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The Effect of Caregiving on the Mental Health of Caregivers of People with Cancer in Nyanza, Kenya: Implications for Cancer Care

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Keywords:
*Cancer,
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and Depression
Scale.*

Introduction: Patients with cancer, just like other patients, need extensive round-the-clock care. Caregiving improves their well-being and quality of life. However, caregiving to people with cancer comes with a lot of challenges and is sometimes a burden to the caregiver. With time, this burden may predispose the caregivers to mental health challenges like anxiety and depression. This study aimed to determine the prevalence and extent of anxiety and depressive symptoms among caregivers of patients with cancer in the Nyanza Region of Kenya. **Methods:** A cross-sectional design was used. Convenience sampling and snowballing were used to recruit 147 study participants. Pretested interview-guided structured questionnaires, slight modifications of the Hospital Anxiety and Depression Scale. Data was analyzed and visualized using GraphPad Prism version 5.03. **Results:** The mean age of participants was 41.19 (\pm 2.510) years, 85(58.1) were females and spent an average of 12.35 (\pm 1.194) hours providing care daily. The prevalence of anxiety and depression were 28.6% and 32.7% respectively. For anxiety, 56 (38.1%) were normal, 49(33.3%) were borderline abnormal and 42(28.6%) were anxious. For depression, 33(22.4%) were normal, 66(44.9%) were borderline abnormal and 48(32.7%) were depressed. For the self-rating of their mental health status since starting caregiving roles, 47(32.3%) were neither satisfied nor dissatisfied, 38(25.8%) were strongly satisfied, 33(22.6%) were satisfied, 24(16.1%) were dissatisfied, and 5(3.2%) were strongly dissatisfied. **Conclusion:** The prevalence and extent of anxiety and depression are relatively high in caregivers of people with cancer compared to the general population. Many caregivers are on the borderline for both anxiety and depression, representing a poor trend in the mental health of this vulnerable group of people. There is a need for continuous mental health screening of caregivers for early diagnosis and treatment. Interventions addressing mental health resilience in caregivers should be a part of cancer care.

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INTRODUCTION

Cancer is a chronic debilitating non-communicable disease with the ability to affect any part of our bodies (Sung et al., 2021). Upon establishment, cancer cells metastasize to other parts of the body, affecting the functioning of the cells (Brown et al., 2023). Cancer takes the second position in causing morbidity and mortality, only after cardiovascular disease (Weir et al., 2016). Globally, it has been estimated that more deaths occur due to cancer than HIV, TB and Malaria combined (Makam & Matsa, 2021). In 2020, approximately 18.1 million people had cancer around the world (Abudu et al., 2021). Breast, lung, colorectal, prostate and stomach cancers were the five leading cancers in the world by 2020 in both sexes (Sung et al., 2021). Cancer morbidity and mortality are on the rise. Indeed, Globocan data shows that 29 million people will have cancer by 2040, with the highest burden increase (96%) occurring in countries with a low Human Development Index, and only 32.2% in very high HDI countries (Zhang et al., 2024). In Kenya, approximately 39,000 new cases of cancer are diagnosed annually, with more than 27,000 succumbing to the disease (Maiyoh & Tuei, 2019). The high mortality rate is attributed to poor health-seeking behaviour, with many individuals having

their first visit long after the cancer has reached its advanced stages (Makau-Barasa et al., 2020).

Cancer has many far-reaching implications for patients, their loved ones, families, and communities (Williams, 2018). They are expected to provide financial, psychological, and physical support throughout the disease journey. Sometimes and in the African setting, this support is left to immediate family members including spouses, children, parents, in-laws and siblings, and most commonly to females (Githaiga, 2017). Since cancer is a chronic disease, providing care to a cancer patient then becomes a limiting factor that prevents the caregiver from achieving their full potential. Globally, the burden of cancer caregiving is substantial, with millions of individuals assuming the role of caregiving to cancer patients each year (Goren, Gilloteau, Lees, & DaCosta Dibonaventura, 2014). In Kenya, where cancer rates are rising, the prevalence of caregiving for cancer patients is also on the rise, placing additional strain on caregivers and their families (Makau-Barasa et al., 2020). However, caregiving for cancer patients is associated with numerous challenges that can adversely affect the well-being of the caregivers themselves (Nemati, Rassouli, Ilkhani, & Baghestani, 2018).

