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### **Issues and Needs of Gynecological Cancer Patients**

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#### **ABSTRACT**

Cancer is being talked more and more frequently in the developing world and the cancer patients had a multitude of issues or needs including physical, psychological, social, emotional, economic, spiritual, informational and practical consequences. A cancer diagnosis is a major event for the person diagnosed and also to his or her family and caregivers. All the more, gynecologic cancer often place a heavy emotional and physical burden on patients. It causes significant difficulties in all major domains of physical, psychological and occupational functioning. Results showed that unmarried, less educated and employed young woman hailing from lower socio-economic background, who do not have the insurance coverage have very high level of distress. Major predictors are found to be physical health, practical considerations, energy/fatigue, pain, general health, physical functioning, and role limitations. This study was undertaken to identify the major issues and needs of patients with gynecological cancer in order to develop an intervention package for them. 130 women completed a 68-item self-report instrument to identify whether they were experiencing problems, how much distress those problems caused, and whether they wanted assistance.

**KEYWORDS:** Gynecological cancer, psychological aspect, social aspect, stigma, social work

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## **INTRODUCTION AND BACKGROUND**

Among females, cancer is the second leading cause of death worldwide, accounting for 14% of all deaths<sup>1</sup> and gynecological and breast cancer are the most common among them. The number of new cancer cases are expected to increase to from 6.7 million to 9.9 million and the cancer related deaths from 3.5 million to 5.5 million deaths among females annually by 2030<sup>2,3</sup>. Gynecological cancers are many a times known as the 'silent killer', as it is generally not detected early enough and by the time the person knows she is in it. All women are at risk for gynecological cancer, and the risk increases with age<sup>4</sup>. It remains the commonest cancer in Indian women. Cancer in Kerala is a serious health hazard. As per cancer registry data, in Kerala there are 974 female cancer patients per million<sup>5</sup>. Breast cancer is the most common malignancy among the women in Kerala; about 30 to 35% is accounted by breast cancer<sup>6,7</sup> contributing significantly to morbidity and mortality in India<sup>4</sup>. Despite the progress that has been made in recent years in both the diagnosis and treatment, many women learn about cancer at the later clinical stages leading to delayed treatment<sup>8</sup> and the therapeutic interventions cause serious side effects and the patients are experiencing negative health outcomes and facing extraordinary coping challenges with distress in particular life situations and compromised quality of life. The major areas of concern of patients with Gynecological cancer include physical, psychological, financial, spiritual, social and environmental aspects and coping<sup>9</sup>. Gynecological cancer cause disturbances to body image, feelings of helplessness, dependency, shame, guilt, vulnerability, loss of femininity and motherhood and sexual difficulties<sup>10,11,12</sup>. Every woman with gynecological cancer constantly grapple with intense feelings ranging from loneliness to isolation, anxiety to suicidal ideations; hopelessness and depression; and distorted family relations to interruption in their societal relationships<sup>10</sup>. The associated issues like physical difficulties, mental exhaustion, sexual disorders, emotional issues and lack of support may lead to poor mental health with increased fear, panic and anxiety and this need management through supportive psychotherapy<sup>9</sup>. The determinants of quality of life in Indian breast cancer patients in general are socio-economic status, educational status, employment support, spousal support, psychosocial challenges and financial stability and earlier studies have also found that the lack of education resources, financial instability, cultural and psycho- social aspects leads to the diagnosis of cancer at a very advanced stage<sup>13</sup>. It is important to understand the broad range of needs of gynecological cancer patients and the barriers in meeting those needs in order to develop appropriate interventions for optimizing the care and allocating the resources effectively to support the gynecological cancer survivors to cope with long-term residual symptoms and lead a better life.

The main purpose of this cross-sectional exploratory study is the need assessment of the gynecological cancer patients for developing specific interventions. Being culture sensitive, an

average Indian woman with children will have other sources of stress as well. The disease and the course of treatment is bound to de-stabilize the entire world of the patient, but it is important that they deal with it in a way which doesn't compromise with their wellbeing. Family understanding, support and reassurance becomes vital in this context. The formal and informal social support systems help the clients to fight with cancer more easily and effectively. The study used a cross-sectional exploratory design to examine the needs and issues of gynecological cancer patients, with major focus on emotional, social and economic aspects along with other dimensions.

