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Informal Caregiving to Chronically III Older Family Members: Caregivers' Experiences and Problems

Khalil Ahmad

University of the Punjab, Lahore

ABSTRACT

Informal caregiving by close ones plays cardinal role in the health and life quality of chronically ill elderly people. Chronically ill older family members are largely dependent upon family caregiving to carry out everyday self-maintenance tasks identified as Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL). The present paper examines experiences and problems of informal caregivers in providing care to their older family members suffering from serious chronic ailments in urban Lahore, Pakistan. The data for the present paper draws from the survey on Management of Chronic Conditions and Healthy Ageing carried out in 2006. Informal caregiving to chronically ill family members varied by gender, age and relationship to care receiver. Younger and female caregivers, particularly daughters-in-law bore the burden of caregiving. Working caregivers experienced stress and financial strain more than non working ones. Family caregivers expressed the need for formal support and special health services for frail and disabled elderly people.

KEY WORDS: Informal caregiving, Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), Stress, Financial Strain, Functional Limitation.

Introduction

Informal caregiving is the assistance provided by family members to their frail and disabled individuals in everyday self-maintenance activities such as bathing, dressing and getting around, as well as other activities such as shopping, preparing meals, and visiting physicians. These activities are classified as Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL). Although caregiving is mostly linked with ADL and IADL, it includes other aspects of life as well (Ekwall et al, 2004). Informal caregivers provide physical, emotional, and financial support to their frail and disabled elderly family members (Yaffe and Jacobs, 2008). Some family caregivers help their relative in managing finances; others assist in health care and provide emotional support to deal with illness.

Informal caregiving can place a great deal of strain on family members, particularly the main care-givers (Taylor, 2003). In addition to the burden of caring, family members may face financial strain, reduced opportunities for recreation and social isolation. Lack of support from other family members may also have implications for both the caregivers and care recipients. This paper investigates major chronic conditions of the care receivers. In so doing, this paper explores differences in informal caregiving by age, gender and relationship to the care receiver with a focus upon the constraints and problems experienced by family caregivers.

Methods

The present study was based on the household survey conducted in September 2006 to accomplish the PhD research, "Management of Chronic Conditions as Predictor of Healthy Ageing: An Analysis of Urban Population, Lahore, Pakistan". The data were gathered by interviewing 921 respondents (483 males and 438 females) aged 50 years and above from the households of six survey sites (Babar Block, Scotch Corner, Rehman Pura, Mohallah Jalutiyan, Qalanda Pura and Babu Sabu) of City District Lahore. The major objective of the study was to ascertain self-reported prevalence of chronic conditions and their management with a focus upon healthy ageing in the study population. Data were gathered from family caregivers who provided care to their older family members impaired in their physical strengths and everyday self-maintenance competencies. The purpose was to ascertain information about the types of activities family caregivers helped their older family members across six neighborhoods in Lahore. In so doing, the present study aimed at examining the experiences and problems of family caregivers in providing the needed care to the chronically ill older family members.

Major Findings

Characteristics of Family Caregivers and Care Recipients

This section deals with identifying the characteristics of family caregivers and the recipients of care. Understanding socio-economic and demographic profiles of informal caregivers and care recipients is deemed to be important in analyzing the constraints and issues confronting the family caregivers.

Characteristics of Family Caregivers

Characteristics of family caregivers are presented in Table 1. The data show family caregiving was a female domain as vast majority (80.3 percent) of the caregivers were females and they provided care to both male and female older

family members. Only 19.7 percent caregivers were males. The data in Table 1 show that most of the male and female caregivers were aged ≤30 years. Caregiving might have certain implications for those in the prime labor force age group

