

Caring for patients with cancer in Qatar: the impact on the mental health of voluntary caregivers

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Abstract

Background: Cancer is a disease where both patients and caregivers receive and provide care, respectively, for extended periods of time, and often amidst challenging personal conditions. In Qatar, with cancer as the third largest cause of death, cancer care has become a national healthcare priority. However, the needs of informal caregivers who are experiencing various psychological issues such as anxiety, depression, and stress are overlooked due to the demanding and time-consuming nature of the care of patients with cancer.

Aim: The aim of this research is to identify the prevalence of psychological issues (anxiety, depression, and stress) among informal Arabic-speaking caregivers of patients with cancer.

Methodology: The research utilized the Arabic version of Depression Anxiety Stress Scales (DASS-21) test to measure the anxiety, depression and stress among caregivers of patients with cancer. A total of 128 participants participated in the study.

Results: According to DASS 21, the results revealed that the overall prevalence of depression, anxiety, and stress in this study was found to be 57%, 52%, and 50%, respectively.

Conclusion: The research concluded that voluntary care givers of patients with cancer were found to experience high levels of depression, anxiety and stress.

Key words: Voluntary Caregivers, Cancer, Mental Health, Depression, Anxiety, Stress, Clinical Nurse Specialist.

Introduction

Cancer is among the leading causes of morbidity and mortality worldwide. In Qatar, cancer is the third leading cause of death [1-3].

Therefore, it is expected to witness an increase in the number of informal caregivers for this group of patients. Both global and local statistics suggest there is a growing need for multi-dimensional approaches to care for patients and voluntary caregivers.

Cancer has a major impact on the physical, emotional, and practical aspects of the lives of patients and their caregivers [4]. Informal caregivers, such as family members and friends provide crucial support to patients with cancer throughout the trajectory of treatment. However, this support is often unrecognized [5]. The multifaceted support provided by such caregivers often changes according to their patients' medical and emotional needs [6].

For instance, during the diagnosis phase and the initial stages of the disease, such caregivers provide psychological support for coping with uncertainty and fear. In addition, they accompany their patients to hospitals for diagnostic and treatments purposes [6]. During advanced stages they provide assistance, personal care, self-care, and emotional support as well [6].

Despite advances in diagnosis and treatment, and improved prognosis, the diagnosis and treatment of cancer continues to be a major stress inducer among patients and their families, presenting patients and their caregivers with numerous questions to be answered, issues to be solved, and emotions to be faced. However, informal caregivers often put their concerns aside and neglect their own health and needs, to focus on supporting their loved ones who are suffering from cancer [7, 8].

As cancer management becomes more complex, aspects of caring for patients with cancer have expanded from treatment monitoring and symptoms management, to emotional and financial support, and assistance with personal care. As a result of increased responsibilities, caregivers often experience increased psychological distress, and display stressful behaviors [9,10].

Studies have also shown that family caregivers of terminally-ill cancer patients experience mental health problems and deterioration of health-related quality of life [8]. The same group of researchers along with other nurse researchers suggest the need for culturally appropriate caregiver support programs to decrease the impact on the family caregiver [8,11].

In terms of emotional, mental, and psychological dimensions, anxiety and depression are the most common problems experienced by caregivers [7]. A better understanding of informal care givers' experiences during the illness' trajectory is essential to develop and design effective supportive cancer care services to reduce care givers' distress [7,11].

Distress is common among patients with cancer and their families, and manifests itself in different aspects of psychological, spiritual and financial needs [12]. Both patients with cancer, and caregivers, seek psychological support during their cancer journeys [12].

In this regard, Clinical Nurse Specialists play a key role in addressing various aspects of patients' and their families' distress. In Qatar, the Clinical Nurse Specialists at Hamad Medical Corporation's (HMC) National Center for Cancer Care and Research (NCCCR) – a tertiary hospital dedicated to the treatment and care of cancer – identify and coordinate the needs, and address the prevalence of the psychological impact on caregivers of patients at the hospital.

Prevalence of mental disorders were investigated in Qatar in primary health care settings [13,14]. Although informal caregivers' psychological impact has received considerable attention in recent literature, to the best of the authors' knowledge this topic has not been investigated among caregivers for patients with cancer, in Qatar.

The aim of this study is to investigate the prevalence of the psychological impact (anxiety, depression, and stress) of caring for patients with cancer, among caregivers of patients who are receiving cancer care services in Qatar.

