RESEARCH ARTICLE

Editorial Process: Submission:09/13/2024 Acceptance:06/03/2025

Prevalence and Associated Factors of Depressive Symptoms among Informal Caregivers of Patients with Advanced Cancer who Received Palliative Care in Sri Lanka

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Abstract

Objective: Cancer is a challenging health problem, and has a significant impact on informal caregivers (ICs) on their day-to-day responsibilities. This study aimed to determine the prevalence of depressive symptoms (DSs) and its associated factors among ICs of patients with advanced cancer who received palliative care at the Apeksha Hospital Maharagama (AHM), Sri Lanka. **Methods:** A cross-sectional study was conducted among 226 conveniently selected ICs at the AHM, Sri Lanka. Data were collected using an interviewer-administered questionnaire and a validated 20-item Center for Epidemiological Studies-Depression (CES-D) scale. Ethical and institutional approval was obtained. Data analysis was done using descriptive statistics, Chi-square, one-way analysis of variance, Pearson correlation, and independent t-tests. **Result:** The mean age (±SD) of the ICs was 41.78(±14.54) years. Most of the ICs were females (60%), married (72%), and educated up to secondary level (83%). Prevalence of DSs (≥16) was 49%. Significantly higher DSs were reported by females vs. males (20.52±9.65 vs. 14.74±3.75) and currently unemployed vs. employed ICs (19.69±9.14 vs. 16.58±7.02). DSs were significantly associated with caregiver relationship with the patient ($p<0.01$), caregiving hours/week ($p<0.01$), caregiving period ($p<0.05$), emotional strain ($p<0.01$), financial strain ($p<0.01$), and self-reported general health ($p<0.01$). There was a negative relationship between DSs, perceived social support ($r= -0.245$; $p<0.01$), and family/friends support ($r= -0.183$; $p<0.01$) of ICs. Further, female gender ($p<0.01$) and cancer type ($p<0.05$) of patients were significantly influenced by the DSs of ICs. **Conclusion:** Almost half of ICs had higher DSs. Some variables related to caregivers, caregiving, and patients are significantly impacted by DSs. Providing psycho-social support for ICs is crucial and recommended educational intervention to provide knowledge and practice on caregiving to reduce depressive symptoms.

Keywords: CES-D scale- Cancer- Depression- Informal caregivers

Asian Pac J Cancer Prev, **26 (6)**, 1997-2007

Introduction

The increasing prevalence of cancer is one of the leading causes of mortality worldwide and similar data have been reported in Sri Lanka [1-3]. Family members or caregivers of patients with advanced cancer play a vital role in reducing mortality of cancer patients through effective palliative care (PC) as in the definition of PC [4], family members are dynamic stakeholders in the cancer journey similar to the patients who receive PC.

However, most persons living with cancer have a caregiver (family caregiver or informal caregiver refers to an unpaid family member; could be a spouse, partner, adult child, relative; or friend or close neighbor other than a healthcare provider) who has an individual relationship or can deliver care intermittently or throughout the disease trajectory [5-7]. Family members are the most involved and essential group in caring for the adaptation and the management of their disease. With the rising of cancer patients, caring duties have been delivering an outpatient basis which increased the burden of different types of caregivers such as primary, family, and/or informal caregivers (ICs). Of the ICs, 72% demonstrate several medical or nursing roles/tasks elsewhere [8]. Therefore, such caregivers play a leading and amazing role as 'unsung heroes' in caregiving for patients with advanced cancer while facing many challenges and obstacles. ICs were responsible person for patient care at home (delivering day-to-day instrumental, financial, social, and psychological support to a family member or a closely connected person in need but not as a job) carrying out specific instructions given by their treating healthcare

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personnel [9, 10], and engaging in many duties of patients such as providing personal care, assistance with mobility, and management/coordination of medical care, etc. (e.g. activities of daily living and instrumental activities of daily living) [11, 12].

The most dreadful and stressful thing that may happen to a patient or their primary carer is receiving a cancer diagnosis. It can lead to emotional reactions including hopelessness, helplessness, worthlessness, guilt feeling, anger, depression, etc. Further, physical, emotional, spiritual, social, and practical components (domains of quality of life) of the life of patients and their family/primary caregivers are seriously impacted (e.g., inability to join other family matters, frustration, and irritation towards self and patient, depression, financial issues, unemployment, etc. [13]. Especially in PC in traditional Indian and other South, Southeast Asian countries, the need for in-house care for such patients would be more than institutional care services according to the current trends [8, 14]. Thus, ICs are more popular where the family is the prime source of caregiving and where filial piety is extremely rooted in social and cultural dimensions as reported due to the existing cultural system promoting family members to be the ICs [14, 15] irrespective of their family role, age or gender; mostly, older adults could be care-receivers as well as caregivers [14]. Hence, caregiving is troublesome, unpaid work and a challenging role for the caregivers and prone to a long-term result on caregivers' physical/emotional well-being, quality of life (QoL) as well as financial stress, anxiety, and social isolation [16].