Table 1 Characteristics of Family Caregivers

Age (in Years)	**%**
≤ 30*	40.2
31-35	14.2
36-40	24.4
	3.9
41-45	
46-50	4.7
51+	12.6
Total	**100.0**
Gender	
M	19.7
F	80.3
	100.0
Total	
Marital Status of Caregivers	
Currently Married	66.9
Widow	2.4
Separated	1.6
Never married	29.1
Total	**100.0**
Education of Caregivers	
Illiterate	16.5
literate (no formal schooling)	4.7
upto 5^{th}	19.7
upto 10^{th}	26.0
Undergraduate	22.0
graduation and above	11.0
Total	**100.0**
Relationship with Care Recipient	
Spouse	14.2
Son or Daughter	39.4
Daughter- in- law	40.9
Grandchildren	4.7
Other relative	0.8
Total	**100.0**
Work Status of Caregivers	
Working	33.8
Non-working	66.2
Total	**100**
N	**127**

Source: Ahmad 2010

(caregivers aged ≤30 years). The caregivers aged 51 years and above either did not have adult children or their adult children were located elsewhere. In such cases, spouses were the main source of care giving. However, it implies that Pakistan

may face the challenge of providing formal care to its growing older population in the coming years. A little more than two third of the caregivers were currently married. Care giving may not only affect the emotional well-being of currently married caregivers but also strain their own inter-spousal relations.

Educational attainment is not only considered to have profound effect on one's health status but also it provides information to cope with the pertinent challenges. The significant number of caregivers had upto matric level educational attainment followed by under graduation and primary levels (up to 5^{th}). Small percentage of caregivers had graduation and above level education. A considerable number of caregivers was illiterate. Overall, most of the caregivers were literate with various levels of educational attainments.

The data in Table 1 show that most of the care was provided to chronically ill older family members by either daughters-in-law or sons and daughters. The impressionistic unpleasant relations between daughters-in-law and their mothers-in-law probably result from this supposedly unpleasant role of caregiving. However, a considerable proportion of spouses was also providing care to their respective spouses.

The data in Table 1 show that most of the caregivers were not working. Work status might have differential repercussions for the pertinent income levels and health of caregivers. It is important to note that most of the working caregivers were engaged in elementary occupations or manual labor. It suggests that caregivers might have been facing financial constraints, which could have ramifications for both the caregivers and care recipients.

Distribution of Care Recipients by age, gender and major chronic conditions

Table 2 provides information about percent distribution of care recipients by their age, gender and major chronic conditions. The data show that a substantial proportion of care recipients with greater share of males was aged ≥70 years, while females constituted greater share in receiving care in younger age group (i.e. ≤ 60 years). It implies that females start to experience chronic ailments at an early age compared to those of males. It could be attributed to the life course disadvantageous position of females in countries like Pakistan. Most of the care recipients (both males and females) were from lower socio-economic strata of Lahore. Low educational attainments and involvement in low paid informal occupations might be important factors for the poor health conditions of the care recipients in lower income groups. However, significant number care recipients were from middle and upper income parts of Lahore.

The data in Table 2 show that significant proportions of both male and female care recipients were suffering from heart diseases (21.3 percent males and 17.3 percent females) followed by diabetes (8.7 percent males and 13.4 percent females), stroke/paralysis (8.7 percent males and 9.4 percent females), arthritis (7.1 percent males and 3.1 percent females), cancer of any type (4.7 percent males and 3.1 percent females) and hip fracture (3.1 percent females only) respectively.

The data show that from a sub-sample of those who received care, 50.4 percent males and 49.6 percent females were afflicted with severely limiting chronic conditions. It is important to note that a substantial number of care recipients afflicted with heart diseases and stroke were also suffering from hypertension stage 2 and high blood sugar levels. It shows that hypertension and diabetes were largely responsible for limiting chronic conditions (such as heart diseases and stroke), apart from other chronic ailments. A small proportion of care recipients was afflicted with hip fracture (age-determined disease of older people). Overall, large proportion of care recipients was afflicted with multiple morbidities, apart from the reported condition for receiving health care from their respective family members. It may, however, be argued that severely limiting morbidities of the care recipients could have resulted from their early life conditions and health related behaviors. Studies indicate not only working conditions, residential conditions and behaviors (Marmot et al, 1991) affect the health status in late life, but also the role of events and situations over life course (Smith et al, 1997). Others, for example, Holland et al (2000) indicated that behaviors in adulthood are largely responsible for inducing multiple morbidities, disabilities and death.