The burden of cancer caregiving could compromise the caregivers' physical, psychological and general well-being. For example, the demanding nature of caregiving tasks, such as assisting with mobility, managing medication, and performing personal care, can result in fatigue, sleep disturbances, and physical strain (Given, 2019). Caregivers often experience heightened levels of stress and psychological distress, anxiety, and depression due to the constant demands, uncertainty, and emotional strain associated with caring for a loved one with cancer (Govina et al., 2019). With time, caregivers start feeling burdened, are often tired, may have disruptions in their sleep patterns, may lose interest in activities that they once found interesting, put on weight or lose it, or have several bouts of sadness (Githaiga, 2017). These put an emotional toll on the caregivers that often leads to guilt for thinking they are not doing good enough, social isolation, and a decline in overall satisfaction with life. These effects of caregiving also predispose caregivers to several health challenges by increasing the risk of infections (Bisi-Onyemaechi, Chikani, & Nduagubam, 2018) due to a weakened immune system, several psychiatric disorders including depression, anxiety, physical ailments like headaches and muscle strain and cardiovascular illnesses like heart disease and high blood pressure (Govina et al., 2019).

Additionally, with more time spent on caregiving, there's a disruption of social relationships, which limits social participation for caregivers (Fisher et al., 2021). The time and energy devoted to caregiving often result in social isolation, as caregivers may have limited opportunities for socializing and maintaining relationships outside the caregiving context (van Roij, Brom, Youssef-El Soud, van de Poll-Franse, & Raijmakers, 2019). Additionally, the role of a caregiver may affect employment, financial stability, and overall social functioning. Caregivers may experience a decrease in social support and engagement in leisure activities, which affects their quality of life (Fisher et al., 2021). With all these effects, caregiving

increases the risk of mortality especially in elderly caregivers and those with underlying health challenges (Pristavec & Luth, 2020).

With the chronic nature of cancer, its rigorous treatment regimens and the excruciating pain episodes that are associated with prolonged agony and suffering, caregiving to a cancer patient is a tormenting experience for the caregiver (Bahrami & Nasiri, 2024). This is more pronounced in resource-limiting settings of Sub-Saharan Africa where limited resources are available to take care of the patients and, later on, the caregivers (Kizza & Muliira, 2020). This study aimed to determine the prevalence of anxiety and depressive symptoms among caregivers of cancer patients attending Jaramogi Oginga Odinga Teaching and Referral Hospital and Muhoroni Hospice found in the Nyanza Region of Kenya.

MATERIALS AND METHODS

The study was conducted in Kisumu County, at Jaramogi Oginga Odinga Teaching and Referral Hospital and Muhoroni Hospices. The area was chosen since another study on cancer patients was simultaneously being carried out in these two hospices.

Research Design, Sampling Method and Sampling Technique

This was a cross-sectional study of caregivers of PWC attending Jaramogi Oginga Odinga Teaching and Referral Hospital and Muhoroni Hospice. Convenient sampling and snowballing were used to recruit caregivers who attended any one of the two facilities between 1st June to 30th August 2024 and consented to be included in the study. The caregivers were then requested for contacts of other caregivers who fulfilled the inclusion criteria. A total of 147 caregivers met the inclusion criteria and were therefore included in the study.

Inclusion and Exclusion Criteria

The inclusion criteria included adults (age 18 or above) who cared for PWC for three or more

months consecutively. Individuals who fulfilled the eligibility criteria but had a confirmed history of anxiety, depression and other neurotic or psychotic disorders were excluded. This is because a history of a mental disorder is a risk factor for another mental disorder, the study could not confirm if the present anxiety or depressive symptoms in the caregiver were due to their caregiving roles or due to the previous mental disorder.