Depression is a common psychological disorder, approximately 280 million people in the world have depression showed the general picture. Also, 4% of men and 6% of women experienced depression [17] evidenced that depression is more prevalent among women; this may be the reason for higher depression among female caregivers as caregiving is prominently done by females. As reported in the literature, 40%-70% of caregivers experience depressive symptoms (DSs) [13], and around two in five caregivers of patients with cancer presented with DSs globally [18].

The pooled prevalence of depression (PPD) among caregivers of patients with cancer in a review study in 2022 was 42.08% (95% CI: 34.71–49.45) [18]. Higher DSs found among female caregivers compared to their male persons which is common in most general settings and trends [18]. Another review in 2022 reported a 25.14% PPD (95% CI, 21.42–29.27%) among caregivers [19]. The prevalence of DS among cancer caregivers was 42.3% in another review [20] which was not much different from before four years might be due to long hours of caregiving without proper support, caregiver burden as the disease deteriorates, and unmet needs (UNs) of caregivers [18]. Another study stated that 19.4% of the PPD among the general population [21]. However, the prevalence of depression among the general population was remarkably lower (9%) in the year 2015 when compared to the cancer caregivers [22].

Studies conducted in diverse countries/regions reported the different DSs among caregivers, revealing that Asian and developing countries with low socio-economic backgrounds have reported higher DSs. The United States America (USA) revealed 22.8% of depression in 2017 [23] and similar figures (18.9%) were reported by Kehoe et al. [24]. China studies reported 25.5% and 31.5% of DSs among caregivers [25, 26]. In India, Chakraborty et al. [14] found 29% of DSs among general ICs; 50% of the caregivers, who cared for more than 40 hours per week had higher DSs irrespective of their socio-economic condition. The prevalence of depression was 45.15% among primary caregivers of adult patients with cancer in Ethiopia and reported associations between socio-demographic and other variables similar to most studies [27]. Depression in primary caregivers was frequently associated with socio-demographic and clinical characteristics of the patient [28]. Further, UNs among caregivers of patients with cancer significantly influenced carer depression [29].

However, data are scarce about DSs among family caregivers or cancer caregivers and their associated factors in published literature in Sri Lanka. One study was conducted in Sri Lanka to identify symptoms of caregiver strain and DSs among principal caregivers of patients with schizophrenia; a higher prevalence of DSs was reported in that study [30]. The findings of existing studies and recommendations cannot be directly applied to developing countries due to insufficient data and different disease conditions. Hence, it is important to identify characteristics and patterns of DSs among informal cancer caregivers in a developing country such as Sri Lanka. Therefore, this study aimed to determine the prevalence of DSs and its associated factors among ICs of patients with advanced cancer in PC at the Apeksha Hospital Maharagama (AHM), Sri Lanka which has not been much considered previously.

Materials and Methods

Study Design and Setting

This descriptive cross-sectional study was conducted at the AHM, Sri Lanka, which is considered the country's national oncology facility.

Population, Samples Size, and Sampling

The study population was ICs of patients with any type of advanced cancer and 226 ICs who attended/accompanied patients for consultations or clinics at the PC unit, oncology, or oncosurgery clinics were selected conveniently [31, 32]. ICs who are 18 years or older and caring currently for patients with any type of advanced cancer for more than three months were included. Adult ICs who are providing care for patients with critical conditions due to advanced cancer or other co-morbidities, who have attended training related to caring or were employed, and, who have a history of mental disorders diagnosed by psychiatrists were excluded. Individuals who are profoundly involved in a patient's care but do not receive payment for their services are known as ICs (e.g., spouses/partners, other family members, and/or close friends, and blood relatives and relatives-in-law who are categorized as family caregivers were considered) [5-7, 11].

Data Collection Instrument

The authors prepared an interviewer-administered (IAQ) questionnaire after the pre-testing. The first part of the IAQ comprised socio-demographic details, clinical characteristics of ICs, and details of care recipients. In the second part of the IAQ, a validated 20-item Sinhala version Center for Epidemiological Studies-Depression scale (CES-D) [33, 34] was included and used to assess DSs; higher scores indicate greater DSs.

Data Analysis

SPSS version 25.0 was used for data analysis. The frequencies, means, and standard deviations (SD) used to describe the socio-demographic characteristics. Further, Chi-square, independent samples t-test, one-way analysis of variance (ANOVA), and Pearson correlation were used to find an association between variables. The level of significance was accepted at $p<0.05$.