Table 2 Percent distribution of care recipients by age, gender and major chronic conditions

Age (in Years)	**Gender**		
	M	**F**	**Total**
≤ 60	6.3	14.2	20.5
61-69	10.2	7.9	18.1
≥70	33.9	27.6	61.4
Total	**50.4**	**49.6**	**100.0**
N	**64**	**63**	**127**
	Major Chronic Conditions		
Hip fracture	0.00	3.1	**3.1**
Heart disease/attack	21.3	17.3	**38.6**
Diabetes	8.7	13.4	**22.0**
Stroke/paralysis	8.7	9.4	**18.1**
Cancer (of any type)	4.7	3.1	**7.9**
Arthritis	7.1	3.1	**10.2**
Total	**50.4**	**49.6**	**100.0**
N	**64**	**63**	**127**

Source: Ahmad 2010

The data in Table 2 clearly show that heart diseases and stroke (usually believed to be life style diseases i.e., largely caused by hypertension and diabetes) could be attributed to adulthood behaviors of the care recipients, apart from their life course situations. Overall, a substantial number of care recipients afflicted with severely limiting chronic conditions was receiving care from their respective family members and this finding is in agreement with previous studies. For example, Yaffe and jacobs (2008) noted that a growing number of individuals with chronic diseases or disabilities require a family caregiver, or several, for physical, emotional, and financial support.

Experiences and Problems of Informal Caregivers

Length of Care-giving

Duration of caregiving may have profound effect on the health of caregivers and can contribute towards their isolation from their social networks. Family caregivers were asked: 'since how long they were taking care of their older family member(s) to ascertain the length of caregiving'. Table 3 provides data about the duration of caregiving to older family members by family caregivers.

The data show that more than one half of the caregivers (56.0 percent males and 53.9 percent females) had been providing care to their older family members for the last five years. About one-fourth males (24.0 percent) and a little over one-third (35.3 percent) females had been providing care to their older family members for the last 6-10 years. Relatively smaller proportions of caregivers (20.0 percent males and 10.8 percent females) were providing care for the last 11+ years. Among females, daughters-in-law were the main source of caregiving for their impaired family members. It could be one of the reasons that parents tend to find younger brides for their sons. A significant number of daughters-in-law was aged up to 30 years and the main source of caregiving to the families of grooms. Among males, son was the major source of caregiving to the impaired older persons. It is interesting to note that relatively greater proportion of daughters-in-law had been providing care to the older family members for the last six and more years compared to those by female spouses and daughters.

Although daughters-in-law were bearing the disproportionate burden of caregiving, significant proportion of daughters (17.7 percent of the total 27.5 percent daughters) either did not marry or stopped attaining further education due to their caregiving role. This finding clearly demonstrates the heavy toll of caregiving for female caregivers, particularly daughters and daughters-in-law, in terms of psychological, physiological, and economic effects. Length of caregiving also reflects the length of impairment of care recipients. Although the length of impairment in terms of receiving care varied, the mean length of caregiving was 6.33 years. It implies that a substantial number of care recipients had been impaired for the last six years.

