Sohag University Sohag Medical Journal Faculty of Medicine

Review Article

Health Related Quality of Life of Family Caregivers of Dependent Elderly

Foad Metry Atia Yousef[1], Esraa Aly[2], Rasha Abd El-Hameed Ali[1]

1- Department of Public Health and Community Medicine, Sohag University
2- Department of Family Medicine, Sohag University

Abstract:

The world has witnessed unprecedented decrease in mortality rates over the past century, which led to dramatic increase in the global population. As a result of the dramatic decrease in the worldwide fertility rates and the progressive increase in the life span, the world witnesses a sustained change in the age distribution of the global population in a phenomenon called population aging. Elderly population is expected to double reaching 2.1 billion by 2050. Elderly are more susceptible to have NCDs which are a major determinant for functional disability. Disabled elderly are those who can't perform one or more of basic ADLs with their own. There is a universal recent trend wherein patients are discharged earlier from hospitals. This creates a great worldwide increasing need for family caregiver. Family caregivers face many challenges and reported higher burden and lower HRQoL scores than their non-caregiver counterparts. Many strategies should be implemented to alleviate stress and improve HRQoL of family caregivers.

Keywords: Elderly, Family Caregivers, Health Related Quality of Life.

DOI: 10.21608/smj.2023.234839.1411

*Correspondence : docesra2aly@gmail.com

Received:07 September 2023
Revised: 17 October 2023
Accepted: 26 September 2023
Published: 01 January 2024

Introduction

The world has witnessed unprecedented decrease in mortality rates over the past century, which led to dramatic increase in the global population. In the 21st century medical and technological improvements and developments achieved a great progress in treating acute conditions, controlling chronic conditions and extending the life span of elderly. Although, increasing life expectancy is one of the great achievements of mankind; but aging carries great challenges not only for the social, economic, and healthcare systems but for individuals and their families too. (1)

Population aging

As a result of the dramatic decrease in the worldwide fertility rates and the progressive increase in the life span, the world witnesses a sustained change in the age distribution of the global population in a phenomenon called population aging. Population aging is the process wherein older adults represent a large proportion of the entire population. (2)

Elderly population aged 60 years and older who represent 1 billion in 2020, are expected to increase reaching 1.4 billion in 2030. By 2050, the global elderly populations aged 60+ will increase by two folds (2.1 billion). Moreover, the share of the oldest elderly (aged 80+) is expected to increase by three folds between 2020 and 2050 reaching 426 million. (3)

Developing vs. developed countries

although the shift in population distribution towards older ages has begun in developed countries, but at the present times, low- and middle-income countries (LMIC) are experiencing the greatest demographic transition of populations aging at an unprecedented speed. (4)

In 1980, 56% of elderly aged 60+ lived in the developing world. In 2017, the developing countries were home to more than two thirds of the world's older adults. Between 2017 and 2050, elderly aged 60+ are expected to double, from nearly 650 million to 1.7 billion in the developing countries. On the other hand, it is expected for the more developed countries to witness less than 40 % increase in the proportion of elderly over that same period (from 310 million elderly in 2017 to 427 million in 2050). [5]

The situation in Egypt

Egypt is going through a rapid demographic transition. Between 2020 -2050, the share of elderly aged 60+ is projected to increase by more than twice from 8.4 million representing 8% of the whole population reaching 22 million representing 14%. While, the proportion of those aged 15-24 will increase only 1.5 times through the same period. [6]

Although, population aging can be considered as a great achievement for human kind, but it also carries a lot of challenges for the society to improve the functional ability of older people, provide the appropriate care for those who require ongoing care services, and to support and maintain an optimal health related quality of life (HRQoL) for both elderly and their caregivers. [1]

Health status of the elderly

With the emergence of the era of population transition and the improvement of health care ideas, the goal is to enhance the ability of older persons to lead a healthy life. WHO illustrated that the main indicators of elderly health evaluation should be through assessment of the capability to live independently not merely death and disease indicators. [3]