Data Collection Instrument

Pretested interview-guided structured questionnaires developed using slight modifications of the Hospital Anxiety and Depression Scale were used to assess anxiety and depressive symptoms in the caregivers. The last question was 'How would you rate your overall mental health status as a caregiver of a person with cancer?'

Data Quality Control

As a means of data quality control, filled questionnaires were checked for completeness and accuracy of responses. The integrity of the data collected was maintained as it was entered in Microsoft Excel version 2410.

Ethical Approval

Ethical approval was obtained from the Jaramogi Oginga Odinga Scientific and Ethics Review Committee number ISERC/JOOTRH/017/24. Permission was sought from the Management of the two study sites before recruitment of study participants commenced. Both verbal and written consent were obtained from each of the caregivers after a thorough explanation of the study objectives. They were also informed of the right to withdraw at any step of questionnaire administration. No personal identification information including names or phone numbers was collected.

Hospital Anxiety and Depression Scale (HADS)

The HADS is a self-reported 14-item validated tool that assesses the extent of anxiety and depressive symptoms in individuals, with 7 items for each subscale. The items are rated in terms of severity on a 4-point Likert scale ranging from 0 to 3. The total score (calculated as the sum of the scores for each of the 7 items of each subscale) ranges from 0 (no anxiety or depression at all) to 21 (maximum severity of anxiety or depression).

Data Analysis

Data was entered into Microsoft Excel version 2410 for cleaning. It was then exported to GraphPad Prism version 5.03 for analysis. Frequencies, percentages and means (\pm standard deviation) were obtained where applicable. Data was visualized in the form of tables and figures.

RESULTS

Demographic Data of the Participants (Table 1)

Of the 147 participants, 62(41.9%) were males and 85(58.1%) were females. Participants age range was 21.00 – 67.00 years, with a mean age of 41.19 ± 2.510 years. These spent between 2.00 and 20.00 hours, with an average of 12.35 ± 1.194 providing daily care to PWC. Majority 71(48.3%) were self-employed, 33(22.4%) were unemployed and 24(16.3%), 10(6.8%) and 9(Sharma et al.) were employed full-time, students or casual laborers respectively. Additionally, most caregivers were siblings to the patients 38(25.8%). Others were spouses 33(22.6%), parents 33(22.6%) and patients' children 19(12.9%). Aunts, mothers-in-law, cousins and friends also provided care 24(16.1%). By their marital status, the majority of the caregivers were married 96(65.3%), 30(20.4%) were single, 14(9.4%) were widowed and 7(4.8%) were divorced and the majority 59(40.3%) had taken between 3 to 6 months providing care to PWC.

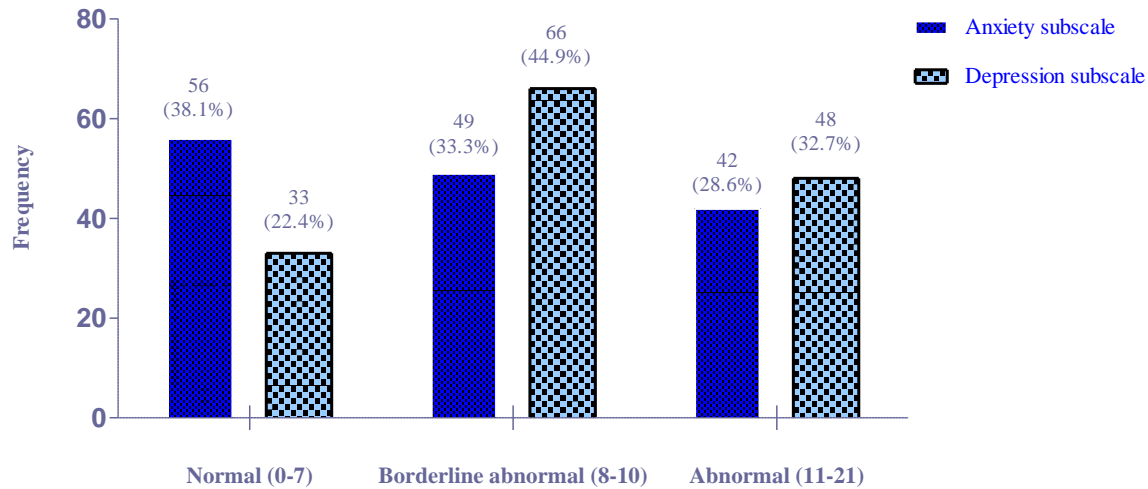
Table 1: Demographic Data of the Study Participants