Table 3 Percent distribution of care-givers by length of care-giving by gender

Gender of Care-giver	Relationship to care recipient	Length of Care-giving (in years) ≤ 5	6-10 yrs	11+ yrs	Total
Male	Husband	4.0	0.00	0.00	**4.0**
	Son	48.0	20.0	20.0	**88.0**
	Son- in- law	4.0	4.0	0.00	**8.0**
	Total	**56.0**	**24.0**	**20.0**	**100.0**
	N	**14**	**6**	**5**	**25**
Female	Wife	7.8	7.8	1.0	**16.7**
	Daughter	10.8	12.7	3.9	**27.5**
	Daughter- in- law	28.4	14.7	5.9	**49.0**
	Grandchild	5.9	0.00	0.00	**5.9**
	Other relative	1.0	0.00	0.00	**1.0**
	Total	**53.9**	**35.3**	**10.8**	**100.0**
	N	**55**	**36**	**11**	**102**

Source: Ahmad 2010 Mean length of caregiving (years): 6.33

This is an important finding that indicates a significant number of care recipients might have started experiencing impairment around the age of 50 years. It clearly suggests that the onset of impairment in everyday self-maintenance activities may be much earlier in developing countries like Pakistan compared to that of developed countries.

Table 4 provides information about number of hours a day, caregivers spent in caregiving to their older family members. The data show the same pattern as that given in Table 3; it is evident that a large proportion of caregivers (48.0 percent males and 60.8 percent females) were spending 4-7 hours a day in caregiving. However, the toll of caregiving was more pronounced for daughters-in-law.

Table 4 Percent distribution of care-givers by amount of time spent a day in caregiving by gender

Gender of Care-giver	Relationship to care recipient	Amount of time spent a day in care-giving (in hours)			
		≤3 hours a day	4-7 hour a day	7+ hours day	Total
Male	Husband	4.0	0.00	0.00	**4.0**
	Son	24.0	40.0	24.0	**88.0**
	Son- in- law	0.00	8.0	0.00	**8.0**
	Total	**28.0**	**48.0**	**24.0**	**100.0**
	N	**7**	**12**	**6**	**25**
Female	Wife	1.0	11.8	3.9	**16.7**
	Daughter	4.9	16.7	5.9	**27.5**
	Daughter- in- law	8.8	30.4	9.8	**49.0**
	Grandchild	3.9	2.0	0.00	**5.9**
	Other relative	0.00	0.00	1.0	**1.0**
	Total	**18.6**	**60.8**	**20.6**	**100.0**
	N	**19**	**62**	**21**	**102**

Source: Ahmad 2010 Mean Hours a day spent in care-giving: 5.50 Hours

Caregivers' Satisfaction with Caregiving Task

Caregivers' satisfaction with caregiving can be important for their own life quality. The extent of satisfaction with caregiving may influence motivation and health of caregivers. Table 5 presents percent distribution of caregivers by their satisfaction with caregiving task by gender. The data show that 92.0 percent male and 45.1 percent female caregivers were highly satisfied about caregiving role. On the other hand, 8.0 percent males and 45.1 percent females reported their satisfaction about the role of caregiving 'to some extent'. It is important to note that a significant proportion of daughters-in-law compared to other family members reported low satisfaction. It is understandable because greater proportion of daughters-in-law compared to other family members were spending larger amount of time on caregiving. Their low satisfaction with caregiving might be due to high demand on their time from life circumstances.

Satisfaction with caregiving role may vary with the burden of caregiving. Physical fatigue and unpredictable nature of illness increases the burden of caregiving (Gays 2000; Dietz and Clasen 1995; Lackey and Gates 2001). However, increased sense of responsibility and a close relationship with care recipient may offset the repercussions of caregiving (Dearden and Becker 2000; Heigh 2004). Therefore, sons' and daughters' satisfaction could be attributed to the positive effects and those of less satisfied (daughters-in-law and female spouses) could be attributed to the negative effects of the caregiving.

