# **ORIGINAL RESEARCH**

# Who are the elder's caregivers in Jordan: A cross-sectional study

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#### ABSTRACT

Aging is expected to be a priority health problem in Jordan because of accelerating number of this age group. Aging and dependency in performing daily activities are highly interrelated, especially in the presence of disabling health problems. Caring of elders group is a challenge health and social issue. Family members in Jordan provide elders with caregiving in their preferable living place. There is inadequate studies that describe who are the elders' caregiver in Arab or in Jordan community. The objective of this study was to describe the characteristics of elder's caregivers in Jordan context. A cross sectional descriptive study was conducted between October 2013 and February 2014. A convenience sample of Jordanian caregivers (n = 489) was recruited from health care center in Amman during follow-up health visits for their ill relatives. A self report questionnaire was used to collect data about socio-demographic characteristics of caregiver, caregiver's health, and additional data about care recipient. The majority of the sample were women (86.2%, n = 422). Women exhibited various undesirable life style practices, and they reported that they had diagnosed of different health problems. Women provide caregiving assistance for very long duration. It is recommended to extend the health follow up for caregiver in addition to elders' themselves. Training, education, and support caregiving program is encouraged for caregivers to continue their role with minimum suffering and to avoid negative physical, emotional, and social caregiving consequences.

Key Words: Caregiver, Home care, Jordan, Women

#### **1. INTRODUCTION**

Caregiver is the person who supports and assists disabled person or provides care for elders.<sup>[1]</sup> Caregiver performs holistic wide range of caring tasks to meet the physical, emotional, economic, and social recipient's needs.<sup>[2]</sup> Chronic diseases which are mainly age-related health problems have a major psychological and social impact on the patients themselves in addition to their families, especially in presence of disability and functional dependency.<sup>[3]</sup> Department of statistics in Jordan indicates that there was an increasing number of chronic diseases that are age related. About 12% of disabilities were found among Jordanian elders population. The physical disability is the most common type affects this age group.<sup>[4]</sup>

For disabled elders, the inability to perform the Basic Activities of Daily Living (BADL) and the Instrumental Activities of Daily Living (IADL) lead to identify elder as care dependent person.<sup>[1]</sup> In Jordan, elders with long-term care needs, and disabled people, rely exclusively on family to provide assistance.<sup>[5]</sup> The family caregiving role in Jordan is driven by religious instructions social values, customs and traditions,<sup>[6]</sup> additionally Akroosh, in 2005,<sup>[7]</sup> documented the

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importance elders for Jordanian families because they are the source of wisdom, leadership, and for conservation of customs, and traditions. Therefore, In contrast to developed countries, in the developing countries, the co-residence of elders with children is commonest arrangement for elders.<sup>[8]</sup> However because of change in societal context in Arab countries such as migration, urbanization, and participation of women in the workforce, institutionalize disabled relatives in long term nursing home could be a solution for such a problem.<sup>[8,9]</sup> In Jordan, there are nine registered elders' nursing homes who are affiliated by the Ministry of Social Development,<sup>[10]</sup> these nine homes are funded by private and charity sector, and none of them is governmental. However, similar to Arab countries there is shortage in elder nursing care institutions.<sup>[11]</sup>

In general, institutionalize elder in long term nursing homes is not an acceptable choice not only for Jordanian population, but globally.<sup>[12]</sup> The negative consequences of institutionalization of elders in long term nursing homes on family members and on elders were well documented.<sup>[13, 14]</sup> For Egyptian caregiver, placing frail elder in nursing homes was to relieve from caregiving burden.<sup>[9]</sup> It was recommended to encouraging intergenerational home based long-term care for elder and disabled relatives to minimize the need for institutionalization in nursing homes,<sup>[15]</sup> to improve their quality of life.<sup>[14]</sup> One important strategic goal for National Council for Family Affair was to support family ties and strengthen the intergeneration bond between elders and young age population.<sup>[6]</sup>

Family members in developing and well developed countries are the major source of support and caring for elder disabled people.<sup>[8]</sup> The multiple social roles of Jordanian women in addition to caregiver role inside family context cannot be ignored.<sup>[16,17]</sup> In international, regional and Jordanian studies, caregiving duties are performed by women.<sup>[9,18,19]</sup> In a Jordanian study targeted 568 worker women, 54% of the sample were caregivers for family member, additionally, the women's health and their feeling of happiness are affected by daily work demands and the caregiving load thus place them to be vulnerable to psychosomatic symptoms and stressors.<sup>[17]</sup> The purpose of this paper is to describe the characteristics of the caregiver within the Jordan context, and to describe their roles and duties for care recipients.

