Prevalence and determinant of psychological impact on informal caregivers in extended care centers, Jeddah 2019

Hanaa Juharji[1*], Laila Alshareef [2], Yahya Makhdoom[3]

[1,2]Resident, [3]Consultant, [1] The Joint Program of Family Medicine, Jeddah, Saudi Arabia

Corresponding author: Yahya Makhdoom
Email: kymakhdoom@gmail.com

Abstract

Introduction: The caregivers of extended-care-patient have many responsibilities, and they are staying for a long period in the extended medical care facilities, which may lead to the psychological impact on them. Such a psychological impact varies from emotional stress to significant depressive symptoms and anxiety.

The main purpose of the study is to recognize and address the psychological status of the caregivers and its determinants, to highlight the magnitude of the prevalence, and identify the determinants of psychological impact on caregivers in private extended care patients.

Materials and Methods: This study is a cross-sectional study design, which was conducted in the International Extended Care Centre (IEC), and the Extended Care Center affiliated to King Fahd General Hospital (KFGH). Both of them are located in Jeddah city, Saudi Arabia. The total sample size was 42 informal caregivers. Depression Anxiety Stress Scale DASS-21 (Arabic version) questionnaire was used for data collection.

Results and conclusion: The most common Psychological disorder was anxiety, 59.5%, followed by depression 55%, and stress 38%. In preparing informal caregivers in extended care facilities to cope with this extraordinary mission, it is recommended to conduct more studies in different parts of Saudi Arabia with larger sample size focusing on factors that have a psychological impact on caregivers. Moreover, in order to intervene early to detect and manage the caregivers and improve their quality of life, a detailed plan should be created to reduce these psychological impacts.

Keywords: Informal caregivers, Psychological impact, Prevalence, determinant, Extended care center**,** DASS 21.

Introduction

In the Kingdom of Saudi Arabia (KSA) diseases of longevity or diseases of civilization are increasing. During 2017, the prevalence rate of diabetes in KSA was 17.75% for the age group 20-79 years. In 2016, KSA's obesity prevalence rate among adults was 35.4%, also one of the highest in the Middle East & North Africa (MENA) region. The prevalence of hypertension among adults in 2015 in KSA stood at 23.3% also one of the highest in the GCC region. This rise in prevalence rates of chronic diseases (diabetes, coronary problems, and obesity-related illnesses), and the rise in life expectancy of the Saudi population, as a result of this urbanization, will impact disease patterns this, in turn, will change the type of healthcare services required.[1]

The age distribution of all developed countries, as well as many developing countries, including Saudi Arabia, is shifting toward older ages[2]. The life expectancy in Saudi Arabia is expected to extend from the current level of 73.1 years and 76.1 years for males and females respectively to 78.4 and 81.3 by 2050[2]. This increase in life expectancy is expected to create demand for extended care facilities.[2]

Patients in the extended care facilities require specialized health care services, which usually provided by professional caregivers with support from informal caregivers. The informal caregivers are usually relatives to the patient who needs extended medical care services. Informal caregivers who are carrying responsibilities for which they are not usually prepared may decrease competency of the caregivers, lead to unpredicted events, and may affect the quality of life of the caregivers.

These unfamiliar responsibilities and staying for a long time in the extended medical care facilities may have a psychological impact on extended-care-patients as well as on both professional and informal caregivers. Such a psychological impact varies from emotional stress to significant depressive symptoms and anxiety. A cross-sectional survey was conducted in Singapore on a total of 350 primary caregivers with relatives seeking treatment at a tertiary psychiatric hospital from the year 2014 to 2015 showed that 18.3% of primary caregivers had symptoms of depression while 12.7% had symptoms of anxiety[3]