Table 5 Percent distribution of care-givers by their satisfaction with care-giving by gender

Gender of Care-giver	Relationship to care recipient	Extent of satisfaction with care-giving			
		Not at all	To some extent	To great extent	Total
Male	Husband	0.00	0.00	4.0	**4.0**
	Son	0.00	8.0	80.0	**88.0**
	Son- in- law	0.00	0.00	8.0	**8.0**
	Total	**0.00**	**8.0**	**92.0**	**100.0**
	N	**0.00**	**2**	**23**	**25**
Female	Wife	2.9	7.8	5.9	**16.7**
	Daughter	1.0	5.9	20.6	**27.5**
	Daughter- in-law	4.9	28.4	15.7	**49.0**
	Grandchild	1.0	2.0	2.9	**5.9**
	Other relative	0.00	1.0	0.00	**1.0**
	Total	**9.8**	**45.1**	**45.1**	**100.0**
	N	**10**	**46**	**46**	**102**

Source: Ahmad 2010

Assistance in Everyday Self-maintenance Activities

Individuals impaired in ADL and IADL competencies require assistance in various activities that are important for their well-being. Table 6 provides data about the assistance provided by family caregivers to their older people in everyday self-maintenance activities by gender. Large proportions of female caregivers were providing assistance in preparing meals, cleaning rooms, doing laundry, helping care recipients in taking medicines. About two-fifths of female caregivers (40.2 percent) helped older family members in doing shopping, 41.2 percent helped in getting to doctor(s), 52.0 percent helped in eating, 39.2 percent helped in bathing, 34.3 percent towards arranging care services and 33.3 percent assisted in dressing. Assistance in ADL and IADL tasks such as, dressing, bathing, medication, preparing meals, eating, doing laundry, doing shopping, and helping visit doctors clearly suggests that care recipients were impaired in mobility, balance, cognitive incapacity or some combination of these deficits. Although caregiving burden was disproportionately borne by females, a significant number of males (19.7 percent of the total 127 family caregivers) were also providing care in ADL and IADL tasks (except for dressing). The appearance of male caregivers seems to imply change in traditional gender roles. However, male may assume caregiving role due to unavailability of female caregiver in the household.

Although male caregiver makes an important contribution in informal care, usually caregiving is viewed as female job (Thompson, 2002). The presence of male caregivers in informal caregiving does not necessarily mean an improvement in gender equality. On the other hand, significant proportion of female caregivers was providing assistance in instrumental activities of daily living. This finding suggests that traditional Pakistani culture is changing. However, most of the caregivers reported that they had less time for other activities and it was difficult for them to deal with older adults suffering from paralysis/stroke and cancer. It could be attributed to unpredictable nature of illness.

Although family caregivers were taking care of their older family members, some of the caregivers had the feeling that they were not providing required care to their impaired older family members.

Table 6 Percent distribution of care-givers providing assistance to older family members by gender

Gender of Care-giver	Types of Activities	*Assistance*		
		Yes	**No**	**N**
	Dressing	0.00	100.0	**25**
Male	Eating	52.0	48.0	**25**
	Bathing	0.00	100.0	**25**
	Preparing meals	8.0	92.0	**25**
	Cleaning room	24.0	76.0	**25**
	Doing laundry	8.0	92.0	**25**
	Medication	100.0	0.00	**25**
	Doing shopping	100.0	0.00	**25**
	Help in visiting doctor	100.0	0.00	**25**
	Help in operating finances	84.0	16.0	**25**
	Arranging care services	96.0	4.0	**25**
Female	Dressing	33.3	66.7	**102**
	Eating	52.0	48.0	**102**
	Bathing	39.2	60.8	**102**
	Preparing meals	92.2	7.8	**102**
	Cleaning room	87.3	11.8	**102**
	Doing laundry	76.5	23.5	**102**
	Medication	91.2	8.8	**102**
	Doing shopping	40.2	59.8	**102**
	Help in visiting doctor	41.2	58.8	**102**
	Help in operating finances	19.6	80.4	**102**
	Arranging care services	34.3	65.7	**102**

