SHORT ARTICLE

Burden of care on family caregivers of patients of gastrointestinal cancers in a tertiary care institute

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Abstract	Introduction	Methodology	Results	Conclusion	References	Citation	Tables / Figures

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Abstract

Background: Gastrointestinal tract cancers are one of the leading causes of morbidity and mortality globally and cause family members to become primary caregivers. **Method:** The observational cross- sectional study was conducted using a pretested questionnaire and BSFC short form scale on 156 primary family care givers of patients suffering from and seeking treatment for cancer of the gastrointestinal tract from June 2021 to May 2022 in a tertiary care institute. **Result:** Mean age of family caregiver was 48.6 (4.7) years and the majority were female 111 (71.1 %). Average duration of primary care given was 2.62(1.24) years. 94 (60.2%) family care givers provided > 8hr duration of care. 103 (66%) of the family caregivers suffered from moderate burden, 39 (25%) from heavy burden and only 14 (8.97%) family caregivers considered burden as mild. Significant association was found between >8 hours of caregiving, caregiver having a comorbid illness, treatment outcome and financial distress borne during the course of treatment and burden of caregiving. **Conclusion:** Burden of caregiving in the family caregivers of cases of gastrointestinal cancer has the capacity to create ripples in the primary life domains of the caregiver and needs to be looked into.

Keywords

Family Care Giver; Burden; Cancer; Short Version of Burden Scale for Family Caregiver

Introduction

Family care giver has been defined as any person viz spouse, adult children, relative who has a personal relationship with and provides unpaid assistance for an older person or person with chronic or disabling disorder (1). Caregiver’s burden has been defined as multidimensional response to the set of physical, mental and socioeconomic problems suffered by those providing care to the sick people (2,3).

The caregiving disrupts the lives of caregivers and may result in physical disorders, psychiatric problems and poor quality of life (4). Pinquart et al. has shown that family caregivers had higher number of depressive symptoms compared to non-family care giver (5).

According to estimates from the World Health Organization in 2019, Gastro intestinal cancers account for 26% of the global cancer incidence and 35% of all cancer-related deaths (6, 7).

The needs of the cancer care givers are often ignored and considered secondary to those of patients (8).

Insufficient data from low and middle income countries burden on family care giver is available (9). In a study on family caregivers, > 20 % of caregivers reported caregiving as financially and physically difficult while 44 % reported it as emotionally difficult (10).

Aims & Objectives

1. Estimate burden of caregiving among the family care givers of patients of gastrointestinal tract cancer
2. Find association of various socio-demographic factors of the family caregivers with the burden of caregiving.

Material & Methods

Study type - Observational cross- sectional study

Study population- Primary family caregivers of patients of gastrointestinal cancer

Study area- Tertiary care institute and cancer hospital in Amritsar.

Study duration- June 2021 to May 2022

Sample size- 156 dyads of primary family care givers and patients.

Inclusion criteria- Only primary family caregivers physically accompanying the patients seeking treatment of various cancers of gastrointestinal tract who gave consent to be a part of the study.

Sampling technique- Total enumerative sampling technique.

Operational definition of primary family caregiver- A family member residing in the same household as the patient and primarily engaged in caregiving without receiving any financial remuneration for the same.

Ethical approval- Institutional Ethical Committee vide letter number SGRD/IEC/2021-04 dated 04/05/2021.

Data collection- A semi-structured proforma consisting of two parts-part one containing questions about the socio-demographic characteristics of the study participants and the second part containing "Burden scale of family caregivers" (BSFC) scale- short form was used. The scale comprises of 10 items loading on to a single factor pertaining to total subjective burden of the care giver. Each question is answerable on a 4 point Likert scale ranging from strongly disagree (0), disagree (1), agree (2) and strongly agree (3). Score from 0-4 was labelled none to mild burden, 5-14 was labelled moderate burden and 15-30 was labelled severe to very severe burden.

Data analysis- Data analysis was done using SPSS version 21.0. Counts and percentages were used for descriptive statistics and chi squared test statistic was used for inferential statistics with p value significant at < .05.

Results

Table 1 shows the mean age of family caregiver was 48.6 (4.7) years and the majority of the family caregivers were female 111 (71.1 %). The relationship of the primary family care giver to the patient was spouse 118 (75.6%), offspring 27 (17.3%), parent 05 (3.2%) and first degree relative 06 (3.8%). Average duration of primary care given was 2.62(1.24) years. Majority of family caregivers 97 (62.17 %) of patients had no personal income while only 59 (37.82%) caregivers had personal income. 94 (60.2%) family care givers provided > 8hr duration of care.