Methodology

A descriptive cross-sectional methodology was used to guide this study in a cancer hospital in Qatar. The study was approved by the NCCCR research committee and HMC's Medical Research Center (MRC).

The participants of this study are informal caregivers of patients with cancer. Informal caregivers are identified in this study as family and non-family caregivers. Family caregivers include parents, spouses, children, aunts, uncles and cousins. Non-family caregivers are identified as friends and neighbors.

The inclusion criteria include (1) Qatari and non-Qatari, (2) Arabic-speaking from different cultural backgrounds, (3) eighteen years and above, (4) informal caregivers of hospitalized and non-hospitalized cancer patients attending ambulatory services at a cancer hospital. For the purpose of this study, we excluded paid caregivers such as housemaids, private attenders and private nurses.

A convenient sampling method was utilized. Data collection started from December 2017 and ended by July 2018. The sample size is 258 participants. 128 participants agreed to complete the survey. Response rate was 50%. The participants were caregivers of cancer patients such as aunts, uncles and cousins, friends and neighbors.

Informal caregivers of hospitalized and non-hospitalized patients were invited to participate. The caregivers who volunteered were considered eligible if he/she met the inclusion criteria. Informed consent was taken prior to participation in the study.

The caregivers were assessed for depression, anxiety, and stress by using DASS 21 scale, Arabic version. DASS 21 is a valid and reliable self-reported instrument which was developed to measure three negative emotional states of depression, anxiety and stress [15].

Statistical Analysis

All statistical analyses were done using SPSS version 21 and Minitab version 17.3. Descriptive statistics are presented as either mean ± standard deviation or median with the 25th to 75th percentiles for continuous variables, and numbers with percentages for categorical variables. Graphs and bar charts were used to analyze the data and to find out the prevalence of depression, anxiety and stress, among the sample in the present study.

Results

Results according to DASS scoring 21 showed that the overall prevalence of depression, anxiety, and stress in this study was found to be 57%, 52%, and 50%, respectively. Seventeen (13%) respondents had mild depression, 19 (15%) had moderate depression, and 19 (15%) had severe depression. Similarly, 9 (7%) respondents had mild anxiety, 22 (17%) had moderate anxiety, and 31 (24%) had severe anxiety. Twenty-nine (23%) respondents had mild stress, 24 (19%) had moderate stress, and 12 (9%) had severe stress. Our study reveals a high level of depression, anxiety and stress among caregivers of cancer patients (Refer to Figures 1 and 2).

Figure 1: Prevalence of Depression, Anxiety and Stress (by DASS Scoring System)