Source: Ahmad 2010

Care Recipients' Satisfaction with Caregiving as Reported by Caregivers

Caregivers were asked to report as to how care recipients were satisfied with the care they were providing to them. Caregivers reported varying levels of satisfaction perceived by the care receivers. Table 7 presents reported satisfaction levels of care recipients. The data show that a little less than one-half (44.9

percent) of the caregivers reported moderate level of satisfaction as perceived by care receivers. It is important to note that 39.4 percent women as opposed to only 5.5 men reported moderate satisfaction of care recipients with care being provided to them. Similarly 23.6 percent female and 14.2 percent male caregivers reported that their respective care receivers were highly satisfied with the care provided to them. This was expected as children were socialized to look after their elderly family members. Moreover, the value of self-sacrifice is instilled among females and the same socialization pattern prepares them for such caring roles. However, female caregivers provided more care in basic activities such as dressing, bathing, eating or preparing meals. Such activities are taken as domestic and feminine and both males and females expect that. It may be noted that males generally provided instrumental support which was valued more than what their female counterparts provided. That is why males thought that their care receivers were more satisfied with their care than their female counterparts. On the other hand, female caregivers faced double jeopardy; spending more hours in caregiving and receiving little appreciation.

Table 7 Perceived satisfaction of care recipients as reported by caregivers by gender

Gender	Satisfaction of care recipient with care-giving			
	Not at all	**To some extent**	**To great extent**	**Total**
Male	0.00	5.5	14.2	**19.7**
Female	17.3	39.4	23.6	**80.3**
Total	**17.3**	**44.9**	**37.8**	**100.0**
N	**22**	**57**	**48**	**127**

Source: Ahmad 2010

Major Problems Faced by Caregivers

Caregivers of impaired family members may experience many problems, which in turn may affect their own health. Table 8 presents data about major problems being faced by caregivers. The data show, ‘difficulty in administering medicines’ was the major problem being faced by the caregivers (64.0 percent males and 59.8 percent females). It is understandable due to the fact that a significant proportion of respondents afflicted with multiple morbidities might have poor self-rated health status, in turn less adhered to prescribed medication.

A substantial proportion of caregivers (56.8 percent females compared to 40.0 percent males) faced 'poor sleep' problem due to caregiving role. Since substantial proportions of females were spending significant amount of time in caregiving, it is understandable that they faced 'poor sleep' problem more often than their male counterparts. Individuals suffering from severely limiting chronic conditions (hip fracture, cancer, heart diseases, arthritis, and stroke) are believed to place more demand on caregivers in terms of night-time care due to toilet need. Caregivers' sleep might have disrupted due to the need of taking the care-receivers (afflicted with severely limiting chronic conditions) to toilet at night.

The data indicate that 56.0 percent males and 53.9 percent females complained non cooperation by their respective care recipients. Sometimes, it is difficult to communicate with older people and it results in the lack of cooperation on the part of older people. It is important to note that caregivers' education was significantly related with the cooperation of care recipients (Chi-square value 13.88, $P \leq 0.016$). It clearly shows that caregivers with more education had the ability to communicate effectively with older family members, which in turn resulted in their cooperation. Significant proportions of caregivers (44.0 percent males and 14.7 percent females) had to take time off the job to provide care to their older family members. This shows that caregivers' job-related time is undervalued and they are whisked to provide care to their elderly, rather than focusing on their own work.

Since significant proportion of female caregivers was providing assistance in dressing activity (to those care recipients afflicted with stroke and hip fracture), they faced the problem of incontinence. The data clearly imply the functional limitations of the care recipients, which (consistent with disablement model) are the most productive predictor of disability (Albert, 2004).