## **EXPERIMENTAL SECTION**

Cross sectional non-interventional exploratory study design using mixed method is employed to examine the needs and barriers to accessing the services of gynecological cancer patients being treated from three different hospitals, both government and private. A total of 130 people were interviewed as part of the data collection using census method, in which all the patients who approached the selected hospitals during the study period were included. Informed consent was obtained from each participant prior to interview and examination. The researchers were given training on interviewing, data collection, analysis and documentation. An In-depth interview was used to extract information that included both quantitative and qualitative data tools such as standardized tools, structured questions and clinical measures to assess the primary and secondary outcomes and social demographic variables. The interview schedule was used to collect the information regarding the economic, cultural, community, interpersonal, social, emotional, spiritual and physical wellbeing of the respondents with gynecological cancer. Data from the different study sites were entered in Excel, merged and the quantitative data was analyzed using SPSS software (SPSS, IBM Corp, 2012). Descriptive and inferential statistical procedures were used to profile the vulnerability levels of the respondents and to identify various predictors. Various statistical procedures and qualitative thematic analysis helped the researcher to identify the most significant variable that contributes to the experience of the patient and to identify variables that predict positive patient experiences.

### ***Outcome Measures***

The major outcome of the study was the positive patient experience of gynecological cancer patients. Outcomes are measured using Health services evaluation in Gynecological cancer (demographic details of client and details of illness), SF-36 Health Survey (functional health and wellbeing scores), Patient experience scores(experiences of care, QOL, unmet needs and prevalence of anxiety and depression), So-NET Interview schedule (economic, cultural , interpersonal, social, community, caregiver, presenting problem, pathway to care and future), Oncology Service

Supportive Care Screening Tool ( emotional distress, present patient feeling on multiple dimensions), Soc CQ to measure the satisfaction of the services already received and the need assessment of the services.

**Health services evaluation in Gynecological cancer: Data collection form:** Demographic details of client and details of illness were included. It includes the age at diagnosis, the present age, the income level, employment status, education, cancer type, stage of cancer, marital status, family history of cancer, behavioral risk factors including tobacco use and alcohol consumption, history of lifestyle diseases, history of gynecological cancer and its treatment.

**SF-36 Health Survey:** SF 36 is a multi -purpose short-form health survey consists of 36 questions that provides a profile of functional health and wellbeing scores. This was used in this study to analyze the functional health of the patients with Gynecological cancer.36 questions were divided into subgroups under the heads Physical function, Role limitation, Role limitation due to emotional problem, Energy/fatigue, emotional wellbeing, social functioning, pain and general health.

**Patient experience scores:** Questionnaire standardized by National Health Service (UK) to assess the experiences of care of Cancer patients. It also assesses quality of life, unmet needs and prevalence of anxiety and depression.

**So NET Interview schedule:** Semi structured interview which cover the areas like economics, cultural aspects, interpersonal, social context, community, carer, presenting problem, pathway to care and future.

**Oncology Service Supportive Care Screening Tool:** It is a standardized tool which consists of a distress scale marked from 0 to 10 which represents the subjective distress of the person in a particular week. It also deals with the issues that are upsetting and contribute to the level of distress of the patient. The major heads include practical considerations, physical symptoms, Family consideration, Emotional consideration, Sexual health and body image.

## **RESULTS AND DISCUSSIONS**

The average age for this study sample of 130 women was  $57.52 \pm 10.4$  years with a range of 23 to 85 years and 36.92 % is elderly. Patients presented with a variety types of cancers in reproductive system and majority of them had Breast cancer (69.2%). 31.5% are employed and 68.5% of them were not employed or unemployed. More than half of the respondents were married women (66.2%) while the rest were either unmarried or separated. The income category showed that majority of the respondents (60%) were in the monthly income category of Rs. 3000/- to 10000. 59.2% belonged to APL category and 40.8% belonged to BPL category thus bringing out a

representative sample of population. It has also been observed that 76.9% of the respondents has been receiving some kind of insurance for their treatment.