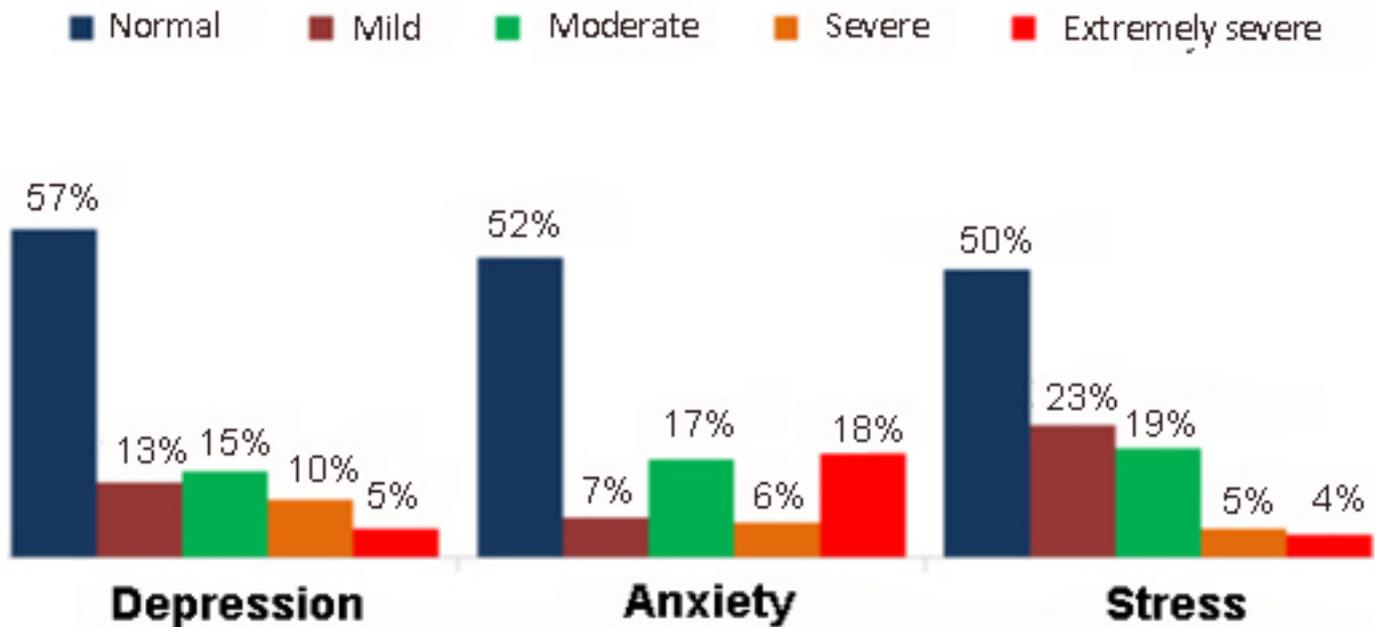
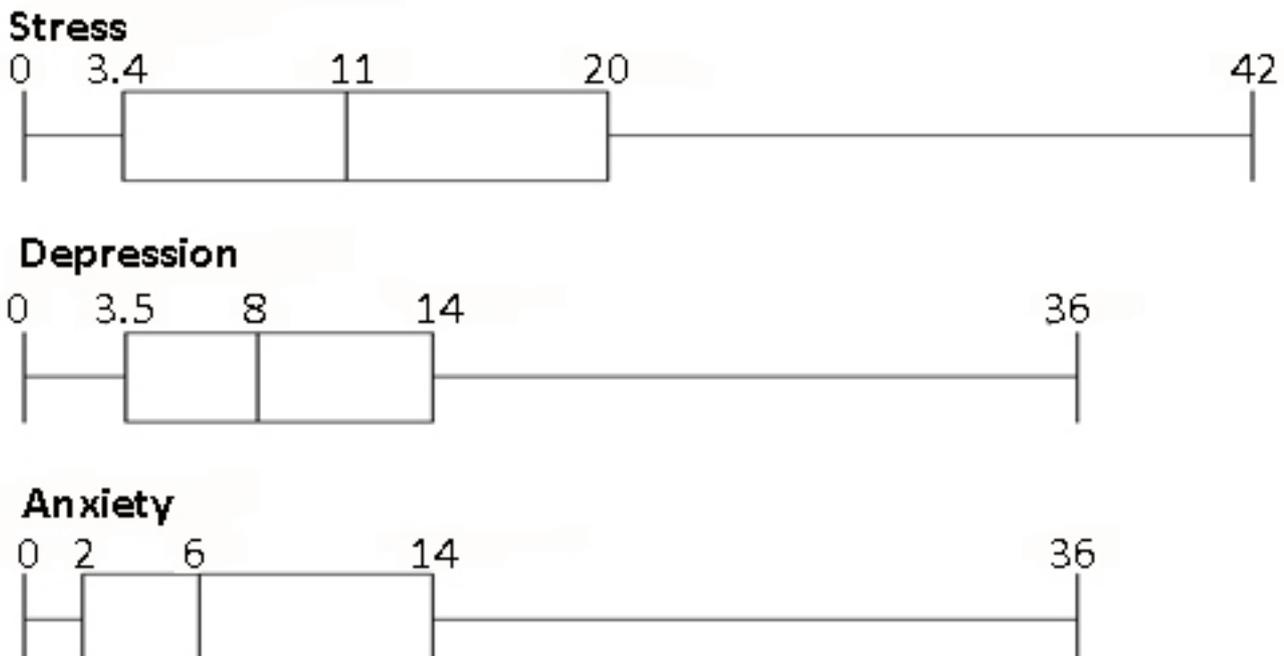


Figure 2: Boxplot illustrating frequency distribution of the observed DASS-21 scores of the Mental Health categories Questionnaires. (box plot shows similar group distribution and median values)



Discussion

The results corroborate existing findings on the universality of depression, anxiety, and stress among caregivers of patients with cancer, across cultures. The prevalence of anxiety, depression and stress varied in the literature.

In a study conducted in Korea, caregivers were found to have high depression 67% and very high depression 35% [16]. The Korean researchers identified the caregivers' level of depression by using the Beck Depression Inventory (BDI). The BDI evaluates 21 symptoms of depression that represent cognitive-affective and somatic aspects of depression. The same tool was used by a research team from Turkey to assess the depression levels of 60 caregivers of cancer patients [11]. They concluded that 71% had serious symptoms of depression.