Table 8 Percent distribution of care-givers by major caregiving problems by gender

Gender of Care-giver	Type of Problem	Facing Problems		
		Yes	No	Total
Male	Poor sleep	40.0	60.0	**25**
	Difficulty in administering medicines	64.0	36.0	**25**
	Incontinence of elderly person	8.0	92.0	**25**
	Taking time off the job for care-giving	44.0	56.0	**25**
	No cooperation on the part of care recipient	56.0	44.0	**25**
Female	Poor sleep	56.9	43.1	**102**
	Difficulty in administering medicines	59.8	40.2	**102**
	Incontinence of elderly person	21.6	78.4	**102**
	Taking time off the job for care-giving	14.7	85.3	**102**
	No cooperation on the part of care recipient	53.9	46.1	**102**

Source: Ahmad 2010

Stress Reported by Caregivers

Caregivers may experience stress in providing care to the impaired older family members. Those who experience stress more frequently may be fatigued and could experience adverse health effects. Caregivers were asked to provide information about the stress they felt in providing care to their impaired older family members. Table 9 presents percent distribution of caregivers by feeling of stress in caregiving by gender. The data show that large proportions of caregivers (92.0 percent males and 63.4 percent females) reported that they 'somewhat' experienced stress in providing care to their respective older family members. On the other hand, 36.3 percent females and 8.0 percent males reported 'no stress' while caring their elderly. However, the findings suggest that majority of caregivers felt stressed in providing care to the elderly. It is important to note that the level of stress was significantly associated with the work status of the caregivers (Chi-square value 39.8, $P \leq 0.022$). Working caregivers were more stressed than those of non-working because they had to take time off the jobs to cater to the care of their impaired older family members.

Table 9 Percent distribution of caregivers by feeling of stress in caregiving by gender

Gender of Care-giver	Relationship to care recipient	Frequency of experiencing stress in care-giving			
		Not at all	Sometimes	Most often	Total
Male	Husband	0.00	0.00	4.0	**4.0**
	Son	8.0	68.0	12.0	**88.0**
	Son- in- law	0.00	4.0	4.0	**8.0**
		8.0	**72.0**	**20.0**	**100.0**
	Total				
	N	**2**	**18**	**5**	**25**
Female	Wife	7.8	3.9	4.9	**16.7**
	Daughter	6.9	13.7	6.9	**27.5**
	Daughter- in- law	19.6	10.8	18.6	**49.0**
	Grandchild	1.0	2.9	2.0	**5.9**
	Other relative	1.0	0.00	0.00	**1.0**
		36.3	**31.4**	**32.4**	**100.0**
	Total				
	N	**37**	**32**	**33**	**102**

Source: Ahmad 2010

Caregivers were also asked to tell how often they faced financial problems due to giving care to their older family members. Table 10 presents percent distribution of caregivers by financial constraints by gender. A large proportion of caregivers (41.1 percent) with greater share of females (36.3 percent) compared to that of males (20.0 percent) faced financial problems 'sometimes'. A significant proportion of caregivers faced financial problems 'often'. Nearly one-third (34.3 percent) of the women caregivers did not face financial problems 'at all'. Since females are not usually the breadwinners in Pakistan, they were not expected to make financial contribution to their respective families. Accordingly, there was no pressure of financial loss to the lady caregivers. However, working caregivers had to bear financial problems more than those of non-working caregivers (Chi-square value 48.58, $P \leq 0.002$).

Among males, greater proportion of sons faced financial problems compared with other family members. It might be due to financial support they were expected to provide to their families. Among females, greater proportion of daughters-in-law faced financial problems due to caregiving.

Table 10 Percent distribution of care-givers by financial problems by gender

Gender of Care-giver	Relationship to care recipient	Frequency of facing financial problems			
		Not at all	Sometimes	Most often	Total
	Husband	0.00	0.00	4.0	**4.0**
Male	Son	12.0	20.0	56.0	**88.0**
	Son- in- law	0.00	0.00	8.0	**8.0**
		12.0	**20.0**	**68.0**	**100.0**
	Total				
	N	**3**	**5**	**17**	**25**
Female	Wife	5.9	4.9	5.9	**16.7**
	Daughter	8.8	8.8	9.8	**27.5**
	Daughter- in- law	18.6	18.6	11.8	**49.0**
	Grandchild	1.0	2.9	2.0	**5.9**
	Other relative	0.00	1.0	0.00	**1.0**
		34.3	**36.3**	**29.4**	**100.0**
	Total				
	N	**35**	**37**	**30**	**102**

Source: Ahmad 2010

It is understandable, as significant number of working females (daughters-in-law) took time off from their jobs to provide care to their older family members. This finding suggests heavy toll of care-giving for females, particularly daughters-in-law, in terms of reduced incomes.