Ethical Consideration

The Ethics Review Committee, Faculty of Medical Sciences, University of Sri Jayewardenepura, Sri Lanka was granted the ethical approval (Ref. no ERC 49/22) after reviewing all needy documents such as information sheets, consent forms, questionnaires, etc. Further, the Board of Study in Medical Sciences, University of Sri Jayewardenepura, Sri Lanka was given the approval.

Results

Socio-demographic and other characteristics of ICs and their patients

The mean age (±SD) of the ICs was 41.78 (±14.54) years (age range 18-76). The characteristics of ICs are summarized in Table 1. A larger percentage of ICs were female and married. The majority of the ICs are currently working and engaged as skilled and non-skilled workers. In addition to the socio-demographic details, information related to caregiving activities (e.g., total time, weekly time spent for caregiving, sleeping time duration, the relationship) among ICs and patients was found. In Table 2, clinical and caregiving-related details among ICs are described. Nearly, 53% of ICs had financial strain/pressure as a consequence of caregiving. Further, self-reported health status is depicted in Table 1. ICs had perceived a high level of social support (SS) (48%) whereas perceived family/friend support (FFS) was lower than expected for most ICs (49%), and 22% reported that they had no family support.

In Table 3, care recipients' clinical and socio-demographics are exhibited. The mean age (±SD) of the ICs was 52.11 (±17.29) years (age range 15-92).

Descriptive Statistics of Depressive Symptoms

The mean±SD of DSs was 18.19±8.31 (range 12-55). The prevalence of DSs (≥16 CES-D) was 49%. Among different age categories, the 39-59 years age group showed the highest mean±SD (19.39±9.84) for DSs. Married ICs had the highest mean DSs (18.79±9.16) than unmarried and separated ICs. Considering the educational level, ICs had degree level education reported the highest DSs

Table 1. Socio- Demographic Characteristics of Informal Caregivers (n=226)

Characteristics/variables	Categories	n	%
Age (years)	18-38	99	43.88
	39-59	98	43.4
	60-80	29	12.8
Gender	Male	91	40.3
	Female	135	59.7
Marital status	Married	163	72.1
	Unmarried/Single	61	27.0
	Separated	2	0.9
Ethnicity	Sinhala	192	85
	Tamil	20	8.8
	Muslim	11	4.49
	Other	3	1.3
Religion	Buddhist	176	77.9
	Hindu	13	5.8
	Islam	12	5.3
	Christian	14	6.2
	Catholic	11	4.9
Education	No schooling	2	0.9
	Grade 1 - Grade 5	16	7.1
	Grade 6-12 (ordinary and advanced level)	188	83.2
	Diploma	9	4
	Degree	11	4.9
Family monthly income (LKR)	1000-5000	56	24.8
	5001-10,000	32	14.2
	10,001-49,999	78	34.5
	50,000-99,999	51	22.6
	100,000-200,000	9	4
Working status	Currently working	109	48.2
	Currently not working	117	51.8
Occupation (engaged before or currently doing)			
	Professionals/Executives	20	8.8
	Military personals	6	2.64
	Skilled worker	37	16.28
	Unskilled worker/Laborer	38	16.72
	Self-employed/Business	11	4.84
	Undergraduate/studying	19	8.56
	No occupation	91	40.3
	Retired/pensioner	4	1.79
Total time spent caregiving (months)	≤ 3	190	84.1
	3-6	14	6.2
	6-12	15	6.6
	12-24	5	2.2
	>25	2	0.8
Weekly time spent caregiving (hours)	72-90	24	10.6
	91-109	22	9.7
	110-128	60	26.5
	129-147	107	47.3
	148-166	13	5.8
Total time spent sleeping/per day (hours)	1-5	152	67.3
	6-10	74	32.7

Table 1. Continued

Characteristics/variables	Categories	n	%
Changes of work/job due to caregiving	No change	108	47.8
	Changed job	1	0.4
	Decreased working hours	17	7.5
	Quit/resigned job	12	5.3
	On-leave/temporary leaving	64	28.3
	Retired	1	0.4
	Discontinued/reduced education	23	10.2
Number of members in the family of the caregiver			
Parents	Yes	118	52.2
	No	108	47.8
Children	Yes	128	56.6
	No	98	43.4
Grandchildren	Yes	13	5.8
	No	213	94.2
Grandparents	Yes	5	2.2
	No	221	97.8
Sisters/brothers	Yes	50	22.1
	No	176	77.9
Care setting	In-patient care/hospital	226	100
Caregiver relationship to care recipient	Child	45	19.9
	Sister	27	11.9
	Brother	18	8.0
	Cousin brother/sister/ uncle/ aunty	20	8.8
	Mother/mother-in-law	60	26.5
	Father/father-in-law	32	14.2
	Neighbor/friend	24	10.6
Living arrangements (resides with care recipient)	Living with family/patient	119	52.7
	Living separately	107	47.3
Levels of care	Day-to-day hands-on care	224	99.1
	Intermittent hands-on care	2	0.9

Frequency- n; Percentage-%

Table 2. Clinical and Caregiving-Related Details among Informal Caregivers (n=226).