Characteristic	Range	Frequency (%) or mean (\pm standard deviation)
Age	21.00 – 67.00	41.19 (\pm 2.510)
Sex		
Male		62(41.9)
Female		85(58.1)
Hours spent caregiving per day	2.00 – 20.00	12.35 \pm 1.194
Employment status		
Unemployed		33(22.4)
Full-time employment		24(16.3)
Casual labourer		9 (6.1)
Self-employment		71(48.3)
Student		10(6.8)
Relationship with cancer patient		
Child		19(12.9)
Parent		33(22.6)
Sibling		38(25.8)
Spouse		33(22.6)
Others (aunts, mother-in-law, cousins, friends)		24(16.1)
Marital status		
Single		30(20.4)
Married		96(65.3)
Widowed		14(9.5)
Divorced		7(4.8)
Time taken giving care (months)		
3-6		59(40.3)
7-12		33(22.5)
13-18		16(10.9)
19-24		27(18.6)
>24		11(7.8)

Prevalence and Extent of Anxiety in Caregivers of PWC

The prevalence of anxiety was 28.6%. Results show that most of the caregivers 56 (38.1%) were normal,

49(33.3%) were borderline abnormal and 42(28.6%) were abnormal (anxious) as shown in Figure 1.

Figure 1: Extent of Anxiety and Depression in Caregivers of PWC

From the seven questions on the scale (Table 2), sudden feelings of panic as the caregivers undertook their caregiving roles had the highest number of participants with a score of 3 (very often indeed) of 68(46.3%). This was followed with ‘Worrying thoughts about the cancer patient’s condition or prognosis go through my mind’ at 38(25.9%).

Likewise, ‘as I carry out my caregiving duties, I sometimes feel so restless that it is hard to sit still’ had the highest number of participants with a score of 0 at 75(57.0%). This was also followed by ‘Even as I undertake my caregiving roles, I find time to sit at ease and feel relaxed’ at 62(42.2) with a 0 score (definitely).

Table 2: Frequency of Anxiety and Depression Subscales Measurement Parameters in the Caregivers of PWC

Anxiety subscale question	Severity Frequency(percentage) N=147			
	3	2	1	0
Worrying thoughts about the cancer patient’s condition or prognosis go through my mind	38(25.9)	25(17.0)	42(28.6)	42(28.6)
How often do you get frightened that something awful will happen while undertaking your caregiving roles?	21(14.3)	24(16.3)	49(33.3)	53(36.1)
How often do you get frightened like butterflies in the stomach due to your caregiving roles?	27(18.4)	37(25.2)	45(30.6)	38(25.9)
My caregiving roles make me feel restless	28(19.0)	36(24.5)	33(22.4)	50(34.0)
Even as I undertake my caregiving roles, I find time to sit at ease and feel relaxed	26(17.7)	26(17.7)	33(22.4)	62(42.2)
As I carry out my caregiving duties, I sometimes feel so restless that it is hard to sit still	17(11.6)	13(8.8)	42(28.6)	75(57.0)
As I carry out my caregiving roles, I get sudden feelings of panic.	68(46.3)	29(19.7)	31(21.1)	19(12.9)
Depression subscale question	3	2	1	0
I still enjoy the things I used to enjoy even as a caregiver	33(22.6)	19(12.9)	38(25.8)	57(38.7)