Several cross-sectional studies have been carried out on caregivers in different areas of Saudi Arabia in the past few years. One study was conducted in the Psychiatric Hospital in Jeddah city in 2017, among caregivers of mental illness patients showing that tension, worrying, and urging were higher among them.[4] Another study was carried in Riyadh on caregivers of elderly patients to determine socioeconomic, psychological, and physical consequences facing them and found that most of them suffer from musculoskeletal pain and they have everyday needs such as providing home blood pressure measurement.[5] A third study was conducted in the Rehabilitation Centers in Riyadh at Majmaah, and Shaqra cities on 100 health-care givers revealed that the prevalence of the somatic disorder, anxiety, and depression range from 1 to 3% and factors such as nationality, gender, educational level, and income were not significantly associated with them.[6] One more study was conducted at the King Abdulaziz Medical City (KAMC) in Riyadh, among a total of 353 of caregivers of hospitalized patients to estimate the prevalence of psychological impact of the caregivers. According to the study, approximately 8 out of 10 caregivers have at least one psychiatric disorder[7]. The psychological impact of this study (stress, depression,

and anxiety) was ranging from 61.5% 72.8% and 76.5% respectivel.[7]

Definitions

1. Anxiety is an emotion characterized by feelings of tension, worried thoughts, and physical changes such as increased blood pressure and fast heart rate.[6]
2. Depression causes feelings of sadness and a loss of interest in activities once enjoyed. It can lead to a variety of emotional and physical problems and can decrease a person's ability to function at work and home.[8]
3. An acute stress reaction is a psychological condition arising in response to a terrifying or traumatic event, or witnessing a traumatic event that induces a strong emotional response within the individual.[9]
4. Extended-care-patient: In this study, we define extended-care-patient is someone who needs continuous medical care in a hospital to survive; such care includes assisted respiratory care, rehabilitation, and dialysis.
5. A caregiver is a person who is responsible for delivering direct care to someone of their relatives, friends, and others.

The current knowledge shows that a large number of caregivers are suffering from various psychiatric disorders.[3,7,10,11] Despite that, research on psychological symptoms among caregivers is lacking in Saudi populations.

Mother of a friend of mine was suffering from a chronic disease, which causes her disability and confines her for long periods in the hospital. She stays all this time with her mother solacing and taking good care of her. During the meantime, she suffered from psychological disturbances, which have adversely affected her quality of life. This story has encouraged the researchers to do this research on caregivers who stay for long periods with their sick loved ones. They are self-denial people who sacrifice their lives for others.

The impact of psychological distress on caregiving can affect the caregiver as well as the patients.

We need to recognize and address the mental status of the caregivers and its determinants and the different strategies need to be studied to reduce this burden such as improving patients' quality of life, Coping Strategies, and psychosocial support.

Aim of the Study

The main purpose of the study is to recognize and address the psychological status of the caregivers and its determinants, to highlight the magnitude of the prevalence, and identify the determinants of psychological impact on caregivers in private extended care patients.

Objectives

1. To estimate the prevalence of psychological impact on caregivers of patients in the Extended Care Centers in Jeddah 2018.
2. To identify the determinants of the psychological impact on caregivers of patients in the Extended Care Centers in Jeddah 2018.

Materials and Methods

Study design

This study was a cross-sectional study design.

Study Area

This study was conducted in the International Extended Care Centre (IEC) and in the Extended Care Center affiliated to King Fahd General Hospital (KFGH), which are located in Jeddah city, Saudi Arabia. The IEC Center is a private hospital for extended patient care and long term therapy. IEC is a long-term care hospital focusing on acute and critical care for patients requiring lengthy hospitalization stay. Other core services include assisted respiratory care, rehabilitation, and dialysis. Essential clinical support services include nursing; pharmacy, clinical nutrition, and occupational therapy are also provided. IEC is accredited by the Saudi Central Board for Accreditation of Healthcare Institutions (CBAHI) and endorsed by Saudi government hospitals of immense repute.[20] The Extended Care Center affiliated to KFGH is 60 beds center. It provides its services through the medical and nursing staff, physiotherapist and physiotherapists, as well as doctors and consultants of King Fahd Hospital when needed.

Study Population and Criteria

All informal caregivers of patients hospitalized in the International Extended Care Centre (IEC) and in the Extended Care Center affiliated to King Fahd General Hospital (KFGH) during the study period (January 2019) were the target study population.