Elderly are more susceptible to have chronic diseases especially non communicable diseases (NCDs) that represent main risk factor for functional disability. Functional disability can be defined as the failure to perform one or more of the basic activities of daily living (ADL) - ambulating, dressing, feeding self-hygiene, continence and toileting- without assistance. Functional disability is followed by abundant effects as higher mortality rates, increase needs for health care, impaired HRQoL and increase costs of care. It is also a direct indicator of the need for daily assistance. [7]

Regarding chronic diseases, most of elderly (85%) have at least one chronic health problem, in addition, 60% have two or more chronic problems. Having chronic diseases specially multi-morbidity is a direct cause to disability which increase in severity with increasing the number of diseases, and a leading cause for impairment of HRQoL of both elderly and caregivers. [8]

There is a universal recent trend wherein patients are discharged earlier from hospitals. In addition, the increase in life expectancy of elderly with many chronic illnesses, this spotlights the exhausting role of family members and friend to care and support their loved elderly at home. [9]

Definition of caregiver: *Informal/family caregiver*

can be defined as the person who provides unpaid care for the person in need based on the social relations between them. Informal caregivers may be a family member as parents, grandparents, siblings, children, cousins, spouses, in-laws, and other relatives. In some cases, informal caregivers could be neighbors or friends. [10]

The International Alliance of Carer Organizations (IACO) – an international organization that supports the caregivers worldwide, located in Washington DC- tried to take into account different circumstances across different countries, so it defined informal caregiver as persons providing at least 24 hour of unpaid care per week over an average duration of five years.[11]

Informal caregiving involves two categories; primary caregivers and secondary caregivers. Those who provide most of the care tasks, spend most of the time with the elderly, usually lives at the same home with the care-recipients or near to them and is perceived by the person in need for care and by themselves as having main responsibility for care are called primary caregivers. They report most of the strain of caregiving either emotional, financial or physical strain. [12]

On the other hand, the secondary caregivers perform some caregiving tasks but are not considered as the principal individual responsible for rendering care for the elderly. They usually don't share home with the care-recipient but provide some financial support and transportation to health centers, etc. [13]

Formal caregivers

are usually professional health care workers as nurses with special training to perform services specially that can't be carried out by formal caregivers and they get paid for this. Families of severely ill or severely dependent elderly usually combine formal with informal care. Depending on the severity and specialty of the illness, formal caregivers are usually in demand alongside informal caregivers for home care services.(14)

Definition of HRQoL

WHO (1997) defined quality of life (QoL) as someone's perception of his position in life depending on the cultural environment wherein he lives and depending on his goals, expectations, principles and values. It is a multidimensional concept, encompasses individuals' physical, emotional health, psychological state, level of independence, social achievements and spiritual state. QoL is dynamic; its perception changes with changing priorities and beliefs of the individual.(15)

QoL involves health as an important domain in its definition. HRQoL is the effect of medical disorder or treatment on individual's physical, emotional, and social well-being. The HRQoL measurement therefore attempts to capture QoL in the context of one's health and illness. In addition, HRQoL also involves an individual's satisfaction about his life, general health and well-being. (16) It was found that caregivers of chronically diseased elderly has impaired HRQoL scores in the whole domains. (17)

Determinants of caregiver outcomes and HRQoL

Several theoretical models have been used to explore caregiver outcomes. They theorized that the increase and the severity of care demands represent a great challenge for caregivers. Caregivers react with these challenges by adapting or care strategies modifications, such as asking for help and joining support groups to decrease their strain. Failure to adapt to overcome caregiving challenges is accompanied by more negative outcomes .(18)

The stress process model (SPM) is considered as an organizing framework explaining caregiving outcomes and its multidimensional determinants. The process model involves three major domains: the source of stress like caring tasks, the mediators of stress as social support and coping skills, and the outcomes of stress as burden and impaired HRQoL. (19)