Anxiety subscale question	Severity Frequency(percentage) N=147			
	3	2	1	0
I can laugh and see the funny sides of life even as I undertake my caregiving duties	28(19.4)	24(16.1)	24(16.1)	71(48.4)
I feel cheerful even as I carry out my caregiving duties	43(29.0)	24(16.1)	28(19.4)	52(35.5)
I feel I have slowed down since I started my caregiving duties	52(35.5)	28(19.4)	5(3.2)	62(41.9)
I lost interest in my appearance since I undertook caregiving roles	14(9.7)	9(6.5)	47(32.3)	76(51.6)
I look forward with enjoyment to things even as I undertake my caregiving roles	43(29.0)	19(12.9)	14(9.7)	71(48.4)
I can enjoy a good book, radio or TV programme even as I undertake caregiving duties	14(9.7)	24(16.1)	47(32.3)	62(41.9)

Prevalence and Extent of Depression in Caregivers of PWC

Of the 147 participants, 33(22.4%) were normal, 66(44.9%) were borderline abnormal and 48(32.7%) were abnormal (depressed), Figure 1.

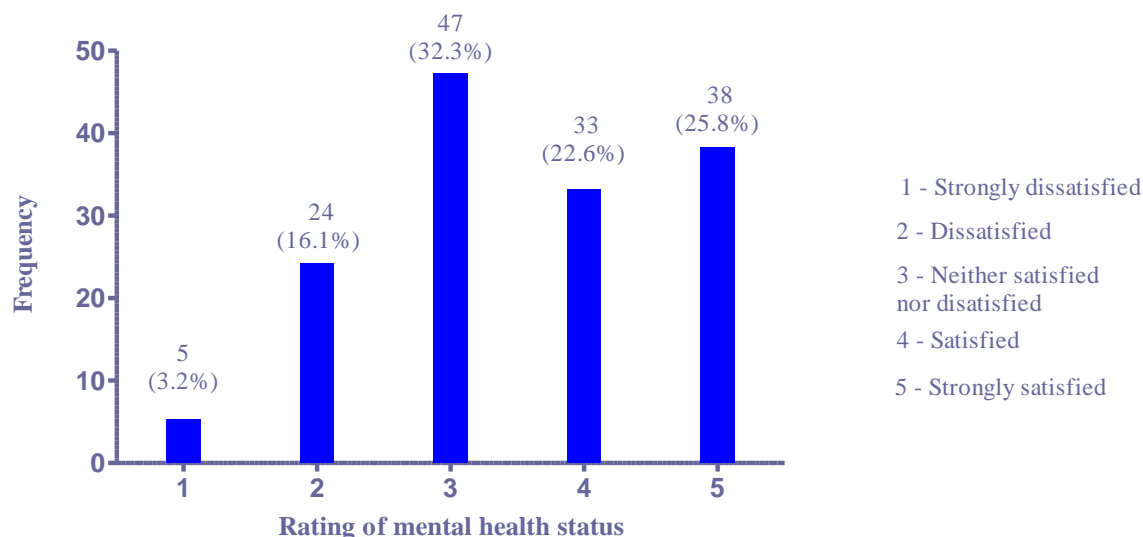
For individual questions on the scale in regards to depression (**Table 2**), ‘I feel I have slowed down since I started my caregiving duties’ had the largest score 3 (nearly all the time) at 52(35.5%). This was followed by ‘I feel cheerful even as I carry out my caregiving duties’ (not at all) and ‘I look forward with enjoyment to things even as I undertake my caregiving roles’ (hardly all the time) at 43(29.0%).

On the other hand, ‘I lost interest in my appearance since I undertook caregiving roles’ had the highest number of participants with a score of 0 (I take it just as much as ever) at 76(51.6%). ‘I can laugh and

see the funny sides of life even as I undertake my caregiving duties’ and ‘I look forward with enjoyment to things even as I undertake my caregiving roles’ followed by 71(48.4%) with a 0 score (as much as always could and as much as I ever did respectively).

‘How would you rate your overall mental health status as a caregiver of a cancer patient?’.

The majority of the caregivers were neither satisfied nor dissatisfied 47(32.3%) with their mental health even as they undertook their caregiving roles, 38(25.8%) were strongly satisfied, 33(22.6%) were satisfied, 24(16.1%) were dissatisfied and 5(3.2%) were strongly dissatisfied with their mental health since taking up caregiving roles to PWC as shown in Figure 2.