Characteristics/variables	Categories	n	%
Consequences due to caregiving			
Physical disease	Yes	41	18.1
	No	185	81.9
Financial strain/pressure	Yes	157	53.3
	No	69	69.5
Psychological distress/ Emotional strain	Yes	131	58
	No	95	42
Self-reported health status	Very good	3	1.3
	Good	185	81.9
	Fair	22	9.7
	Poor	16	7.1
Chronic disease conditions			
Medical/comorbidities	Yes	36	15.9
	No	190	84.1
Surgical	Yes	2	0.9
	No	224	99.1
Psychological/psychiatric	No	226	100
Perceived social support (SS)	None	9	4
	Poor	35	15.5
	Moderate	73	32.3
	Strong	109	48.2
Perceived family/friend support (FSS)	I do not need any help	8	3.5
	Receive no help	50	22.1
	Less help than needed	111	49.1
	Received what I need	57	25.2
Has a person to look after	Yes	198	87.6
	No	28	12.4
Received government funds	Yes	12	5.3
	No	214	94.7
Has own place/home to stay	Yes	216	95.6
	No	10	4.4

Frequency- n; Percentage-%

(19.18±8.94) unexpectedly, and the lowest DSs reported by illiterate ICs (13.00±1.41). Higher DSs (20.22±9.50) were reported by ICs who had high family income (Sri Lankan Rupees/LKR 100,000-200,000) while the lowest DSs (16.88±5.70) had ICs who earned LKR 5,001-10,000 surprisingly. According to employment status, ICs who quit/resigned from their job reported a higher level of DSs (20.50±8.57). Parent-child relationship (ICs was child-daughter/son/or daughter/son-in-law) had the highest DSs (22.33±13.13) followed by patient-spouse (husband/wife) (21.40±9.37), child-mother relationship (19.48±7.57) than other relationships.

ICs who did day-to-day caring reported a higher level of DSs (18.21±8.35) than those with intermittent caring. ICs who cared for more than two years of period reported a higher level of DSs (33.00±16.97) and reported lower DSs (17.53±7.73) than ICs who cared for less than three months. Caring between 72-90 hours/week had the highest DSs (25.54±11.41). ICs who had fewer sleeping hours reported lower DSs (17.14±7.11) unexpectedly while others reported higher DSs (20.34±10.09).

ICs who had physical diseases (20.44±10.72), financial strain (18.62±8.15), and emotional strain (19.99±9.04) reported higher DSs as expected than that of others. ICs with a ‘very good’ level of self-reported general health (SGH) attained lower DSs (13.67±1.15) whereas a ‘poor’ level of SGH reported the highest level of DSs (25.69±13.99). Poor perceived SS was reported the highest DSs (23.67±11.05) and FFS, and those who received ‘no help’ reported the highest DSs (21.00±9.95).

If the patient’s age between years 15-35 reported a higher level of DSs (21.10±9.60) among ICs and if the patient was female caused to increase in DSs among ICs. Further, a higher level of DSs was reported by patients who had been diagnosed before 4-5 years.

Associated factors of Depressive symptoms among ICs

Several variables of ICs (e.g., caregiver-related and caregiving-related) were significantly associated with DSs (Table 4). Significantly advanced DSs were reported

Table 3. The Socio- Demographic and Clinical Characteristics of Care Recipients

Characteristics/variables	Categories	n	%
Age	15-35	41	18.1
	36-56	83	36.7
	57-77	94	41.6
	78-98	8	3.5
Gender	Male	91	40.3
	Female	135	59.7
Type/site of cancer (primary)	Bladder	6	2.7
	Brain	6	2.7
	Breast	31	13.7
	Cervix	10	4.4
	Colon	22	9.7
	Liver	5	2.2
	Lymph Node	9	4
	Lung	13	5.8
	Oesophagus	6	2.7
	Oral	20	8.8
	Ovary	4	1.8
	Pancreas	4	1.8
	Rectum	8	3.5
	Stomach	19	8.4
	Throat	6	2.7
	Thyroid	5	2.2
	Tongue	8	3.5
	Uterus	19	8.4
	Other	15	6
Time since diagnosis (months)			
	6-12	73	32.3
	13-24	109	48.2
	25-37	10	4.4
	38-50	4	1.8
	51-63	7	3.1
	64 and above	23	10.2

Frequency- n; Percentage-%

Table 4. Factors associated with DSs of Informal Caregivers (n=226)