In contrast, the mean age of cancer patients receiving care was 54.3 (8.6) years. Most of the cancer patients were males 92 (58.9%) and married 121 (77.6%). As far as the primary organ involved in cancer was concerned, oesophageal cancer was the most common GI tract cancer among the patients 58 (37.1%). Majority of cancer patients were in stage III-84 patients (53.84%), followed by stage IV- 41 patients (26.28%), stage II- 22 patients (14.1%) and stage I- 7 patients (4.48%) (Table 2).

Burden of care on family caregiver of case of GI cancer

Using the BSFC s scale to measure subjective burden of caregiving, 103 (66%) of the family caregivers suffered from moderate burden, 39 (25%) from severe to very severe burden and only 14 (8.9%) family caregivers considered burden as none to mild (Figure 1).

A significant association was found between hours devoted to caregiving and burden of caregiving (Table 3). Caregiver providing more than 8 hours of care were significantly more distressed than those providing less than 8 hours of care($X^2(2)= 18.16, p < .05$). Also, perceived burden of care was less when caregivers were assisted by helper ($X^2(2)= 12.92, p < .05$). The presence of comorbidity in the caregiver was also significantly related to perceived burden of care ($X^2 (2)= 23.18, p < .05$).

Association was significant between presence of health insurance of the patient of GI cancer and burden of caregiving ($X^2 (2)= 15.38, p < .05$). Likewise, financial distress experienced as the treatment and related costs escalated was also significantly linked to the burden of caregiving ($X^2 (2)= 12.37, p < .05$). The nature of treatment modality in terms of curative or palliative was also significantly associated with burden of caregiving ($X^2 (2)= 16.17, p < .05$).

No significant association between factors like gender of care giver, the residence in urban or rural locale, ease of access to health care and burden of caregiving was found ($p > .05$).

Discussion

Gastrointestinal tract cancers are one of the leading causes of morbidity and mortality globally causing significant physical and mental suffering to not only the patient but also to the primary care giver. In the traditional Indian value system, family members become or are forced to become primary caregivers. Various clinical observational research studies have conclusively proven that a caregiving role has the potential of turning into a chronic stress experience for the caregiver (11, 12, 13).

In our study on 156 primary care givers using 'Burden scale of family care giver scale (BSFC) - short form', we observed that majority of care givers were female i.e 107 (68.6%). 145 (92.94%) were either spouses or offspring of cancer patients. This female predominance and first degree relative association of care giver was similar to other studies (14, 15). Wolf and Kasper in their study on care givers of frail elders had found that 80% of care provided to older individuals were by either spouses or adult children (16). In a study by Shim and Ng. female care givers were twice the number of male care givers (17).

In our group of care givers 97 (62.17%) experienced financial stress during course of treatment. Alsirafy et al. in a study on 218 care givers has shown that financial concern is a significant factor associated with burden (18). Similarly Vahidi M et al. in a study on care giver of breast cancer has shown that lack of enough income is significantly associated with level of burden (19).

Family care givers have to devote significant time in care of cancer patients. They help in lot of important tasks ranging from supporting daily living activities, accompanying patient to hospital and providing social support. In our study, 94 (60.2 %) of family care givers were providing more than 8 hours of care. In a study to find the association between depression, religiosity and religious coping with burden in family care giver, Shim and Ng. have found that median time of 128 hrs (range 2- 168 hrs) was spent in a week (17). Borghes et al. study on caregivers of lung cancer patients has shown that more than half of the caregivers spend > 4 hours per day (20). Similarly Zubaidi et al.reported significant association between longer duration of care and level of burden (21). We have found that longer duration of hours spending in the care of patient significantly increases the burden on the caregiver ($p<0.05$).

In our study only minority 8.97% (n-14) experienced mild burden care i.e BSFC score <4, significant number n-103 (66%) considered burden to be moderate i.e score 5-14. 25% (n-29) considered burden to be heavy i. e score 15-30. Culture of strong family structure could be the possible reason for only 25% of subjects experiencing burden to be heavy. Lukhmana et al. in their study on family care giver's burden among cancer patients using Zarit Burden Inventory scale reported moderate burden in 37.5% care givers and severe burden in 1% of care givers (22). The authors attributed low severe burden to cultural norms of joint family system. Galvan et al. found 41.6% of care giver's to be intensely burdened while giving palliative care to cancer patients (14). Similarly Mirsoleymani et al.reported high burden in 48.1% of Iranian family care givers of cancer patients (23).