Sample Size and Technique

The target population was all informal caregivers present during the time of the study. The expected number of patients who were staying for three weeks or more was 125 patients. For each patient, we took at least one caregiver. Out of the 125 patients, only 42 had informal companion caregivers. All 42 caregivers were included in the study.

Data Collection and Technique

A modified questionnaire was used in this study. This questionnaire consists of two parts. The first part is the modified part where all the demographical information was included, and the second part contains questions to assess psychological impact. The second part is the Depression Anxiety Stress Scale DASS-21 (Arabic version), which was used without any modification. The (DASS-21) is a self-report questionnaire developed in the English language and used for assessment and evaluation of the emotional states of depression, anxiety, and stress.[7] The DASS-21 uses a four-point scale (0–3). The highest score of DASS-21 is 42.

The DASS-21 has been developed in the Arabic language and used for the evaluation of negative emotional states of depression, anxiety, and stress in the Arabic-

speaking population.[8] According to the authors; the Arabic DASS-21 is a reliable and valid tool for the evaluation of psychological symptoms. The Arabic DASS-21 has a good level of internal consistency. Cronbach's alpha coefficients for the three scales of depression, anxiety, and stress are 0.93, 0.90, and 0.93, respectively.

After taking the verbal informed consent, the researchers interview all the participants in the patient's room by using the questionnaire. The interview was carried out at the period from 11:00 AM to 2:00 PM during the weekdays. The caregivers who were not available at the time of the study period were contacted by phone to answer the questionnaire.

Study Variables

The independent variables in this study were Age, Gender, Nationality, Marital status, Educational level, Income level, Relation to the patient (family member or not), Occupation (employed or not) and Length of stay. The dependent variables were the Psychological status (anxiety, depression, and stress)

Data Entry and Analysis

The statistical products and services solution program (SPSS) version 21was used for data entry and analysis. Measuring the measures of central tendency, and dispersion summarized qualitative data. Qualitative data were summarized as frequency and percentages. The t-test and Chi-square test were used to assess the impact of predictor's variables. P value < 0.05 was considered as an indication for statistical significance.

Ethical considerations

The researchers obtained permission from the Directorate of Health Affairs Institutional Review Board Committee (IRB), Jeddah, and from International Extended Care Center and KFGH Administrations.

Results

The mean age of the 42 caregivers was 37±13.5 years. The median age was 33 years; it ranges from 16 years to 65 years. The median income of 27 caregivers who reported their income was 2200 SR, the minimum and the maximum of income was ranged from 1000 up to 18000 SR respectively. Two-third of the caregivers (67%) were relatives to the patients, 67% were females, and 62% holding Saudi nationality. Two-third (66.7) holding secondary school degree or less, nearly one half (45%) were married and the majority 86% reported that they are healthy and do not suffer from any chronic illness (Table 1).

Regarding the psychiatric impact of long staying in an extended care facility on informal caregivers, in general, the results of this study show that 17 (40.5%) of the caregivers were healthy and did not have any psychiatric illness. Only two (5%) having anxiety, eight (19%) having both depression and anxiety, and 15 (36%) having depression, anxiety, and stress all together. (Fig. 1)

Regarding specific psychiatric impact (depression, anxiety, and stress), 25 (59.5%) of the caregivers having anxiety, 23 (55%) having depression, and 16 (38%) having stress. Nine (36%) of those who had anxiety having severe anxiety, 7 (28%) having moderate anxiety, 7 (28%) having extremely severe anxiety and the rest 2 (8%) having mild anxiety. Thirteen (57%) of those who had depression having moderate depression, 5 (22%) having mild depression, 4 (17%) having extremely severe depression and the rest 1 (4%) having severe depression. Seven (44%) of those who had stress having mild stress, 4 (25%) having moderate stress, 3 (19%) having extremely severe stress and the rest 2 (13%) having severe stress (Figure 2). Regarding the factors, which may have a psychological impact on caregivers, family relationship, and nationality have a statistically significant relationship with all psychiatric illnesses (depression, anxiety, and stress) (P-value< 0.05).