Caregiving outcomes are affected by contextual variables as socio-demographic factors of the patient and caregivers and caregiving-related factors, Primary stressors are directly correlated with patients and disease severity, secondary stressors including challenges that originate from the caregiving role but do not directly related to providing care as financial strain, work conflicts. Interventions and social support are expected to decrease the perceived strain. (20)

researchers have illustrated that with the increase in age, caregivers will be more liable to experience higher levels of stress and poorer HRQoL compared to younger caregivers. This can be explained by the better physical health of the younger caregivers. Moreover, younger caregivers have more informal support networks, and usually can get included in many fields of work which provides more steady incomes compared to older counterparts. (21)

Its known worldwide that women are the main persons responsible for informal care for their family, including the elderly. Female caregivers represent 75%- 81% of all caregivers of elderly. Daughters are more likely to render care for their dependent parents. On the other hand, mlaes usually participate in the caregiving in absence of female relatives. (22)

Gender has a great association with caregiving outcomes. Because of facing more caregiving stressors, having lower financial resources and having poorer physical power, female caregivers report lower HRQoL scores compaired to men. Moreover, Several studies have reported a great sense of responsibility, emotional and social bonds between female caregivers and their care-recepients which can lead to more emotional stress and affect their emtional HRQoL. (23)

Employment of caregivers may affect their caregiving role and their HRQoL. Insufficient time and energy may be the cause. Caregiving tasks may make the caregiver unable to commit to his work schedule or tasks leading to job turnover which will be followed by more stress. (24)

Its doubtless that financial resources are a corenerstone in the journy of disease and the journy of caregiving. Yihedego and colleagues reported that caregivers with lower monthly

income reported significant lower HRQoL scores in comparison to those with higher income. [25]

Caring for dependent elderly in the home-based setting usually requires increased demands like home modifications, such as wheelchair ramps, safety bars, and durable medical equipment, beside medications costs. It has been reported that most of caregivers (80%) report financial stress for caregiving process. [26]

The health status of caregivers is difficult to be assessed as if it is affected as a result of caregiving tasks or the caregiver had the health problem before caregiving time. Researchers reported that it is difficult for the caregiver to take care of dependent elderly while the caregiver himself is chronically ill. Moreover, this can worsen his health condition. [25]

Regarding duration of care, some investigators found that the increase in the caregiving duration is associated with more depressive sympoms and poorer HRQoL among caregivers, although others find no relation. This conflict may be explained by the difference in cping abilities among caregvers which make them differently adapt the situation with the time. [27, 28]

QoL of both caregivers and care-recipients is strongly affected by the relationship between them. Positive relations are considered as social resources that help caregivers to deal with caregiving stresses in better way. On the other hand, negative relationships as marital conflicts, impair individuals' well-being and makes them more sensitive toward stressful situations. [29]

It's not unexpexted to find that caregivers knowledge regarding elderly disease progression has a major role in decreasing stress and improving their HRQoL by decreasing the fear of the unknown. It's the health care providers who should provide caregivers with the proper information about their relatives case, tell them the prognosis in a simple way and try to explain their role. [30]

Caregiver can experience different types of burden for the hardships associated with caring for chronically diseased elderly. Depression among caregivers has been illustrated to be closely correlated with the burden they perceive. In addition, caregiver burden has been found to be negatively associated with caregiver quality of life. [25]

Presence of secondary or assisstant caregiver can lower the perceived stress among caregivers. This is may be due to the fact that being the main caregiver means taking the main responsibility for caregiving, which is a very distressful job. Family caregivers are in a deep need to support from relatives and healthcare providers during hospitalization. Caregivers with restricted social relations or dissatisfied with support experience more stress. [31]

Most family caregivers lack knowledge and often feel unready to perform caregiving tasks, especially those who provide more medically complex tasks such as changing catheter bags, providing wound care, or supervising complicated medication regimens. Caregivers who deals directly with the health care system often receive inadequate support from health care providers and frequently feel frgotten and unrecognized by the health care system. [32]