Figure 2: Caregivers' Self-rating of Their Mental Health Status Since Taking on Caregiving Roles to PWC

DISCUSSION

Care for the vulnerable members of the community including the sick is of significant importance, especially in ensuring the smooth running of healthcare systems (Raj et al., 2023). It ensures they have their meals, attend hospital visits, feel loved and provides a sense of belonging, subsequently improving treatment outcomes. Caring for the sick improves social bonds and is an important moral and cultural value in many communities [24]. Caregiving, when done at home greatly reduces the healthcare system's burden. This contributes to reducing congestion and the burden of healthcare workers (Determeijer, Leopold, Spijker, Agyemang, & van Vugt, 2023), especially in resource-limited settings with few hospitals and staff. However, providing care to patients with chronic diseases like cancer comes with a lot of challenges, which predispose caregivers to mental health disorders (Albani et al., 2024). In this study, 42(28.6%) of the caregivers of cancer patients had anxiety, with the severity ranging between 11(moderate) to 21(severe) anxiety.

This prevalence is slightly lower than a global pooled prevalence of anxiety of 46.56% in caregivers of patients with cancer, which could be

attributed to the heterogeneity of the studies that were included in the review. This was even higher (52%) in caregivers of cancer patients in Nepal and lower (37.29%) in the United States (Gupta, Hurley, Mangal, Daniel, & Ganti, 2024). In fact, there is a positive association between subjective caregiver burden and anxiety symptoms in informal caregivers. This could be attributed to the use of different study designs in the Nepal study compared to the current study and the fact that only informal caregivers of patients with cancer were included (Sharma et al., 2024). Different tools were also used to measure the anxiety. 56(38.1%) and 49(33.3%) of the caregivers had normal anxiety scores (0-7) or borderline abnormal (mild anxiety) in this study. This implies that the burden of caregiving to cancer patients is too great that only a few survive the constant worry, restlessness, panic and fright associated with it. Many of the participants 68(46.3%) had feelings of panic as they provided care. This could be due to the overwhelming nature of cancer care and the feeling of not doing enough, even after putting in maximum effort (Govina et al., 2019). Many 38(25.9%) worried about their patient's condition and prognosis. In the African setting where cancer is mostly diagnosed in its

advanced stages and therefore a poor prognosis, this worry is almost obvious.

With limited financial resources often hindering obtaining recommended treatment regimens, many cancer patients experience the maximum intensity of signs and symptoms including excruciating cancer pain (Smith et al., 2019), which could increase the worry. Additionally, with many cancer caregivers in Sub-Saharan Africa being informal and therefore having minimal knowledge of the management of signs and symptoms of cancer (Diniz et al., 2018), the real-time experience could cause excessive worry towards the prognosis in their patients. However, even with these effects, a number of the caregivers (75, 57.0%) were never restless and 62(42.2%) still found some time to sit and relax. This is of great importance because it enables them to relieve stress, meditate, decrease tension and worry and improve sleep (Parajuli & Larson, 2024), factors that could protect or improve their anxiety.

Globally, depression affects about 4.4% of adults in the general population (Adjaye-Gbewonyo, Rebok, Gallo, Gross, & Underwood, 2019). However, this study reports a high prevalence of moderate to severe depression (48, 32.7%) and 66(44.9%) for borderline normal. With more stresses and burdens of caregiving, many of the latter may slip into depression. This is slightly higher than the pooled prevalence of clinical depression of 25.14% in caregivers of people with cancer but is within the range of the reviewed studies that used the HADS (Pan & Lin, 2022), but is within the range of Nearly 29% of informal caregivers of elderly patients in India had depression, with depressive symptoms increasing in intensity depending on the length of time spent caregiving (Chakraborty, Jana, & Vibhute, 2023). The results of our study are lower than the 45.15% and 45% prevalence of depression obtained in an Ethiopian (Wassie, Azagew, & Bifttu, 2022) and Ugandan (Katende & Nakimera, 2017) cross-sectional study. This could be attributed to the fact that systematic random sampling was

used as compared to the non-probabilistic and snowballing methods used in this study.