Sex of the caregivers and marital status are less likely to have a statistically significant impact on depression, anxiety, or stress (P-value >0.05) (Table 2).

Table 1: Demographic characteristics of informal caregivers in extended care centers, Jeddah, 2019.

Characteristics	Total N (%)
Nationality	
Saudi	26 (62)
Non-Saudi	16 (38)
Marital Status	
unmarried	23 (55)
married	19 (45)
Gender	
Male	14 (33)
Female	28 (67)
Relationship	
Relative	28 (67)
Nonrelative	14 (33)
Education	
< Secondary	14 (33)
Secondary	14 (33)
Diploma	3 (7)

Bachelor	7 (17)
PhD	4 (10)
Chronic disease	
No	36 (86)
Yes	6 (14)

Table 2: Factors which may have a psychological impact on caregivers in extended care centers, Jeddah, 2019

Characteristics	Depression N (%)	Anxiety N (%)	Stress N (%)	Total N (%)
Nationality				
Saudi	18 (69)^{S}	19 (73)^{S}	13 (50)^{S}	26 (62)
Non-Saudi	5 (31)	6 (38)	3 (19)	16 (38)
Relationship				
Relative	19 (68)^{S}	20 (71)^{S}	14 (50)^{S}	28 (67)
Nonrelative	4 (29)	5 (36)	2 (14)	14 (33)
Marital Status				
unmarried	12 (52)^{NS}	14 (61)^{NS}	7 (30)^{NS}	23 (55)
married	11 (58)	11 (58)	9 (47)	19 (45)
Gender				
Male	6 (43)^{NS}	7 (50)^{NS}	5 (36)^{NS}	14 (33)
Female	17 (61)	18 (64)	11 (3)	28 (67)

S, NS chi-square test show the significant relationship and no significant relationship, respectively.

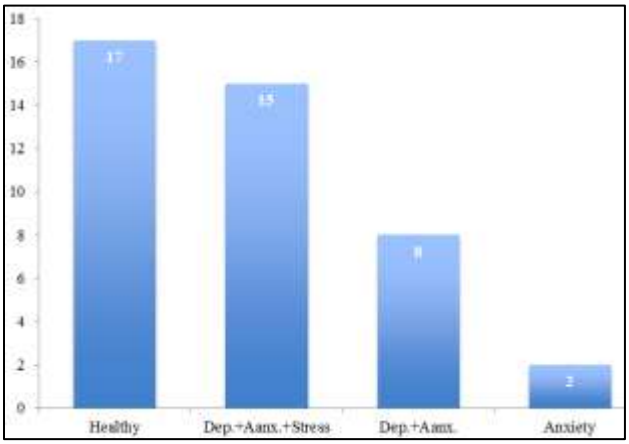

Fig. 1: Freqency destription of Informal caregivers according to psychraitic symptoms