A recent research report on the topic in the US investigated the effect of caregiving on the emotional health of caregivers of cancer patients. According to that study caregivers of adults – on average – reported emotional stress of 3 on a 5-point scale – around 4 out of 10 (36%) caregivers found their caregiving experience to be highly stressful, while 28% reported moderate emotional stress [17].

Evidence clearly identified this as an area of high priority that needs the attention of multiple stakeholders, including health care professionals, educators, program planners, decision-makers and policy-makers.

Despite the fact that diagnosis of malignant disease has distressing effects on patients and their caregivers, little is written in the health or social science literature about caregivers' experience in the GCC countries, especially given the differences in cultural attitudes and responses.

In Qatar and other GCC countries, the family is the center of society; members of a family see caring for sick relatives as an obligation and duty, irrespective of the age of the patient. The absence of care-homes and hospices are an indication and tangible extension of this outlook. This automatically amplifies the stress and anxiety of caregivers who know that caring for a relative with a terminal or life-threatening illness, is not a choice; it is their responsibility.

In two Saudi Arabian studies, the effect on informal caregivers when caring for relatives with cancer was evaluated by psychiatrists. Researchers compared terminally ill cancer patients and their caregivers with chronically ill patients and their caregivers. The study reported that the former group had higher levels of depression and anxiety, as well as poorer quality of life scores compared with the latter group [18].

A more recent Saudi study exploring the prevalence of depression, anxiety and stress in family members (n=353) providing constant attendance to hospitalized patients, reported similar findings [19]. Results indicated 80% of

family caregivers experienced at least one of the three symptoms. Overall, high levels of depression were noted in 73% of those surveyed; anxiety levels were also high in 76.5% of participants; stress levels were reported to be high in 61.5%.

Results from both studies emphasize the need for caregiver support. Investigators suggested the need for different types of support provided to both patients and their family caregivers, including psychological, spiritual, social and physical [18,19].

Understanding variables associated with informal caregiver anxiety, stress and depression can lead to optimal referral and supportive care services and inform the tailoring of interventions to address those variables.

Limitations:

For the purpose of this study, paid caregivers were excluded. Also, it was limited to Arabic-speaking caregivers. Additionally, the study was further limited to informal caregivers who are accompanying their patients to the cancer hospital only. Furthermore, it was based on subjective screening tools, and also there may be a recall bias. Therefore, the result cannot be generalized to all caregivers of patients with cancer.

Conclusion

The DASS-21 assessed the negative emotions of depression, anxiety and stress and it showed that there is a high prevalence of anxiety followed by stress among caregivers of patients with cancer. Informal caregivers' support is overlooked internationally.

The findings of this study suggest that the prevalence of depression, anxiety and stress is common among caregivers of patients with cancer, in Qatar. We anticipate that the results will increase awareness about the psychological disorders that caregivers' experience and its impact on caregivers as well as on patients. In addition, it will help health care professionals and policy-makers to consider new ways of thinking about careful interventions that need to be provided to caregivers of patients with cancer attending the cancer hospital, in order to support them better and reduce their levels of depression, anxiety and stress.