Social support networks assessed in the present study include support from siblings which is considered as the close family members, support from extended family members, support from friends, support from other peers at work and other external support from clubs and churches. Support has been assessed in the form of contact with the patients which are categorized as frequent contact, occasional contact and no contact which accounts for limited support. Descriptive analysis of the support networks is shown in table 1. It has been seen that the respondents are getting adequately good emotional support from close siblings (71.5%), extended family members (66.9%) and close friends (52.3%). The respondents were getting additional support from either their close family (45.4%), relatives (5.4%), neighbors (5.4%), colleagues (2.3%), employer (0.8%) or other support groups (3.8%). Majority of the financial assistance for the treatment course was met by the immediate family members. 37.7% of the respondents has responded that they are part of some or the other clubs in the locality which acts as their source of support.

**Table 1: Social networks of the respondents (N=130)**

Support systems	Frequency(%)
<i>Support from siblings</i>	
Frequent contact	93(71.5%)
Occasional contact	33(25.4%)
No contact	4(3.1%)
<i>Support from extended family</i>	
Frequent contact	87(66.9%)
Occasional contact	31(23.8%)
No contact	12(9.2%)
<i>Support from friends</i>	
Frequent contact	68(52.3%)
Occasional contact	46(35.4%)
No contact	16(12.3%)
<i>Support from peers at work</i>	
Very supportive	9(6.9%)
Moderately supportive	13(10%)
Not supportive	19(14.6%)
Not applicable	89(68.5%)
<i>Financial support from others</i>	
Family members	59(45.4%)
Relatives	7(5.4%)
Neighbours	7(5.4%)
Colleagues	3(2.3%)
Employer	1(.8%)
Support groups	5(3.8%)
Nil	40(30.8%)
All	8(6.2%)
<i>Membership in religious groups-yes</i>	22(16.9%)
<i>Membership in other clubs-yes</i>	49(37.7%)

**Supportive care needs of the patients**

The needs of the gynecological cancer survivors in the present study is categorized in 11 different domains including physical needs, practical considerations, personal needs, social support needs, familial needs, emotional needs, healthcare needs, sexual needs and body image needs and spiritual and cultural needs. Among the physical needs, the most prominent needs were in managing memory and concentration problems (63.1%) and managing pain (53.1%). Sleep and fatigue problems affected 26.9% of the respondents. Work related (93.1%), accommodation related (82.3%), homecare related (82.3%), transportation related (62.3%) and relating to the care of dependents (65.4%) were the major practical needs of the survivors in the present research.

**Table 2: Supportive care need assessment (N=130)**

<i>Domains of needs</i>	<i>Specific needs</i>	<i>Frequency(%) of respondents who would like to receive help</i>
Physical needs	Managing memory or concentration problems	82(63.1%)
	Managing pain	69(53.1%)
	Managing fatigue and sleep problems	35(26.9%)
Practical considerations	Work	121(93.1%)
	Accommodation	107(82.3%)
	Homecare	107(82.3%)
	Transportation	81(62.3%)
	Care of dependents	85(65.4%)
	Finance	52(40%)
	Personal needs	Managing finances
Child bearing and parenting		20(15.4%)
Being in control of their lives		15(11.5%)
Social support needs	Remaining socially connected to friends	28(21.5%)
	Telling family and friends about treatment	11(8.5%)
Familial needs	Relationship with partner	114(87.7%)
	Relationship with children	107(82.3%)
	Sharing feelings with someone	97(74.6%)
	Relationship with the family	15(11.5%)
Emotional needs	Managing isolation	92(70.8%)
	Managing fear	84(64.6%)
	Managing sadness	76(58.5%)
	Managing loss of interest in activities	72(55.4%)
	Managing anxiety	61(46.9%)
	<i>Professional services for emotional support</i>	34(26.2%)
Health care needs	Managing side effects of treatment	36(27.7%)
	Planning life relation to treatment	14(10.8%)
	Understanding the future in relation to diagnosis	12(9.2%)
	Information about diagnosis	12(9.2%)
	Information about treatment pathway	11(8.5%)
	Sexual needs	Managing concerns regarding sexual relationship
Managing concerns regarding sexual attractiveness		123(94.6%)
body image needs	Managing concerns regarding self-consciousness of body	85(65.4)
	Managing concerns regarding body image	72(55.4%)
Spiritual needs	Spiritual wellbeing	117(90%)
Cultural	Connected to culture	8(6.2%)

Managing finances was considered one of the most important need in a good majority of the respondents (40.8%) in the personal need domain. 21.5% of the survivors expressed need in remaining socially connected to friends and neighbors and this social integration was seen as the major need in the social support domain among the respondents studied. Maintaining relationship with partner (87.7%) and children (82.3%) was reported as major needs in the familial needs domain. 74.6% of the respondents has also expressed that they need assistance in sharing their feelings to some significant people.