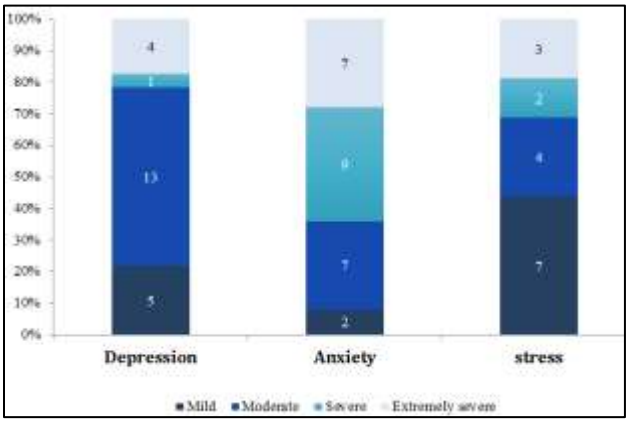

Fig. 2: frequency distribution of psychiatric illnesses accoding to severity

Discussion

In this study, we aim to determine the prevalence of depression, anxiety, and stress in caregivers of patients admitted to extended care facilities for a long period in Jeddah City and identify factors related to the presence psychological disorders. The majority, two-thirds of the caregivers were female which dissimilar to other studies conducted in different parts of the Kingdom Saudi Arabia.[4,6] in a study conducted at Rehabilitation Centers in Riyadh, Saudi Arabia, the majority (75%) of the participants were males.[6] In another study which was conducted at a psychiatric hospital in Jeddah, males constituted more than one-half (55%) of the caregivers.[4] In contrast, 53.8% of the caregivers were female in a study conducted at one of the largest tertiary care hospitals in Riyadh and (52.7%) were female in another study where participants were recruited from different hospitals and primary care clinics in Riyadh.[5,7] This discrepancy in sex distribution of caregivers may be due to differences in the study locations.

The high prevalence rate of psychiatric disorders; depression, anxiety, and stress reported in the current study is close and comparable to the prevalence rates found in other national and international studies. The highest prevalence rate for depression was 94%, 80% for anxiety, and 62% for stress. [7,10,11,21] One study conducted in Riyadh reported a very low prevalence of psychiatric disorders.[6]

The association between specific demographic characteristics of caregivers is well documented; however, in one study which was conducted in Malaysia, no significant association was observed between gender, duration of care, and depression[22].

In the current study, the family relationship has a statistically significant relationship which is similar to a Systematic Review conducted by Johnson, C. C., et al. in 2019.[11]

Sex of the caregivers and marital status are less likely to have a statistically significant impact on either depression, anxiety, or stress

Conclusions

In conclusion, the psychological burden of informal caregivers in the current study was associated with specific demographic factors, namely nationality and family relationship.

The most common Psychological disorder was anxiety, 59.5%, followed by depression 55%, and stress 38%.

Limitations

This study has several limitations; the sample size was small; the study was conducted at two extended care centers excluding other centers such as military rehabilitation center and National Guard

Recommendations

In preparing informal caregivers in extended care facilities to cope with this extraordinary mission, it is recommended to conduct more studies in different parts of Saudi Arabia with larger sample size focusing on factors that have a psychological impact on caregivers. Moreover, in order to intervene early to detect and manage the caregivers and improve their quality of life, a detailed plan should be created to reduce these psychological impacts.

Acknowledgement

We would like first to thank our family for their continuous support, love, and comfort they have given us during our research.

Thanks go out to our supervisor, Dr.Yahya Makhdoom, and our statistical advisor Dr. Bakr Bin Sadiq for all their help and guidance.

We want to express our sincere gratefulness to the CEO of International Extended Care Centre Dr. Adel Makhdoom, who accommodated us in their facilities.

Also, we would like to thank the informal caregivers for their time and patience and the office staff member of the extended care centers for allowing us to do the research and facilitate our work.

Lastly, we would like to express our gratitude to the staff members of the Joint Program doctors for supporting us during the research period.

Conflict of Interest: None.

