudes; while policy makers should consider articulating social welfare programmes to relieve the psychosocial burden of cancer(11).

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