The severity, type, number and duration of the illness have been identified as predictors of caregiver stress. Multiple researches reported presence of association between deteriorated functional status of elderly and higher stree levels of caregivers.There is a relationship between a high level of caregiver burden and caring for persons with mental or severe illnesses or persons with multi-morbidity cause higher stress to caregivers and cause more impairment to their HRQoL. [33]

Coping strategies are specific behavioral and psychological adaptation mechanisms performed by caregivers to minimize the effect of stressful situations. There are different coping mechanisms such as emotion-focused, problem-focused and dysfunctional coping. Some coping strategies can be harmful and may increase burden and depression. [34]

Another important determinant in the SPM is social support. Happiness and psychological health are greatly determined with a supportive social network of relatives and community. Social support can involve informational, emotional, and instrumental support which has a significant reversed correlation with caregiver distress. [35]

Strategies to decrease caregiver burden: Societies must take actions to encourage and support caregivers of elderly and improve their HRQoL as:

1. Proper management of chronic diseases specially multi-morbidity to improve functional capacity of elderly and decrease level of dependence.
2. Health insurance agencies should cover the caregiving tasks which in most cases are performed by caregivers' own time and resources.
3. Establishing proper education programs and training for caregivers.
4. Online support and information on daily aspects of care giving.
5. Telephone and email support groups for caregivers.
6. Providing psychological counseling or psychiatric intervention for stress management. For example, forming support groups, providing home visits.
7. Trying to provide more suitable working conditions for caregivers allowing them to care for their loved ones and decreasing their stress as adopting telecommuting that enable caregivers to work at home while caring for their family member.
8. Extensive research to assess caregiving obstacles and improve their HRQoL. [9]

Summary

As people continue to age, elderly individuals are living longer with many chronic illnesses and hospitals discharge patients earlier, more family members and friends are caring for loved ones at home. Unpaid caregivers often operate in a reality of inadequate support systems and lack of information and skills. They need guidance, someone to listen to them, and a place they can share concerns, express needs,and receive answers. National strategies, local and workplace policies,and other supportive systems must be established to decrease caregiver burden. [36]

References:

1. Lunenfeld B, Stratton P. The clinical consequences of an ageing world and preventive strategies. Best practice & research Clinical obstetrics & gynaecology. 2013;27(5):643-59. Epub 2013/04/02. doi: 10.1016/j.bpobgyn.2013.02.005. PubMed PMID: 23541823; PubMed Central PMCID: PMCPMC3776003.

2. UN. World Population Ageing 2020 Highlights: Living arrangements of older persons. United Nations Department of Economic and Social Affairs, Population Division. 2020.

3. WHO. Ageing and health 2022 [cited 2022 7/8]. Available from: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health.

4. WHO. 10 facts on ageing and health 2017 [cited 2022 16/9]. Available from: https://www.who.int/news-room/fact-sheets/detail/10-facts-on-ageing-and-health.

5. UN. World Population Ageing 2017 - Highlights. United Nations, Department of Economic and Social Affairs, Population Division 2017.

6. UNFPA. The rights and wellbeing of older persons in Egypt. 2021:1-3.

7. Fong H. Disability incidence and functional decline among older adults with major chronic diseases. BMC geriatrics. 2019;19(1):323. Epub 2019/11/23. doi: 10.1186/s12877-019-1348-z. PubMed PMID: 31752701; PubMed Central PMCID: PMCPMC6873710.

8. Hosseini S, Zabihi A, Jafarian Amiri S, Bijani A. The Relationship between Chronic Diseases and Disability in Daily Activities and Instrumental Activities of Daily Living in the Elderly %J Journal of Babol University Of Medical Sciences. Journal of Babol University of Medical Sciences. 2018;20(5):23-9. doi: 10.18869/acadpub.jbums.20.5.23.

9. Carmeli E. The invisibles: unpaid caregivers of the elderly. Frontiers in public health. 2014;2:91. Epub 2014/08/08. doi: 10.3389/fpubh.2014.00091. PubMed PMID: 25101257; PubMed Central PMCID: PMCPMC4104642.