#### 2. METHODS

A cross sectional survey was conducted in one health care center in Amman between October 2013 and February 2014. A convenient sample of 489 caregivers was recruited. A selfreport questionnaire was used: socio-demographic characteristics of the caregivers, socio-demographic characteristics if the care recipient, and health status of the caregivers were areas of interest to the researcher in this study.

Caregivers and care recipients were provided by sufficient information regarding the purpose and the procedure of the study before signing the consent forms. In case of cognitive incapability in care recipient, caregivers were asked to sign consent on behalf of their relatives. A group of eligible criteria were set as basis for sample selection such as, caregiver should be relative for care recipient, should not receive any money compensation for the provided service; living with care recipient in the same home, and care recipient should be above 60 years old.

This study was approved by the ethics and research committee in the School of Nursing an addition to the ethics committee in the health institution were study was conducted. Researcher used all measures to ensure protection of the women's rights. The data was analyzed using descriptive statistics via SPSS software.

# **3. RESULTS**

The total sample of the study was 489 caregiver, and the vast the majority of caregivers were women (86.2%, n = 422). More than 75% of the sample was below ten level of education, 64% of women were unemployed, and their monthly income was less than 500JDs (705\$). Women considered their income as inadequate (87.9%).

The mean of caregiving duration was 1.5 years, for average of two hours daily. Because the number of women in this study was constituted more than 86.0%, researcher was interested to describe exclusively the women's socio-demographic characteristics, in addition to health related data (see Tables 1 and 2).

Women were in their middle age (M = 49.3), with maximum age of 70 years. Women provided caregiving for more than two and half years, with mean time of four hours (see Table 1). The majority of women were married (46.4%), were daughters (45.0%), or spouses of the care recipients (see Table 2).

**Table 1.** Women's age, caregiving duration, and caregiving daily time (n = 422)

	M (±)	Min	Max
Women's age	49.3 (18)	18	71
Number of family member	4.9	2	14
Duration of caregiving (month)	30.2	12	384
Daily caregiving time (min)	220 (45)	30	560

Items		n	%
Marital status	Single	123	29.1
	Married	272	64.4
	Divorced	16	3.7
	Widower	9	2.1
	Other	2	0.5
	Spouse	112	26.5
Relationship with care recipient	Daughter	190	45.0
	Sister	65	15.4
	Daughter-in-law	48	11.3
	Other relationship	7	1.6
Educational level	Illiterate	50	11.8
	1-6	174	41.2
	7-10	129	30.5
	11-12	54	12.8
	Post high school	13	3.0
	Post graduate level	2	0.5
Job	Employed	152	36.0
	Not employed	271	63.9
Monthly income	$\leq 400$	285	67.5
	$\geq 500$	131	31.0
	Un known	6	1.4
Income adequate	Yes	51	12.0
	No	371	87.9
	No	118	27.9

 Table 2. Socio-demographic characteristics of women

Table 3 represents that about 70% of women (n = 422) perceived their own health as poor and fair, and more than 70% of women sought medical advice on regular basis . The most common type of smoking in 96 smoker women was the water pipe (55%) then the cigarette (40%). Surprisingly, the percentage of second-hand smoke in the non smoker women (n = 326) was (60%). Only 6.1% and 9.7% of women exercise on daily regular basis or have leisure time respectively. Back, neck, and joint pain in addition to headache was reported by around 44% of the women (n = 422). The most common problem reported by women (n = 201) was the sleep problem specifically; interrupted sleep (43.6%) and insomnia (36.8%). Data reveals that about one quarter of women were overweight or obese. One quarter of the sample used to take over-counter-medication excessively for different complains.