In some studies, it has been shown that higher stage of the cancer increases the symptoms of anxiety and depression of care giver (24, 25). Availability of helper to care giver significantly reduces the burden ($p<0.05$) in our finding. Single status of care giver has been found significant factor contributing to the burden in a study by Chindaprasirt et al (26). Sklenarova et al. while studying the supportive care needs of caregivers providing support to cancer patients reported that 48.3% were in need of psychosocial support (27).

The modality of treatment palliative versus curative were significantly associated ($p<0.05$) with score of BFSC scale short form in our study. Advanced cancer disease increases burden on family care giver has been reported in other studies (28)

Conclusion

Family care givers of gastrointestinal tract cancer patients experience significant burden of care in our region. Routine screening of family caregiver will help in identifying group of persons suffering from significant burden. Targeted interventions for this group might help alleviate some of their sufferings.

Recommendation

Supporting caregivers in maintaining their well-being is not only beneficial for them personally but also has broader implications for the overall health and resilience of communities. Public health initiatives should consider the unique needs and challenges faced by caregivers to ensure a holistic approach to healthcare.

Relevance of the study

The healthcare needs of the family caregiver are often placed at low priority and are often ignored. The study aimed to bring out the hidden cost to the health of the caregiver so that appropriate public health interventions may be designed to reduce the burden of caregiving in the family caregivers.

Authors Contribution

All authors have contributed equally.

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Tables

TABLE 1- SOCIODEMOGRAPHIC PROFILE OF FAMILY CAREGIVERS OF CASES OF GI CANCER

Mean age in years (SD)	48.6 (4.7)	
Mean years of 10 caregiving (SD)	2.62 (1.24)	
Gender	Male Female	45 (28.9 %) 111 (71.1 %)
Marital status	Married Single	132 (84.6%) 24 (15.3%)
Relationship to the patient	Spouse Offspring Parent First degree relative/ daughter/son in law	118 (75.6%) 27 (17.3%) 05 (3.2%) 06 (3.8%)
Personal income	Yes No	59 (37.82%) 97 (62.17%)
Duration of hours care given	<8hrs >8hrs	62 (39.7%) 94 (60.2%)

TABLE 2- SOCIODEMOGRAPHIC PROFILE OF CASES OF GI CANCER

Mean age in years (SD)	54.3 (8.6)	
Gender	Male Female	92 (58.9%) 64 (41.1%)
Martial status	Married Single	121(77.6%) 35 (22.4%)
Type of GI Cancer	Oesophagus Biliary Colorectal Stomach Pancreas Liver	58 (37.1%) 38 (24.3%) 25 (16.0%) 18 (11.5%) 08 (05.1%) 09 (05.7%)
Stage of Cancer	Stage I Stage II Stage III Stage IV	07 (4.48 %) 22 (14.1 %) 84 (53.8 %) 41 (26.3 %),
Modality of treatment	Curative Palliative	106 (67.9%) 50 (32.05%)

TABLE 3- ASSOCIATION OF BURDEN OF CARE WITH VARIOUS SOCIODEMOGRAPHIC FACTORS

Sociodemographic factor	None to mild burden (n=14)	Moderate burden (n=103)	Severe to very severe burden (n=39)	Chi squared value	p- value
Gender of caregiver					
Males (45)	5	28	12	0.53	0.76 (NS)
Females (111)	9	75	27		
Residence					
Urban (82)	8	53	21	0.19	0.909 (NS)
Rural (74)	6	50	18		
Time spent in caregiving					
>8 hours (94)	1	68	25	18.16	<0.05
< 8 hours (62)	13	35	14		
Reliever/ help in caretaking					
Yes (96)	4	73	19	12.92	<0.05
No (60)	10	30	20		
Co-morbidity in the caretaker					
Present (108)	2	74	32	23.18	< 0.05
Absent (48)	12	29	7		
Ease of access to healthcare					
Present (86)	6	57	23	1.08	>0.05 (NS)
Absent (70)	8	46	16		
Health insurance of the patient					
Uninsured (124)	10	91	23	15.38	< 0.05
Insured (32)	4	12	16		
Financial distress experienced due to treatment and related costs					
No (59)	11	38	10	12.37	<0.05
Yes (97)	3	65	29		
Treatment modality for patient					
Curative (104)	12	76	16	16.17	< 0.05
Palliative (52)	2	27	23		

Figures

FIGURE 1 BURDEN OF CARE ON FAMILY CAREGIVER OF A CASE OF GASTROINTESTINAL CANCER