10. de Klerk M, de Boer A, Plaisier I. Determinants of informal care-giving in various social relationships in the Netherlands. Health & social care in the community. 2021;29(6):1779-88. doi: 10.1111/hsc.13286. PubMed PMID: 33477204; PubMed Central PMCID: PMCPMC8596597.

11. Tur-Sinai A, Teti A, Rommel A, Hlebec V, Lamura G. How Many Older Informal Caregivers Are There in Europe? Comparison of Estimates of Their Prevalence from Three European Surveys. International journal of environmental research and public health. 2020;17(24). doi: 10.3390/ijerph17249531. PubMed PMID: 33352669; PubMed Central PMCID: PMCPMC7767284.

12. Gorostiaga A, Etxeberria I, Salaberria K, Kortabitarte I. Primary and Secondary Caregivers of People with Dementia (PwD): Differential Patterns and Implications for Psychological Support. Healthcare (Basel, Switzerland). 2022;10(6). doi: 10.3390/healthcare10061102. PubMed PMID: 35742153; PubMed Central PMCID: PMCPMC9222750.

13. D'Ippolito M, Aloisi M, Azicnuda E, Silvestro D, Giustini M, Verni F, et al. Changes in Caregivers Lifestyle after Severe Acquired Brain Injury: A Preliminary Investigation. BioMed Research International. 2018;2018:2824081. doi: 10.1155/2018/2824081.

14. CDC. Understand Your Audience: Older Adults,Tips for Caregivers 2021 [cited 2022 15/9]. Available from: https://www.cdc.gov/healthliteracy/developmaterials/audiences/olderadults/tipsforcaregivers.html.

15. Barcaccia B. Definitions and domains of health-related quality of life. Outcomes Assessment in End - Stage Kidney Disease - Measurements and Applications in Clinical Practice Bentham Science Publisher; 2013. p. 12-24.

16. Martin MP, McEntee ML, Suri Y. Caregiver Quality of Life: How to Measure It and Why. American Journal of Health Promotion. 2021;35(7):1042-5. doi: 10.1177/08901171211030142f.

17. Costa A, Lopes M, Campanharo C, Batista R, Okuno M. Quality of life and burden of caregivers of elderly people. Texto & Contexto Enfermagem. 2021;29.

18. Shubair A. Determinants of caregiver burden along informal caregivers looking after older adults with Alzheimer's disease in Saudi Arabia [Doctoral Dissertation]. ThinkIR: The University of Louisville's Institutional Repository, Electronic Theses and Dissertations: University of Louisville; 2022.

19. Judge K, Menne H, Whitlatch C. Stress Process Model for Individuals With Dementia. The Gerontologist. 2009;50:294-302. doi: 10.1093/geront/gnp162.

20. Kim H, Chang M, Rose K, Kim S. Predictors of caregiver burden in caregivers of individuals with dementia. Journal of advanced nursing. 2012;68(4):846-55. doi: 10.1111/j.1365-2648.2011.05787.x. PubMed PMID: 21793872.

21. Duggleby W, Williams A, Ghosh S, Moquin H, Ploeg J, Markle-Reid M, et al. Factors influencing changes in health related quality of life of caregivers of persons with multiple chronic conditions. Health and Quality of Life Outcomes. 2016;14(1):81. doi: 10.1186/s12955-016-0486-7.

22. Sharma N, Chakrabarti S, Grover S. Gender differences in caregiving among family - caregivers of people with mental illnesses. World journal of psychiatry. 2016;6(1):7-17. doi: 10.5498/wjp.v6.i1.7. PubMed PMID: 27014594; PubMed Central PMCID: PMCPMC4804270.

23. Kim Y, Mitchell H, Ting A. Application of psychological theories on the role of gender in caregiving to psycho-oncology research. Psycho-oncology. 2019;28(2):228-54. doi: 10.1002/pon.4953. PubMed PMID: 30488661; PubMed Central PMCID: PMCPMC6377312.