Variables- Informal caregiver	≤16 CES-D mean±SD	>16 CES-D mean±SD	p-value
Age[a]			0.148
Gender[b]	Male 14.74±3.75	Female 20.52±9.65	0.000**
Working status[b]	Employed 16.58±7.02	Currently unemployed 19.69±9.14	0.005**
Marital status[a]			0.217
Ethinicity[a]			0.46
Religion[a]			0.682
Educational level[a]			0.909
Family income (LKR)[a]			0.809
Employment status[c]			0.734
Physical disease[c]			0.182
Self-reported general health[a]			0.000**
Financial strain[c]			0.002**
Emotional strain[c]			0.000**
Perceived social support (PSS)[a]			0.000**
Perceived family/friends support (PFFS)[a]			0.006**
Caregiver relationship with patient[c]			0.000**
Care level (day-today vs. intermittent)[c]			0.148
Caregiving period[c]			0.024*
Caregiving hours/week[c]			0.000**
Sleeping hours/day[c]			0.3
Variables- Patient/care recipient			
Age[a]			0.094
Gender[c]			0.000**
Cancer type[c]			0.046*
Time since diagnosis[c]			0.758

[a], ANOVA test findings; [b], Independent t-test findings; [c], Chi-square test findings; r-Pearson correlation test findings; SD, standard deviation; p<0.001**; p<0.05*

by female ICs compared to males (p<0.01) and currently unemployed vs. employed ICs (p<0.01). SGH, financial strain, and emotional strain of ICs were significantly influenced by DSs (p<0.01). A statistically negative relationship was found between DSs, and perceived SS and FFS of ICs (p<0.01). DSs were significantly related to the caregiver's relationship with the patient (p<0.01), caregiving period (p<0.05), and caregiving hours/week (p<0.01). Two variables of the patient (e.g., gender and cancer type) were significantly influenced by the DSs of ICs.

Discussion

This study examined the prevalence of DSs and its associated factors among ICs of patients with advanced cancer in PC, in Sri Lanka. To our knowledge, this is the first study done in Sri Lanka considering DSs among informal cancer caregivers while searching the literature. Nearly, half of the ICs in the current study had higher DSs and the reported significant associated factors were; gender, working status, SGH, financial strain, emotional stain, perceived SS, perceived FFS, caregiver relationship with patient, caregiving period, and caregiving hours/week. In addition, the gender and cancer type of the patients with advanced cancer were significantly influenced by the DSs of ICs.

Previous literature has supported findings related to the lower and/or higher DSs than the current study among ICs in different countries and also reported diverse associated factors for DSs. The PPD was 25.14% (95% CI, 21.42–29.27%) among caregivers of patients with cancer in a systematic review [19] and expressed a higher prevalence of DSs; however, it was four times higher (62.7%) than the general population in Kenya [13] and higher than in Turkey general population [35]. According to Pan and Lin [19], the PPD among caregivers of patients with cancer was changed by geographic region, study design, the demographics of caregivers (e.g., age, sex, etc.), patients' medical information (e.g., cancer type, stage, etc.) and different measures/scales used to assess depression (e.g., self-reported tools/scales, diagnostic interviews/standard guidelines by medical professionals) similar to some associated factors in the current study. Further, they found that the prevalence rate was higher among caregivers of patients with terminal or palliative cancer than the caregivers of patients with non-advanced and advanced cancer due to the impact of the cancer stage as the cancer palliation is a very troublesome period. However, the cancer stage was not an associated factor in the current study and DSs were increased while increasing the time since diagnosis of their patients might be due to increasing caring responsibilities while deteriorating the current condition.

Further, caregivers frequently have to deal with changes in role, changing UNs [29, 36], and new caregiving duties of caregivers; these changes are prone to caregiver burden and influence on DSs [29]. However, the level of care (caring day-to-day vs. intermittent) in the current study was not significantly influenced by DSs. As described, the DSs of caregivers could often increase overlapping with anticipatory bereavement and DSs might transition from treating the patient's disease to accepting the patient's impending death. However, this review reported that caregivers of other illnesses had higher DSs than patient's cancer caregivers [19]; accordingly, 40.2% (95% confidence interval 30.1% - 51.1%) of DSs were reported by caregivers of stroke survivors in Loh et al. [36].

Another important finding was that the PPD estimated from the Eastern population was significantly higher than the Western population due to the changes in a geographic region reported previously also (e.g., might be due to cultural discrepancies, filial piety, and mandatory care among Eastern family members compared to Western people) reported as one moderator of DSs [19]. A study done in the USA revealed 18.9% of depression [24] and 35% of DSs reported by bereaved family caregivers of patients with advanced cancer in Germany [37] as evidenced by the geographic changes than the rate of the current study. He et al. [25] reported that 25.5% of depressive prevalence among China lung cancer caregivers is lower than the current study. In Kenya, DSs were higher among caregivers of patients undergoing PC (62.7%) [13] which was much higher than the above-mentioned studies and the current study. Among the primary caregivers of adult patients with cancer in Ethiopia [27], the reported prevalence of DSs was 45.15% (95% CI: 40.38–50.001), mostly similar to the current study and higher than the developed and/or Western countries mentioned earlier and proved by Pan and Lin [19].