**Table 3: Sub Group Analysis**

Different variables	Low distress	High distress
<i>Type of cancer</i>		
<b>Gynecological cancer</b>	22(55%)	18(45%)
Breast cancer	58(64%)	32(35.6%)
<i>Marital status</i>		
Married	56(65.1%)	30(34.9%)
<b>Unmarried/separated</b>	24(54.5%)	20(45.5%)
<i>Employment status</i>		
<b>Employed</b>	24(58.5%)	17(41.5%)
Unemployed	56(62.9%)	33(37.1%)
<i>Income status</i>		
APL	49(63.6%)	28(36.4%)
<b>BPL</b>	31(58.5%)	22(41.5%)
<i>Insurance</i>		
Insurance available	63(63%)	37(37%)
<b>No insurance</b>	17(56.7%)	13(43.3%)
<i>Cancer stage</i>		
Stage 1	26(65%)	14(35%)
Stage 2	36(58.1%)	26(41.9%)
Stage 3	14(73.7%)	5(26.3%)
<b>Stage 4</b>	4(44.4%)	5(55.6%)
<i>Age</i>		
<b>Below 60</b>	55(61.1%)	35(38.9%)
Above 60	25(62.5%)	15(37.5%)
<i>Education status</i>		
Educated	74(62.2%)	45(37.8%)
<b>Uneducated</b>	6(54.5%)	5(45.5%)
<i>Breadwinner role</i>		
Primary role	10(62.5%)	6(37.5%)
Secondary role	14(56%)	11(44%)
Nil	56(62.9%)	33(37.1%)
<i>Contact with siblings</i>		
Frequent contact	59(63.4%)	34(36.6%)
<b>Occasional contact</b>	18(54.5%)	15(45.5%)
No contact	3(75)	1(25%)
<i>Contact with extended family members</i>		
Frequent contact	58(66.7%)	29(33.3%)
<b>Occasional contact</b>	15(48.4%)	16(51.6%)
No contact	7(58.3%)	5(41.7%)

## DISCUSSIONS

Gynecological cancer patients are at risk of developing various emotional problems and they will have unmet needs in all domains. Providing evidence based care in the assessed domains is very



much essential for the cancer survivors to lead a good quality life. The quality of life outcome thus becomes directly proportional to the services that these women receive during their course of treatment. There can be varied subgroups within these survivors where some of them would be able to meet their needs by their own and there would be others who would require an external assistance. The major task here is identifying those survivors who are in most need of the treatment services and providing these services according to their prioritized needs and to identify what are the domains of areas to be intervened which is where the role of a professional social worker comes into play.

Considering psychological distress as the outcome, the present study has brought out the finding that among the gynecological cancer survivors studied, younger people compared to elder ones, married people compared to unmarried/separated people, uneducated people compared to educated ones, employed people compared to unemployed ones and people from lower economic background than higher income people are found to have higher odds of psychological distress. Interventions for reducing psychological distress and subsequently improving the quality of life outcome should be tailored to these subgroups in order to maximize the outcome. This tailoring of services is very much crucial as most of the health care services lack adequate resources to cater to the needs of the larger group<sup>14</sup>. Social workers can function as facilitators where they can make effective use of the resources by profiling the women in need of support and looking for support and in developing ways/ performers to develop ways of assessing multiple domains concurrently. Social workers need to be resourceful and innovative in providing information and care to fulfill the needs or address the needs through using various technologies including e- mails, whatsapp, Facebook and other medias of internet as computerized information, advise, assessment and feedback.

