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Symptom Experience of Patients with Hepatobiliary and Pancreatic Cancers and Burden of Family Care Givers

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Abstract: ***Background**: Hepatobiliary cancers, frequently with a gloomy prognosis also have a high symptom experience. With the primary focus on the patient, the needs of the family care givers are often overlooked, leading to a significant care-givingburden. The influence of symptom experience of patients among other factors on burden of caregivers is not often investigated. **Methods**: A correlational study to assess the relationship between symptom experience of patients with hepatobiliary and pancreatic cancers and burden of family care-givers was conducted in a tertiary hospital in South India.Patients with a confirmed diagnosis of hepatobiliary cancers, above 18 yrs of age,with no psychiatric illness and their family care givers who lived with the patient and cared for them were included. An informed written consent was obtained and ninety nine dyads of patients and their family caregivers were recruited by consecutive sampling.Data were obtained using the Zarit Burden Interview and MSAS questionnairewhich were self-administered. **Results**: Majority of the patients had a low symptom experience. A major proportion of the family caregivers experiencedminimal tomild burden. There was a significant positive correlation between symptom experience of patients and burden of care-givers. Burden of caregivers was also significantly associated with patients' age, gender, presence of metastatic disease, intent of treatment, time since diagnosis and educational status of the family caregivers. **Conclusion**:Family caregivers of patients with hepatobiliary and pancreatic cancers experience considerable burden which is closely related to the symptom experience of the patients and metastatic disease. This necessitates Nurses to recognize burden in family care givers along with symptoms in patients.***

Keywords: Hepatobiliary and pancreatic cancers, family caregivers, symptom experience, caregiver's burden

1. Introduction

Hepatopancreatobiliary (HPB) cancer refers to primary malignancies of the liver, bile ducts, gallbladder and pancreas. Liver cancer is the sixth most common cancer and second most common cause of death from cancer worldwide. Pancreatic cancer is the twelfth most common cancer and seventh most common cause of death from cancer in the world (Ferlay et al., 2015).Statistics reflect the gloomy reality of Hepatobiliary and pancreatic cancers which are often diagnosed at advanced stages with a dismal prognosis. In addition, they also have a high physical and psychological symptom burden resulting in a rapid decline in patients' quality of life (QOL). Treatment modalities frequently lead to morbidity and symptom burden. Multiple symptom burden has been reported in patients with HPB cancers with high symptoms scores(Sun et al., 2008).

The high symptom burden coupled with a grave prognosis allows little time to cope for both the patients and their care givers. In contrast to the health care professionals, the family caregivers receive little preparation, information or support to carry out their care giving role. This could develop into a chronic stressor with negative psychological, behavioural, and physiological effects (Bevans& Sternberg, 2012).Caregivers of patients with cancers in general were reported to have a higher level of burden and distress throughout the course of treatment (Kim & Schulz, 2008; Palos et al., 2011).Family caregivers, in particular with pancreatic cancer had a QOL below the general population average (Janda et al., 2017).

This burden experienced by the family caregivers seems to be influenced by various factors. It is reported that burden is influenced by patients' and care givers symptoms and problems (Johansen, Cvancarova, &Ruland, 2018).Socio-demographic and clinical characteristics of the patient and caregiver like marital status, education, type of family of caregivers, and occupation of patients are also reported to be associated with care-giving burden. (Kurtz, Kurtz, Given & Given, 2004; Li, Mak, &Loke, 2013;Lukhmana, Bhasin, Chhabra, & Bhatia, 2015).

Despite numerous studies focusing on care givers in general and in other chronic illness and although there are a few reports of high care giving burden in advanced pancreatic cancer, there is a dearth of studies on caregivers of hepatobiliary and pancreatic cancers in India. Hence this study aimed to identify the care-giving burden and its relationship with thesymptom experience of patients.

The objectives of the study were to

- Assess the symptom experience of patients with hepatobiliary and pancreatic cancers and burden of their family care givers
- Determine the relationship between the symptom experience of patients with hepatobiliary and pancreatic cancers and the burden of their family care givers

The secondary objectives were to

- Determine the relationship between the burden of family care givers and socio-demographic and clinical variables of patients with hepatobiliary and pancreatic cancers
- Determine the relationship between burden and socio-demographic variables of family care-givers of patients with hepatobiliary and pancreatic cancers

2. Methods

A descriptive- correlational study was conducted in a tertiary hospital in South Indiato assess thesymptom experience of patients, its relationship withthe care-giving burden. Family caregivers, in this study included the primary family members of the patient who lived with and cared for the patient. It included spouse, parents, children or extended family members living with the patient.