Pan and Lin [19] further suggested identifying the cultural aspects, social norms, and beliefs about caring among caregivers to reduce the burden and DSs while caregiving [14] as an important matter to consider. They reported the importance of having a good relationship between caregivers and patients and caused to reduction in DSs due to the percentage of spousal caregivers increased [19] in addition to providing enough support to their patients [18]. Previous studies reported that the caregivers had high DSs due to delivering long-term care without obtaining adequate support [14, 18]. Caregiver relationships with the patient; mother/mother-in-law and daughter/daughter-in-law (as ICs) were the prominent relationships in the current study which scored the highest DSs than other caring relationships may be due to very close relationships [13]. The majority of such daughters/daughters-in-law were mothers/spouses and engaged with many day-to-day responsibilities in their families [13, 38, 39] in addition to caring for their mother/mother-in-law admitted to the hospitals. Usually, mothers/wives care for their children and husbands which could increase the societal gender characteristics of the woman. Similar facts were reported in India and other countries [14, 19] due to the status of Eastern-extended families, cultural and traditional norms, and religious beliefs could be seen in Sri Lanka too. Another way in some countries, spousal caregivers (husband or wife) were found to have higher DSs [13, 20].

Caring-related variables such as caregiving period (nearly three months) and caregiving hours/week (nearly 150 hours) were significantly associated with DSs among ICs in the current study might be due to the caregiving workload (e.g., duration, weekly tasks, sleeping hours, sleep quality, etc.) similar to Indian informal caregivers of patients with different chronic diseases [14], and act as predictors of depression [20]. Grief and distress are mostly associated with family caregivers of patients with cancer further increased depression [20] and poor sleep quality caused high anxiety and depression [25]. Further, DSs among the current ICs were higher when caring day-to-day and caring for more than two years. As reported among family carers of cancer patients in Uganda, there was an important association between depression; the caregiver relationship with the patient (being a first-degree relative family carer), and carers in the extended family prone to get higher DSs [28] mostly similar to the current ICs.

Although the current ICs had reported 'good' for SGH (82%) (due to not having physical, psychological, medical, surgical, and mental illnesses/comorbidities), it was caused to increase DSs significantly. Medical illnesses of caregivers could increase the anxiety level of patients and lead to uncertainty about ongoing care provided by caregivers as reported by Karabekiroğlu et al. [40] different from the current findings. Further, emotional strain (58%) and financial strain (53%) among current ICs were significantly influenced by DSs due to psychological stress and the current economic crisis in Sri Lanka. DSs among cancer caregivers were higher than the general population might be due to the heavy and continuous physical and psychological burdens of cancer caregivers than that of others as reported elsewhere [19] and similar to the significant effects of emotional strains among current ICs. Further, general ICs in India had reported 29% DSs and they were at a higher risk of getting depression especially those who were widowed and lived in rural areas/not satisfied with existing living arrangements than non-caregivers [14] which was lower than most of the reported findings of informal cancer caregivers.

As another opinion of Pan and Lin [19], the heterogeneity of tools/scales used by different studies and diagnostic interviews done by the relevant consultant/mental healthcare specialists might be reasons for different prevalence DSs. The DS scores obtained using CES-D and Beck Depression Inventory (BDI) scales reported higher depression than other scales and interview methods done by medical professionals. This reason was proved by Bedaso, Dejenu, and Duko [18], who reported that DS prevalence was higher among studies using CES-D, BDI, etc. scales rather than using the Diagnostic and Statistical Manual of Mental Disorders-IV. Similar to previous trends, the CES-D scale was used to assess DSs in the current study might be a reason for higher DSs among ICs [18, 19].

Another systematic review stated that 42.30% higher PPD among cancer patients' caregivers [20], and DSs had significantly varied between 2.6 to 82.2%. The caregivers' psychological, social, and economic factors, the health of the caregiver, the duration of caregiving, relationship, and communication between caregiver and patient could exaggerate the DSs. Variables related to caregivers (e.g., spouse caregiver, unemployed, caregiver with chronic disease, caregiver's sleep quaity and avoidence, financial problems, and female), caregiving (e.g., caregiving burden, caregiving duration), and patient's condition were positively influenced to DSs. Considering the current associated factors, ICs who were young [24, 29], unemployed [20], with financial hardships [20], and longer caregiving duration [13] caused higher DSs whereas did not study about the caregiver burden in the current study. caregiver burden in the current study. The overall QoL of the caregiver, age of the caregiver, pre-loss grief, education level of caregiver, caregiver's sense of coherence, and caregiver's bondage with the patient were negatively related to DSs among caregivers. In contrast, the age and education of ICs were not influenced by DSs in the current study [28] while DSs were negatively associated with perceived SS and FFS. As reported, the age of caregivers was associated with DSs and older caregivers had higher DSs than younger [13] contrast to another finding that younger caregivers had higher DSs [24]. However, most caregivers are usually in older ages and their comorbidities are linked to poor emotional health and QoL [24].