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References

- 1 Al-Kindi, S., Abu Zeinah, G., and Hassan, A. (2012). Pattern of Hospitalization of patients with cancer in an acute palliative care setting: Qatar experience. *American Journal of Hospice and Palliative Medicine* 30(1), 25-28.
- 2 Brown, R., Kerr, K., Haoudi, A., Darzi, A. (2012). Tackling cancer burden in the Middle East: Qatar as an example. *Lancet Oncology* 13. Retrieved from [http://dc8qa4cy3n.scholar.serialssolutions.com.ezproxy.lib.ucalgary.ca/?sid=google&auinit=R&aulast=Brown&atitle=Tackling+cancer+burden+in+the+Middle+East:+Qatar+as+an+example&id=doi:10.1016/S1470-2045\(12\)70461-8&title=Lancet+oncology&volume=13&issue=11&date=2012&spage=e501&issn=1470-2045](http://dc8qa4cy3n.scholar.serialssolutions.com.ezproxy.lib.ucalgary.ca/?sid=google&auinit=R&aulast=Brown&atitle=Tackling+cancer+burden+in+the+Middle+East:+Qatar+as+an+example&id=doi:10.1016/S1470-2045(12)70461-8&title=Lancet+oncology&volume=13&issue=11&date=2012&spage=e501&issn=1470-2045)
- 3 World Health Organization. (2012). World Health Statistics: Demographic and Socioeconomic Statistics. Retrieved from http://who.int/gho/publications/world_health_statistics/EN_WHS2012_Full.pdf
- 4 Park, B., Kim, S. Y., Shin, J. Y., Sanson-Fisher, R. W., Shin, D. W., Cho, J., & Park, J. H. (2013). Prevalence and predictors of anxiety and depression among family caregivers of cancer patients: a nationwide survey of patient-family caregiver dyads in Korea. *Supportive Care in Cancer*, 21(10), 2799-2807.
- 5 Livingston, P. M., Osborne, R. H., Botti, M., Mihalopoulos, C., McGuigan, S., Heckel, L., & Williams, M. (2014). Efficacy and cost-effectiveness of an outcall program to reduce carer burden and depression among carers of cancer patients [PROTECT]: rationale and design of a randomized controlled trial. *BMC health services research*, 14(1), 1.
- 6 Romito, F., Goldzweig, G., Cormio, C., Hagedoorn, M., & Andersen, B. L. (2013). Informal caregiving for cancer patients. *Cancer*, 119(S11), 2160-2169.
- 7 Lambert, S. D., Girgis, A., Lecathelinais, C., & Stacey, F. (2013). Walking a mile in their shoes: anxiety and depression among partners and caregivers of cancer survivors at 6 and 12 months post-diagnosis. *Supportive Care in Cancer*, 21(1), 75-85.
- 8 Song, J., Shin, D. W., Choi, J. Y., Kang, J., Baik, Y. J., Mo, H., ... & Kim, E. J. (2011). Quality of life and mental health in family caregivers of patients with terminal cancer. *Supportive Care in Cancer*, 19(10), 1519-1526.
- 9 Kim, Y., Ryn, M., Jensen, R. E., Griffin, J. M., Potosky, A., & Rowland, J. (2015). Effects of gender and depressive symptoms on quality of life among colorectal and lung cancer patients and their family caregivers. *Psycho-oncology*, 24(1), 95-105.
- 10 Valeberg, B. T., & Grov, E. K. (2013). Symptoms in the cancer patient—Of importance for their caregivers' quality of life and mental health? *European Journal of Oncology Nursing*, 17(1), 46-51.
- 11 Sahin, Z., & Tan, M. (2012). Loneliness, depression, and social support of patients with cancer and their caregivers. *Clinical journal of oncology nursing*, 16(2), 145.
- 12 Dempsey, L., Orr, S., Lane, S., & Scott, A. (2016). The clinical nurse specialist's role in head and neck cancer care: United Kingdom National Multidisciplinary Guidelines. *The Journal of Laryngology & Otology*, 130(S2), S212-S215.
- 13 Bener A, Ghuloum S, Abou-Saleh MT. Prevalence, symptom patterns and comorbidity of anxiety and depressive disorders in primary care in Qatar. *Soc Psychiatry Psychiatric Epidemiol.* 2012; 47(3): 439–446.
- 14 Ghuloum S., Bener A., Abou-Saleh M.T., et al. (2011). Prevalence of mental disorders in adult population attending primary health care setting. *JPakMedAssoc.* 61(3), 216–221.
- 15 Osman, A., Wong, J. L., Bagge, C. L., Freedenthal, S., Gutierrez, P. M., & Lozano, G. (2012). The depression anxiety stress Scales—21 (DASS-21): further examination of dimensions, scale reliability, and correlates. *Journal of clinical psychology*, 68(12), 1322-1338.
- 16 Rhee, Y., Yun, Y., Park, S., Shin, D., Lee, K., Yoo, H., Kim, J., Kim, S., Lee, R., Lee, Y., Kim, N. (2008). Depression in Family Caregivers of Cancer Patients: The Feeling of Burden As a Predictor of Depression. *American society of clinical oncology*, 26(39).
- 17 AARP-Family Caregiving & National Alliance for Caregiving. (2020). Caregiving in the U.S. Retrieved from https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf
- 18 Sherif, T., Jehani, T., Saadani, M. & Andejani, A.W. (2001). Adult oncology and chronically ill patients: comparison of depression, anxiety and caregiver's quality of life. *EMHJ - Eastern Mediterranean Health Journal*, 7 (3), 502-509, 2001
- 19 Al-Zahrani R, Bashihab R, Ahmed AE, Alkhodair R, Al-Khateeb S. The prevalence of psychological impact on caregivers of hospitalized patients: the forgotten part of the equation. *Qatar Med J.* 2015;2015(1):3.