The sample size was estimated at 85 after the pilot study, with α- 5%, β- 80%. However,ninety nine dyads of patients and their family caregivers were recruited in the study, anticipating factors such as incompleteness of reported data.

Patients above 18 years of age with a confirmed diagnosis of HPB cancers,and no co-morbid psychiatric illness were identified from the medical records in the outpatient and in-patient departments of HPB surgery. Patients with metastatic disease with primary cancer elsewhere were excluded. Family care givers who lived with the patient and cared for them as identified by the patients were included by consecutive sampling technique. Ethical clearance was obtained from the Institutional Review Board.Data were obtained from the subjects by the investigators using self-administered questionnairesafter obtaining informed written consent. The family care giver was administered the Zarit Burden Interview (ZBI) and the patient was administered the Memorial Symptom Assessment Scale (MSAS).

The ZBI is a standardized tool to assess care giver's burden. It is a 22-item likert scale, which assesses five main domains of burden namely burden in the relationship, emotional well-being, finances, social and family life, andloss of control over one's life. Higher score indicates higher caregiver distress (Zarit, Reever, & Bach-Peterson, 1980). The burden scores ranged from 0-88 and the obtained scores were categorized into minimal (0-20); mild (21-40); moderate (41-60) and severe burden(61-88). The instrument has a good internal consistency with a Cronbach's alpha of 0.85 in this study.

The MSAS questionnaire is a standardized tool used to assess the symptoms among patients with cancer. It measures 32 physical and psychological symptoms along three dimensions namely frequency, severity and distress. The symptom experienced is measured for its frequency, severity on a 4-point, while it's associated distress on a 5-point categorical scale. It has subscales namely-physical(MSAS-PHYS), psychological (MSAS-PSYCH) and global distress(GDI).The total MSAS score is the average of the scores for all 32 symptoms.(Chang et al., 2004; Portenoy et al., 1994).The total MSAS scores ranged from 0-128. The scores obtainedwere categorized based on percentiles of the scale into low(>33.3 percentile), moderate(33.3-66.6 percentile) and high (<66.6 percentile) symptom experience. The scale has an internal consistency (Cronbach's alpha) of 0.95 in this study.

Data were analysed using SPSS version 15. A p value of <0.05 was considered significant for statistical analysis.

3. Results and Discussion

The mean age of the patients was 50.5 years while that of family caregivers was slightly lower at35.20 years. There was a male preponderance in both the groups (63 patients and 66 caregivers). About 99% of the patientsand a major proportion of the caregivers (66.7%) were married. Majority of the patients and caregivers had primary or secondary schooling. A sizeable proportion of caregivers were graduates (45.5%). Majority of them belonged to the middle class socioeconomic status. Majority of the family caregivers were either spouses (37.4%) or children (51.5%) with a minor proportion being the extended family members (11.1%). The average time spent in caring for the patients was about 8.92 hrs.

A major proportion of the patients were diagnosed with carcinoma gallbladder (30.3%), followed by liver and periampullary carcinomas. Only 9.1% of the subjects had cancer of the pancreas. A huge proportion of the patients (36.4%) had metastatic disease and about 11.1%had locally advanced disease. Almost one half of the patients (46.5%) were on palliative intent of treatment. The mean duration of illness was 6.9 (± 8.5) months.The time since diagnosis ranged from 1-44 months with a mean of 3.6 months (± 5.9) with patients on various treatment modalities with curative or palliative intent like surgery(36.4%), chemotherapy(30.3%) or procedures like stenting or PTBD (Percutaneous transhepatic biliary drain)(9.1%). About 23.23% of the patientsreceived supportive treatment.

Symptom experience of patients

Majority of patients (69.7%) reported low symptom experience and 30.3% had moderate symptom experience as presented in Figure 1.