This study emphasizes the needs and concerns of gynecological cancer survivors in five different domains; physical, psychological, social, economic and spiritual. Majority of the respondents in the present study emphasized unmet needs in the economic, social and emotional domains and managing treatment side effects which is in accordance with other studies where physical and psychological domains met the top unmet need category<sup>15</sup>. Physical dimension is a crucial area to be intervened in case of gynecological cancer as the survivors in the present study had needs regarding the side effects of treatment child bearing and parenting and so on. Addressing the physical concerns are crucial as these issues lead to further emotional consequences which can disrupt quality of life of these women surviving the cancer. In this study, the major physical issues such as lack of energy to carry out their day to day duties, especially the family caring duties gives them maximum distress. In this study, the major factors contributing to psychological distress include physical health issues, fatigue, role limitations due to poor physical functioning, pain and issues with practical considerations. These results are consistent with the previous study results



describing the most common emotional concerns of gynecological cancer patients that include feeling nervous, being worried, fear, needing someone to talk to, sadness, and loss of control<sup>16</sup>, sexual and reproductive concerns, fatigue and menopausal symptoms<sup>17</sup>. Cancer diagnosis and treatment brings changes in patients' personal paths of life, in their daily activities, work, relationships, and family roles, and is associated with a high level of patient psychological stress that shows up as anxiety and/or depression<sup>18</sup>, suicidal ideations, hopelessness, distorted family relations<sup>10,11</sup>, loss of intimacy and instrumental life domains<sup>19</sup> feeling of nervousness, worry, needing someone to talk to, loss of control<sup>16</sup>, frustration and despair, problems with their sex lives<sup>17</sup>, fear of cancer recurrence, fluctuations in mood, feelings of vulnerability and uncertainty and subsequently reduction in quality of life<sup>20</sup>. Psychosocial interventions are very much crucial in addressing the psychological distress of these patients and identifying those women in need of the services.

Care coordination in the different domains is crucial as the addressed needs of the survivors most often will be the immediate physical issues rather than the emotional and social ones. Identifying women who have needs and are looking for help has to be set as the priority. There is a need to modify the current care patterns, staffing patterns and implementation of new practices as the existing services are either fragmented or unavailable<sup>4</sup>. Apart from the consultation with medical oncologist the patient who have more supportive needs, like psychological needs requires referral to more appropriate supportive care resources. Psychosocial interventions may improve wellbeing and survival for patients with cancer and it is very important to identify people in need of such services and it is well established that these women might require essential psychosocial support to overcome their fears<sup>21</sup>. Medical staff who deals with physical issues usually lacks time and skills in providing complex psycho-social interventions. Usually, medical practitioners rarely refer those patients for other services than the pharmacologic treatment. In this case, professionals need to take pro-active role in accessing available services and emphasis should be given on multidisciplinary teams for better care co-ordination and case management. Social workers could play pivotal role in increasing access to appropriate assessment and intervention. They need various skills and competencies in order to build rapport with the clients, conduct ongoing assessments and case management with sufficient follow up which will help in referral, direct services, and management of all the services. Both geographical and functional co-ordination will result in better quality of life and satisfaction with care.

## **IMPLICATIONS FOR RESEARCH**

Psycho social screening, a necessary component of comprehensive cancer care can be incorporated to future researches on gynecological cancers. There is an increased need of

standardized tool and approach to screen all the gynecologic cancer patients for supportive care needs. Women could be triaged and those with needs could be identified. The health professionals can speak about services and assistances available to them. The clients have to be facilitated with timely referral to care and development of tailor made intervention after an in-depth assessment with development of assessment tools acceptable by patients and provider. This research is useful for development of interventions for the management of emotional issues of gynecological cancer patients. Researches emphasizing on psychosocial intervention and care coordination is the need of the hour and realizing what kind of help to whom is crucial.

## **CONCLUSION**

Women with gynecological cancer need help for variety of unmet supportive needs and the interventions can be put in place as quickly if the needs are identified early. Lack of energy and inability to fulfill familial responsibilities are the major issues of many women. Resources need to be put in place to ensure a quick and easy identification of needs that can be followed by adequate intervention. There is a need of developing acceptable, appropriate and affordable interventions. The present research analyzes the prospects of a holistic intervention to be implemented so as to improve the overall wellbeing of the gynecological cancer patients. This article explores the major needs of the gynecological cancer patients and their issues regarding the same. The need assessment enables to develop and implement the needed interventions for improving their wellbeing. The major needs emerged from the research study include financial management, emotional support, managing treatment side effects and social connectedness.

## **ETHICAL CONSIDERATIONS**

Ethical approval for the study was obtained from the ethics committee of Rajagiri Hospital. Participation for the research was purely based on their consent and the information was strictly kept confidential.

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