In a review by Bedaso, Dejenu, and Duko [18], the founded PPD among caregivers of patients with cancer was 42.08% (95% CI:34.71–49.45) and found some reasons for higher DSs; ICs who provided care for lengthy hours/day [13] without receiving satisfactory support who cared for terminal cancer patients caused to increase caregiver burden with the deteriorating the existing condition, and due to the UNs [29]. In the current study, lower perceived SS and FFS among ICs caused to increase in DSs significantly [40] although Sri Lankan families mostly consisted of extended family members interestingly like in the current study. Further, Southeast traditions, cultural systems, and religious practices in Sri Lanka tend to change as Western countries nowadays to a certain extent due to several reasons such as families are consisted with fewer members, more females entering the paid workforce, facing economic hardships, financial challenges, increasing household costs [20, 41], shifting socio-economic environment [39], increased migration abroad for work in recent past, or children migrating within Sri Lanka, etc. [39]. However, family members are still considering good faith/practices, and reluctance to discuss such issues faced by ICs deeply might be due to cultural and religious factors including in Sri Lanka [7]. A study done in a suburb of Sri Lanka revealed the status/hardships faced by family caregivers such as loss of income due to loss of job/occupation, financial problems, transport issues when shifting patients' home to hospital and traveling long distances, failure to do day-to-day activities, lack of support from family members for caring, and schooling and education of children [42] similar to some of the current associated factors. Further, revealed that those caregivers of cancer patients who had UNs [29, 42-44] often sacrifice their own needs, putting themselves at risk for a bigger burden and probable psychosocial damage and the psychological burden on the caregiver may surpass that of the patient, and insufficient knowledge, skills, and experience to provide PC could be reasons for increasing DSs among ICs in addition to the above-mentioned hardships [42].

According to the previous findings, family members especially children, elderly parents, and spouses were distressed physically and psychologically due to migration [45]. Higher support from other people may buffer the burden, stress, and depression [40]. In 2018, Heckel and colleagues [29] reported that ICs provide prolonged support/uncompensated care to patients with cancer while obtaining a little support to assist them in their caring role in the healthcare system. According to the observation, DSs were higher in the cross-sectional studies (42%, 95% CI: 31–52) than in longitudinal studies (34%, 95% CI: 18–50) as another reason.

Female caregivers had a higher level of DSs when compared to their male counterparts [18, 35] which are similar to the female ICs of the current study and may be due to biological theories and genetic impacts as reported earlier [20, 38]; and women are prone to perceive a higher level of psychological ailments and had the opportunity for sexual violence than males [46]. In contrast, DSs were higher among Turkey and Uganda male caregivers of patients with advanced cancer [28, 40] due to the male patients' hope for more support for personal care and this reason could influence depression among caregivers. Not only the gender of ICs, gender and cancer type of patients were significantly impacted on DSs among ICs in this study while age and the time since diagnosis were not impacted significantly. As reported by Geng et al. [20], the condition of the patients was positively associated with DSs of caregivers of cancer patients.

However, married ICs found to have higher DSs in the current study, and the marital status of ICs was not significantly influenced by DSs which could not be found in most published studies [28]. In particular, married female ICs might have many responsibilities and household chores within their own family in addition to the day-to-day caring responsibilities of patients with advanced cancer as mentioned earlier [13, 38]. In a study by Wassie and others [27], gender, education, marital status, occupation, relationship, residency, comorbidity, alcohol use throughout life, type of treatment, and average monthly income were associated significantly with depression.