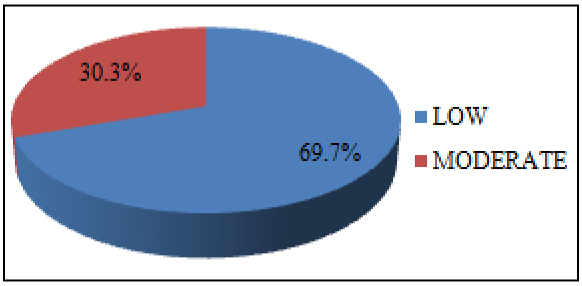

Figure 1: Distribution of patients based on the symptom experience

The symptom experience of the patients varied widely with a total mean MSAS symptom score of 32.75 (SD=18.05). The symptom scores in the various subscales of MSAS revealed that patients experienced more of physical symptoms compared to psychological symptoms.

Among the physical symptoms, majority (80.8%) of the patients experienced pain and a lack of energy. About 70.7%

had dry mouth, 63.6% had weight loss and 62.6% felt drowsy Almost similar proportions of patients experienced loss of appetite, dizziness, nausea, vomiting. About 41.4% of patients also reported changes in skin due to jaundice. This study reveals that patients with HPB cancers experienced a diverse and huge symptom burden. A similar spectrum of multiple symptoms has been found in patients with HPB cancers with high symptom scores for weight loss, appetite, fatigue and abdominal pain (Sun et al., 2008).

Among the psychological symptoms, majority (74.7%) experienced feeling nervous and 60.6% had difficulty with sleeping. More than half of the patients experienced 'feeling sad' and 'worrying'. Similarly, Kelsen et al., (1995) and Steel, Geller, Gamblin, Olek, and Carr (2007) also reported high levels of psychological and depressive symptoms among patients with HPB cancers.

Burden of family care-givers

The mean burden score was found to be 22.19(±12.86).This is slightly higher than the mean ZBI score of 20(±11) in caregiversof general cancer patients (Lukhmana et al., 2015) and 18.5(±11.0) among caregivers of advanced cancer patients (Higginson, &Gao, 2008) and 11.37(±2.53) among caregivers of patients with pancreatic cancer (O'Driscoll et al., 2010). Although the burden scores are comparable, the slightly higher scores in this population need to be noted.

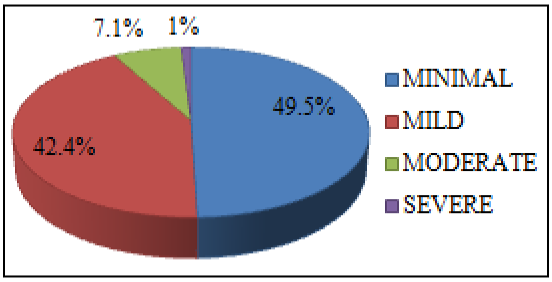

Figure 2: Distribution of Family care-givers based on burdenscores

Figure 2 shows that despite a slightly higher mean burden score,upon categorizing the burden scores, it is found that about 49.5% of the family caregivers experienced minimal burden and 42.4% reported mild burden. Only 7.1% reported moderate burden and 1% reported severe burden. This is in contrast with other studies by Johansen et al., (2018)where family caregivers reported to have experienced between medium and high caregiving burden. These findings have to be viewed in the context of the socio-cultural behaviour of people in our country where care giving is considered to be an inherent responsibility of family members and caregivers may not consider it a burden. There is also a possibility that Indian families being relatively closely knit, the social support system enables the family caregivers to cope well. Similar findings were reported by studies in India by Lukhmana et al., (2015) among caregivers of cancer patients where 56.5% of caregivers reported no or minimal burden while 1% reported severe burden.

While examining the various domains of burden, the highest proportion experiencing severe burden is seen in the domain of finances (26.3%), followed by loss of control over ones' life (6.1%) and burden in relationships(5.1%).The highest proportion of caregivers experiencing minimal burden was seen in the domain of social and family life. This could possibly be attributed to the immense family support received during a crisis. However, besides spending a sizeable part of the day in caring for the patients, the lower burden in this domain needs to be viewed in the context of social life taking a back seat in the caregivers whose focus is only on the patient. This again is distinct to our socio-cultural background.