24. Longacre M, Valdmanis V, Handorf E, Fang C. Work Impact and Emotional Stress Among Informal Caregivers for Older Adults. The journals of gerontology Series B, Psychological sciences and social sciences. 2017;72(3):522-31. doi: 10.1093/geronb/gbw027. PubMed PMID: 27048567; PubMed Central PMCID: PMCPMC5926991.

25. Yihedego E, Aga F, Gela D, Boka A. Quality of Life and Associated Factors Among Family Caregivers of Adult Cancer Patients in Addis Ababa, Ethiopia. Cancer management and research. 2020;12:10047-54. doi: 10.2147/cmar.S266416. PubMed PMID: 33116861; PubMed Central PMCID: PMCPMC7569250.

26. Liu Z, Heffernan C, Tan J. Caregiver burden: A concept analysis. International journal of nursing sciences. 2020;7(4):438-45. doi: 10.1016/j.ijnss.2020.07.012. PubMed PMID: 33195757; PubMed Central PMCID: PMCPMC7644552.

27. Zhong Y, Wang J, Nicholas S. Social support and depressive symptoms among family caregivers of older people with disabilities in four provinces of urban China: the mediating role of caregiver burden. BMC geriatrics. 2020;20(1):3. doi: 10.1186/s12877-019-1403-9. PubMed PMID: 31898490; PubMed Central PMCID: PMCPMC6941264.

28. Chakraborty R, Jana A, Vibhute V. Caregiving: a risk factor of poor health and depression among informal caregivers in India- A comparative analysis. BMC Public Health. 2023;23(1):42. doi:

10.1186/s12889-022-14880-5. PubMed PMID: 36609312; PubMed Central PMCID: PMCPMC9817300.

29. Huo M, Kim K. Lasting impact of relationships on caregiving difficulties, burden, and rewards. Journal of Social and Personal Relationships. 2023;40(1):288-310. doi: 10.1177/02654075221118095.

30. Refaat A, Hassan E, Mohamed N. Relationship between Caregiving Burden, knowledge and stigma of Caregivers Caring for Older Adults with Alzheimer disease %J Egyptian Journal of Health Care. Egyptian Journal of Health Care. 2021;12(2):332-44. doi: 10.21608/ejhc.2021.153171.

31. Mohammed A, Elmawla D, Abd Elhameed S, Elhameed A. Relationship between Caregiving Burden and Health Status of Elderly Patients with Parkinson's Disease. Journal of Nursing and Health Science. 2022;9(1):47-59. doi: 10.9790/1959-0901024759.

32. Lilly MB, Robinson CA, Holtzman S, Bottorff JL. Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada. Health & social care in the community. 2012;20(1):103-12. doi: 10.1111/j.1365-2524.2011.01025.x. PubMed PMID: 21851447.

33. Tabootwong W, Kiwanuka F, Vehviläinen-Julkunen K, Turunen H. Factors Associated with Anxiety and Depression among Family Caregivers of Critically Ill Elderly Patients: A Systematic Review. International Journal of Caring Sciences. 2022;15(1):87.

34. Hawken T, Turner-Cobb J, Barnett J. Coping and adjustment in caregivers: A systematic review. Health psychology open. 2018;5(2):2055102918810659. doi: 10.1177/2055102918810659. PubMed PMID: 30450216; PubMed Central PMCID: PMCPMC6236498.

35. Akosile CO, Banjo TO, Okoye EC, Ibikunle PO, Odole AC. Informal caregiving burden and perceived social support in an acute stroke care facility. Health and Quality of Life Outcomes. 2018;16(1):57. doi: 10.1186/s12955-018-0885-z.

36. Zarit SH, Femia EE. A future for family care and dementia intervention research? Challenges and strategies. Aging & mental health. 2008;12(1):5-13. doi: 10.1080/13607860701616317. PubMed PMID: 18297475.