Usually in Sri Lanka, the older population and patients with chronic illnesses have traditionally been cared for in their own homes by their children/family members since a long time ago due to the strong family support system, active interest among family members, traditional customs/laws, and religious obligations; both elders and caregivers' sense that elders must be taken care of in the home by their children [39]. Compared to many findings in other countries, data relevant to caregivers especially in the cancer field were very limited in Sri Lanka. Among a few studies done in Sri Lanka among caregivers, one study was conducted to identify DSs among principal caregivers of patients with schizophrenia; a 37.5% prevalence was reported [30] and it was lower than the current study. Another study about carer burden among patients with schizophrenia and affective disorders found that carers of schizophrenia had a higher burden; the burden was influenced by female gender and stigma [47] proving the discrimination against caregivers of mental health patients in Sri Lanka. However, 5.9% of patients with diabetes reported the DSs; female gender, living without a spouse (single/divorced/widowed), a lower education level, and peripheral neuropathy were the significant factors of diabetic patients (53). QoL of caregivers of patients with dementia revealed that QoL was lower among caregivers than their respective patients in Colombo, Sri Lanka [48] and impaired QoL is associated with DS in elsewhere [24]. A global study done about societal perceptions of caregivers incorporating 20 countries/ territories revealed that 18 countries had neutral to positive views about caregivers while Sri Lanka and Tanzania had the most negative perceptions [49]. Nevertheless, there are some studies done to assess depression/DSs among the general population [21] and patients with different diseases [50], and for cancer [51], Parkinson's disease [52], type 2 diabetes mellitus [53], etc. However, those studies investigated different caregivers, and no studies conducted regarding DSs among informal cancer caregivers so far [54]. As in other countries, Sri Lankan society is continuously changing to age, changes are occurring in socio-economic structures and patterns of non-communicable disease. By 2030, the number of people aged 60 and above will be more than doubled. As the population approaches this significant demographic turning point, more people will need to assume the job of caregiver. It simply makes logical that compassion develops into a common trait throughout all cultures [49] along with this new field in Sri Lanka, PC.

There are some limitations in our study. This study was done as a cross-sectional design, which has the limitation of providing evidence of a temporal relationship between exposure and outcome. The convenience sampling method might limit the generalizability; however, participants around Sri Lanka attended this study, which increased the generalizability. IAQ could be bound to the expression of real ideas and opinions.

In conclusion, ICs who cared for patients with advanced cancer receiving PC at the AHM, Sri Lanka reported a higher level of DSs, which needs due attention and is not surprising due to challenges faced by ICs. DSs were found to be significantly more prevalent mostly in female and unemployed carers. Being a first-degree relative family carer such as a daughter, caregiving more than two years of period, caregiving 72-90 hours/week, and ICs having financial and emotional strain were associated with high DSs in addition to lower levels of SGH. Perceived lower levels of SS and FFS tend to have higher DSs. Further, the patient's gender and cancer type were significantly impacted on DSs among ICs.

Healthcare providers (HCPs) mustn't focus only on the patients but also on the ICs of patients receiving PC since they experience a lot of strain and incapacities which causes their depression. HCPs in both primary and tertiary PC facilities need to deliberately examine DSs (early and routine screening) [13] and their associated factors among ICs of patients with advanced cancer, not just on patients alone [13]. Appropriate remedies may need to focus on variables related to caregivers and caregiving especially diversity of UNs among caregivers [29]. In addition, the provision of psychological support and culturaly sensitive intervention intervention [19], and psychosocial involvement for ICs of patients with cancer is highly recommended which minimizes DSs among ICs [18]. This not only expands the care of the provider but also advances the care of the patient. Also, escalating other evidence-based practices linked to addressing DSs among caregivers of cancer patients would be beneficial. Upcoming research should study specific caregiver-directed interventions during PC. Further studies should be done to study the possible reasons for a higher prevalence of depression among informal cancer caregivers.

Author Contribution Statement

Study conception and design: EW; analysis and interpretation of results: EW; draft manuscript preparation: EW, SG, LM. All authors reviewed the results and approved the final version of the manuscript.

Acknowledgements

General

Firstly, the authors would like to highly acknowledge all participants who were involved in this project during their busy schedules. We would like to express our appreciation to the Ethics Review Committee, Faculty of Medical Sciences, University of Sri Jayewardenepura, Sri Lanka for the ethical approval. Further, we would like to express our gratitude to the Director of the Apeksha Hospital Maharagama for granting permission to conduct the study. All authors appreciate Dr. Sujeewa Weerasinghe (Consultant Oncologist, Apeksha Hospital Maharagama, Sri Lanka), Ms. Samindra Ranasingha (Former In-Charge/ Palliative Care Unit, Apeksha Hospital Maharagama, Sri Lanka), and respective nursing staff for the permission of data collection.

Data Availability

Data is available on reasonable request from the corresponding author.

Approval

The Ethics Review Committee, Faculty of Medical Sciences of the University of Sri Jayewardenepura, Sri Lanka approved the study in addition to the Board of Study in Medical Sciences, University of Sri Jayewardenepura, Sri Lanka. Further, the Director of Apeksha Hospital Maharagama, Sri Lanka, and the respective consultants permitted the data collection.

Ethical Declaration

The Ethics Review Committee, Faculty of Medical Sciences, University of Sri Jayewardenepura, Sri Lanka was granted ethical approval (Ref. no ERC 49/22).

Conflict of Interest

All authors declare that they have no conflicts of interest.

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