Relationship of symptom experience and burden of family care givers

Symptom experience of patients has a significant relationship with theburden of family care-givers. This is observed as a statistically significant positive correlationwith total symptom scores, psychological subscale and global distress scores ($p<0.05$) as seen in Table 1. This is in contrast to the findings by Johansen, Cvancarova, andRuland (2018), where symptoms of patients were not associated with burden. It is also found that the care-giving burden increased with the symptom burden of the patient. However, there was no significant relationship between burden and physical subscale scores, although patients experienced more of physical symptoms than psychological, indicating that the caregivers' burden was most likely influenced by the psychological symptoms of the patients.

Table 1: Relationship between Symptom Experience of Patients and Family Caregiver's Burden

	R-value	p-value
MSAS Total & Burden	0.20	0.04*
MSAS-PSYCH& Burden	0.25	0.01**
MSAS-PHYS& Burden	0.13	0.20
MSAS-Global distress& Burden	0.20	0.04*

*p<0.05; **p<0.01

Relationship of burden of family caregivers with socio-demographic and clinical variables of patients and family caregivers

This study found a significant correlation between burden of family care givers and age of patient (r=-0.2; p=0.004) and time since diagnosis (r=-0.19;p=0.05). A negative correlation is observed between burden and age of the patient implying that the family caregivers experienced a higher burden when the patients are younger and burden was lower among those caring for older patients. Also, a negative correlation between burden and time since diagnosis is found. This would imply that the caregivers possibly experienced a higher burden in the initial period when the diagnosis is made.

Statistically significant association was found between burden of family care giversand socio-demographic and clinical characteristics of the patients like gender (χ^2=7.16; p=0.02), presence of metastatic disease (χ^2=9.19; p=0.01) and intent of treatment (χ^2=7.46; p=0.002).Presence of metastatic or locally advanced disease is found to have a significant association with burden. Since metastatic disease at diagnosis and inoperability is widely observed in this population, this could mean a sudden feeling of helplessness and thus an overwhelming sense of burden. These findings are in contrast to other studies where no significant association was found with duration since diagnosis, but occupation of patients was found to be a predictor of caregiving burden. (Lukhmana et al., 2015)

Statistically significant association was also found between educational status of the caregiver and their burden (χ^2=16.82; p=.002).However, there was no relationship with other socio-demographic variables of the caregivers. This may possibly be due to a small sample size in this study. Nevertheless, similar findings are reported by O'Driscoll et al., (2010) andJohansen et al., (2018) where the burden did not vary by socio-demographic variables. Contrary to this, other studies have found significant association with marital status and type of family (Lukhmana et al., 2015), impact on schedule, restriction on daily activities, social functioning and younger age of care givers.(Kurtz et al., 2004 andGoldstein et al., 2004).However, this study did not find a significant relationship with the time spent by caregivers. Burden was also not associated with the type of caregiver whereas Wang et al., (2011) found a higher burden among spousal caregivers. These results need to be interpreted with caution since the sample size estimation was not done for a sub group analysis and findings could be due to a small sample size.

4. Limitations

This being a cross-sectional study measured the outcome variables at a single pointwith most of the patients in the early course of their disease and hence results could have been different in a population with a longer duration of illness or advanced disease.The data were also obtained from in-patients and out-patients of a surgical unit and hence cannot be generalized to patients attending chemotherapy or radiation therapy departments. The sample size was small to do subgroup analysis for association of burden with socio-demographic variables.

5. Implications for Nursing practice and research

The results of this study support the need for interventions to reduce burden of family caregivers in this population like counselling, information and support. Additional research is warranted on the impact of various interventions in this regard. Since burden is influenced by symptom experience of patients, identification and management of the multiple symptoms becomes a directive for the nurses caring for this population.

6. Conclusion

Family care givers are frequently the primary source of social and emotional support for patients and play a foremost role in the patient coping with the disease and treatment. A major proportion of family caregivers experienced minimal to mild burden. This was closely related to the symptom experience, age and gender of the patient, presence of a metastatic disease and the educational status of the caregivers. Family caregivers of patients with HPB cancers in particular, where a considerable proportion of the patients have metastatic or inoperable disease at diagnosis, experience a substantial amount of burden. However, it is often difficult for the caregivers to admit the burden due to care-giving, in a country like India, where care-giving is not perceived as a distinct role within the bounds of a family, resulting in a huge chasm of untold and unmet needs of the caregivers. Itis therefore imperative for Nurses to recognize and identify this challenge along with early interventions for symptoms of patients.

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