Figure 1 presents that the vast majority of women who seek medical advice on regular bases were suffered from cardio vascular diseases (n = 132, 43%). Hypertension, increase cholesterol level, coronary vascular diseases were of common diseases reported by women. Diabetes mellitus, hy-

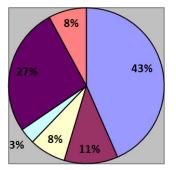
per/hypothyroidism, and osteoporosis are the common health problems in the endocrine and metabolic disorders. Regarding to cancer breast cancer was reported by six women out of ten were received treatment for breast cancer.

Women provided caring for elders with different health problems such as diabetes mellitus and its complications (27%), stroke (20%), heart problems (15%), renal problems including kidney dialysis (7%), different types of cancer (6%), disability because of aging (7%), dementia and Alzheimer (5%), and orthopedic problems including fractures (4%).

Twenty-five women (5.9%) of 422 women provided caring for more than one elder. Women provided different caring tasks on behalf of elders such as their BADL, and IADL. Women provided care in the domain of BADL as in the following percentage; bathing (sponge, tub, or shower) as 76%, cloth dressing (80%), going to toilet (45%), assisting in transfer and mobility (80%), and feeding (32%). Regarding the IADL caregiving activities (91%) of women reported assisting elders in taking their medications.

#### Table 3. Frequencies and percentage of women's life style and other health related data (n = 422)

Items		n		%	
Caregiver's perception of own health	Poor	91	292	21.5	69.1
	Fair	201		47.6	09.1
	Good	76		18.0	
	Very good	38	130	9.0	30.8
	Excellent	16		3.7	
Caregiver receive medical advice on regular basis		304		72.0	
Smoking		96		22.7	
Excessive consumption of coffee (more than 4 cups/day)		168		39.8	
Exercising daily		26		6.1	
Have a leisure time		41		9.7	
Headache		187		44.3	
Backache, joint and neck pain		189		44.8	
Sleep problem		201		47.6	
Obesity and overweight		98		23.2	
Excessive use of over-the-counter medication		109		25.8	



Cardiovascular diseases
Gynacological problems
🗆 Renal
□ Cancer
Endocrine and metabolic disorder
OTHERS

Figure 1. Percentage of diseases affected women (n = 304)

# 4. DISCUSSION

With increasing number of elders in Jordan community, many family members are becoming caregivers. In Jordan, the need of family member to take on the caregiver role is important and challenging. The presence of elder in his home and receive care by his family is the commonly encouraged option in Jordan context. Policy makers, health care provides, families, and elders themselves prefer and encourage remaining elders at their own homes to minimize feeling of isolation and marginalization, and avoiding cost institutionalization.<sup>[20]</sup> Receiving care from family member and the close family times were closely associated with high level of elder's health and longer healthy life span.<sup>[15]</sup>

The multi international definitions of the caregiver concepts are congruence with the actual caregiver role performed by Jordanian caregivers. Providing "holistic care", "for someone in need", and "on behalf of another" are the main theme emerged in many studies.<sup>[2,8,21]</sup>

Consistent with other local and international studies, caregivers in the present study are women in their middle age.<sup>[5,9,18,19]</sup> The rational of the small number of men in this study could be explained by a report of ESCWA<sup>[22]</sup> and Jullimate *et al.*,<sup>[23]</sup> perception of caregiving as "women's duty" and responsibility, or because men are the main source of income for the family, and they cannot accompany elders to health center because of their compliance to their works.