References

1. KSA-Healthcare-Overview-ThePulse-8th-Edition.pdf>.
2. Kinsella K, Velkoff VA. Life expectancy and changing mortality. *Aging Clin Exp Res* 2002;14(5):322-32.
3. Jeyagurunathan A, Sagayadevan V, Abdin E, et al. Psychological status and quality of life among primary caregivers of individuals with mental illness: a hospital based study. *Health Qual Life Outcomes* 2017;15(1):106. doi: 10.1186/s12955-017-0676-y
4. Alzahrani SH, Fallata EO, Alabdulwahab MA, et al. Assessment of the burden on caregivers of patients with mental disorders in Jeddah, Saudi Arabia. *BMC Psychiatry* 2017;17(1):202. doi: 10.1186/s12888-017-1368-1
5. Alshammari SA, Alzahrani AA, Alabduljabbar KA. The burden perceived by informal caregivers of the elderly in Saudi Arabia. *J Family Community Med* 2017;24(3):145-50. doi: 10.4103/jfcm.JFCM_117_16
6. Alzahrani M, Alfahaid F, Almansour M. Prevalence of generalized anxiety disorder and major depression in health-care givers of disabled patients in Majmaah and Shaqra cities, Kingdom of Saudi Arabia. *Int J Health Sci (Qassim)* 2017;11(3):9-13.
7. Al-Zahrani R, Bashihab R, Ahmed AE. The prevalence of psychological impact on caregivers of hospitalized patients: The forgotten part of the equation. *Qatar Med J* 2015;2015(1):3. doi: 10.5339/qmj.2015.3
8. Ranna Parekh MD, M.P.H. What Is Depression? : American Psychiatric Association; 017 [updated January 2017. Available from: https://www.psychiatry.org/patients-families/depression/what-is-depression accessed 2019.
9. Reynaud E, Guedj E, Trousselard M, et al. Acute stress disorder modifies cerebral activity of amygdala and prefrontal cortex. *Cogn Neurosci* 2015;6(1):39-43. doi: 10.1080/17588928.2014.996212
10. Okewole A, Dada MU, Ogun O. Prevalence and correlates of psychiatric morbidity among caregivers of children and adolescents with neuropsychiatric disorders in Nigeria. *Afr J Psychiatry (Johannesbg)* 2011;14(4):306-9. doi: http://dx.doi.org/10.4314/ajpsy.v14i4.8
11. Johnson CC, Suchyta MR, Darowski ES. Psychological Sequelae in Family Caregivers of Critically-Ill Intensive Care Unit Patients: A Systematic Review. *Ann Am Thorac Soc* 2019 doi: 10.1513/AnnalsATS.201808-540SR
12. Lunenfeld B. An Aging World--demographics and challenges. *Gynecol Endocrinol* 2008;24(1):1-3. doi: 10.1080/09513590701718364
13. Trovato F, Lalu NM. Contribution of cause-specific mortality to changing sex differences in life expectancy: seven nations case study. *Soc Biol* 1998;45(1-2):1-20.
14. Yanagishita M, Guralnik JM. Changing mortality patterns that led life expectancy in Japan to surpass Sweden's: 1972-1982. *Demography* 1988;25(4):611-24.
15. Crimmins EM, Hayward MD, Saito Y. Changing mortality and morbidity rates and the health status and life expectancy of the older population. *Demography* 1994;31(1):159-75.
16. Lefroy RB. Extended care: medical care of the elderly disabled. *Aust Physician* 1978;7(3):259-65.
17. Kanasi E, Ayilavarapu S, Jones J. The aging population: demographics and the biology of aging. *Periodontol 2000* 2016;72(1):13-8. doi: 10.1111/prd.12126
18. Karlin NJ, Weil J, Felmban W. Aging in Saudi Arabia: An Exploratory Study of Contemporary Older Persons' Views About Daily Life, Health, and the Experience of Aging. *Gerontol Geriatr Med* 2016;2:2333721415623911. doi: 10.1177/2333721415623911
19. Affairs H. Long Term and Extended Care Center Medical Cities, AlRiyadh: Ministry of National Guard, 2019 [updated 02-Sep-2014 01:19 PM. Available from: http://www.ngha.med.sa/English/MedicalCities/AlRiyadh/MedicalServices/Pages/LongTerm.aspx accessed 5/21/2019 2019. <NEC_International_extended_care_centre_EN.pdf>.
20. Miyashita M, Narita Y, Sakamoto A, et al. Care burden and depression in caregivers caring for patients with intractable neurological diseases at home in Japan. *J Neurol Sci* 2009;276(1-2):148-52. doi: 10.1016/j.jns.2008.09.022
21. Mulud ZA, McCarthy G. Caregiver Burden Among Caregivers of Individuals With Severe Mental Illness: Testing the Moderation and Mediation Models of Resilience. *Arch*

Psychiatr Nurs 2017;31(1):24-30. doi: 10.1016/j.apnu.2016.07.019

How to cite this article: Juharji H, Alshareef L, Makhdoom Y. Prevalence and determinant of psychological impact on informal caregivers in extended care centers, Jeddah 2019. *J Prev Med Holistic Health* 2019;5(1):32-7.