Many participants (52,35.3%) felt they had slowed down since taking on caregiving roles, especially with respect to the performance of their own daily needs, 43(29.0%) were never cheerful and never looked forward to enjoying things. This is not surprising since the caregivers devote an average of 12.35 ± 1.194 hours of the day giving care. Spending more time caregiving is a risk factor for depressive symptoms (Chakraborty et al., 2023). The extensive demands of caregiving limit caregivers' opportunities in almost all spheres of life. Formally employed caregivers may lose their jobs. Self-employed caregivers will miss business time, decreasing their daily profits and may eventually have to close their businesses (Castor, Bolin, Hansson, Landgren, & Kristensson Hallstrom, 2020), especially for Small and Medium Enterprises (SMEs). On the other hand, 62(41.9%) were not at all slowed down by their caregiving roles. This could be due to the sharing of caregiving tasks with other members of the family, reducing time spent caregiving. These could also have developed coping mechanisms like meditation and praying, seeking emotional support and accepting reality to reduce the burden of caregiving (Parajuli & Larson, 2024). The use of positive coping strategies is known to create resilience in individuals, therefore improving their mental health outcomes (Macia, Barranco, Gorbena, Alvarez-Fuentes, & Iraurgi, 2021).

Self-rating of caregivers' mental health status gave different results than anticipated. Many caregivers (47, 32.3%) were neither satisfied nor dissatisfied whereas 19.3% were dissatisfied with their mental health status since taking on caregiving roles. Our findings are slightly higher than those of (Long et al., 2020), who determined a 16.5% prevalence of self-reported psychological stress in caregivers of people with cancer. This was correlated with being female, having obtained above secondary education and being the provider of both financial and direct support to the patient (Long et al., 2020). This

finding is consistent with that of (Taniguchi et al., 2022) who reported a self-reported deterioration in mental health in informal caregivers of COVID-19 patients (Taniguchi et al., 2022).

This study had a number of limitations. Its cross-sectional design limited the ability to determine the likely causes and projection of anxiety and depression in the caregivers of people with cancer over time. Also, the convenience sampling used to recruit study participants and then snowballing for more participants is not generalizable and therefore cannot be used to draw a substantial conclusion in other settings. Furthermore, patient characteristics including stage of cancer, treatment regimen and cancer type were not considered yet these could directly or indirectly affect the mental health of the caregivers.

Practical Implications

The results of this study are an indication of the need for targeted interventions, programs and policies aimed at creating mental health resilience in caregivers of people with cancer. These may include workshops and training on stress management, self-care and other coping strategies. Healthcare institutions are encouraged to devote some resources of cancer care to the care for the mental health of caregivers of cancer patients since their well-being is a significant contributor to that of their patients. With many caregivers being at the borderline for both anxiety and depression, there is a need for regular screening of the caregivers to enable early diagnosis and treatment before exacerbation of the symptoms.

CONCLUSION

The results of the study show a high prevalence of anxiety and depression in caregivers of people with cancer. Many are not on the borderline of the two conditions and a continuing burden due to their caregiving roles could push them to anxiety or depressive disorders. Several caregivers experienced feelings of panic and were worried about the progression and prognosis of their

patients' cancer, increasing their anxiety scores. However, they still found some time to sit at ease and relax. Depression scores were mostly increased by the feelings of slowing down and cheerlessness experienced by the caregivers whereas still maintaining interest in their appearance, laughing and seeing the funny side of life and looking forward with enjoyment decreased the scores. Most caregivers had either average or above-average satisfaction with their mental health. For better support to cancer patients and therefore improvement in treatment outcomes, there's a need to regularly screen their caregivers for anxiety and depression. Different interventions including training, formulation of policies and programs aimed at fostering resilience are encouraged. This quite neglected group of support providers make a great contribution to the smooth running of cancer healthcare systems.

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