Similar to other Arab study,<sup>[11]</sup> Jordanian elders are living with their immediate close family members such as sons, spouse, daughters, and grandchildren. Finding of this study are divergent from western studies,<sup>[18]</sup> where spouses assumed the caregiver role. In the present study, and consistent with a previous study,<sup>[9]</sup> daughters were the primary caregivers of elders; this may reflect the filial piety phenomenon in the Arab communities similar to other cultures.<sup>[24–26]</sup>

Daughters-in-law were found to be as caregiver in this study, this result reflects the cultural norms and the intergenerational ties and family support.<sup>[25–27]</sup> Other rational for finding daughter-in-law in the present study was the limited financial resources for Jordanian families; therefore, sons assume responsibilities for their parents in their own homes, and the caregiving responsibilities extended to their wives. In some instants, caring of husband's parents in Jordanian society is not a choice, but rather an obligation and duty enforced by elder's son on their wives.

An unexpected finding in this study was to find some women were over 70 years old, and they were primary caregivers for their relatives, particularly for their spouses for more than 25 years. Women represented the theme of a previous study where they perceive the experience of the living with care recipient for a long time as "living with their own shadows".<sup>[2]</sup>

More than one-third of elders' caregivers in the study were employed and have outside home careers, this issue highlighted the importance of women in the Jordan work force,<sup>[22]</sup> in addition to taking the role of main long term care provider for elder parents or other relatives. This finding of multiple social roles of Jordanian women is expected in the light of similar neighboring Arab country results.<sup>[16,17]</sup>

Caregiving duration in this study was recorded by women as two years and a half, and for some women the period was extended to more than thirty years. This result of caregiving duration was less than other studies.<sup>[28]</sup> It was found that caregiver reported long term commitment for their elder relatives, and being on call for assisting them for extended daily hours. And this may explained the women's report of decreasing leisure time and in appropriate life style practices.

The toll of providing care for elders is heavy on caregivers' health. Although caregivers in the study provide different and intense assistant for elders, caregivers themselves may be at risk for different physical, emotional and social challenges, because of their unhealthy life style practices such as smoking, consumption of coffee, and excessive use of overcounter medication. In the current study, more than 70% of the women had been diagnosed with different health problems, this result was congruent with other studies,<sup>[18,28]</sup> after engaging in caregiving duties, women experienced changes from daughter or spouse to full time caregiver, consequently they may neglect their own health and show a decline in performing preventive health, and promotion health practices particularly for a such sample of limited income. Negative caregiving consequences on families were well documented previously,<sup>[21,28]</sup> however the positive aspects of caregiving

were out of this study objectives.

Women in this study reported feeling of sleep problem, headache, joint pain, and this may explained by a Jordanian study<sup>[17]</sup> that different psycho somatic symptoms and, sleep problems related to the multiple roles performed by women, particularly the role of caregiver for elder relatives. To minimize the impact and to avert the effect of negative life style practices on families, different interventions could be provided such as information and knowledge, family support, and caregiving skill training.<sup>[18]</sup>

Health care system should be responsive to the elders' and their caregivers' needs. Within the scarce resources in Jordan and Arab countries, the civil society and the non-governmental organizations have a role in providing assistant not only for elders themselves, but also for their caregivers. Accessible and affordable home based care services, family training, and capacity building were of available alternatives to assist the caregivers.<sup>[2, 20]</sup> Periodical assessment programs should be activated for caregiver to maintain his own health and the health of care recipients.<sup>[29]</sup> Economic and Social Commission for Western Asia (2013)<sup>[20]</sup> recommended strengthen the informal support system through mobile units, respite programs, financial incentives, training, home based and family welfare programs.

#### 5. CONCLUSION

Based on the findings of the present study, Jordanian families are responsible for the burden caregiving role; however they are vulnerable to decline in their own health because of overwhelming physical and emotional consequences of caregiving.<sup>[30]</sup> It is recommended to support the role of the families in their caregiver role through screening and help caregivers who are most at risk for deteriorating health so that they can continue to provide care while maintaining their own well being. Activate the role of community nurse especially in home visit program. Educate and train elders' families about the principle of home caregiving, and the healthy lifestyle they can comply to maintain their health. Medical and nursing schools should emphasis in their curriculum on the "caregiving" concept especially for disabled elders. Because of the increasing number of Jordanian elders, investigating elders' caregiving could be one of medical and nursing research priority areas.

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# **CONFLICTS OF INTEREST DISCLOSURE**

The author declares that there is no conflict of interest.

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