Services/Facilities Needed for Care Recipients

Caregivers were asked to give their opinion about the services/facilities needed for chronically ill older people. Table 11 provides data about opinions of caregivers regarding services/facilities needed for chronically ill older individuals. Larger proportions of caregivers were of the view that older persons should be provided with health facilities, financial resources and special health care services. They were of the view that older people were the assets for any civilized society. Older people, just like the younger individuals, need services and facilities; and government should pay some attention to formal support to informal caregivers.

Smaller proportions of both male and female caregivers were of the view that receiving financial aid from government functionaries (making reference to Bait-ul-mal scheme) was too cumbersome and humiliating. However, they were of the view that provision of health facilities could help reduce the burden of disease on families.

Table 11 Percent distribution of care-givers by their opinion about provision of different services/facilities by gender

Gender of Care-giver	Type of service/facility	Provision of services/facilities		
		Yes	No	N
Male	Health facilities	17.3	2.4	**25**
	Financial facilities	14.2	5.5	**25**
	Special health care services	12.6	7.1	**25**
	Other	3.1	16.5	**25**
Female	Health facilities	70.9	9.4	**102**
	Financial facilities	63.0	17.3	**102**
	Special health care services	43.3	37.0	**102**
	Other	8.7	71.7	**102**

Source: Ahmad 2010

Caregivers were also asked to opine regarding establishment of community centers for older persons. Table 12 provides information about caregivers' opinions regarding the establishment of community centers for older persons. Large proportions of both male and female caregivers (64.6 percent females and 16.5 percent males) opined that there should be community centers for older people so that they may recreate and refresh themselves. Some caregivers with frail and impaired older family members were of the view that home facilities should be provided and no community centers were needed.

Table 12 Percent distribution of caregivers by their opinions about establishing community centers for older people by gender

Gender	Opinion about establishment of community centers		
	Yes	No	Total
Male	16.5	3.1	19.7
Female	64.6	15.7	80.3
Total	**81.1**	**18.9**	**100.0**
N	**103**	**24**	**127**

Source: Ahmad 2010

Caregivers were asked whether or not they were willingness to send their elderly to purpose built old homes. Table 13 presents percent distribution of caregivers by their willingness to send older family members to old homes by gender. The data show that majority of the caregivers (74.0 percent) were not willing to send their older family members to old homes. However, a considerable number of caregivers (26.0 percent), with greater share of females (22.8 percent), compared to that of males (3.1 percent) were willing to send the elderly to old homes. Most of these caregivers were daughters-in-law. Being overburdened with caregiving and other household tasks, they were of the view that old homes must be established by government or other agencies. However, a few male caregivers were of the view that there should be old homes to provide care to selected but

really frail persons. In other words, the elderly who could not be looked after at home, they should have such a government provided facility.

Table 13 Percent distribution of caregivers by their willingness to send older people to old homes by gender

	Willingness to send older people to old homes		
Gender	**Yes**	**No**	**Total**
Male	3.1	16.5	**19.7**
Female	22.8	57.5	**80.3**
Total	**26.0**	**74.0**	**100.0**
N	**33**	**94**	**127**

Source: Ahmad 2010

Table 14 provides reasons for not sending elderly people to old homes. The data show that 27.7 percent females and 10.6 percent males reported that it was natural obligation to look after their elderly. They were of the view that it was their responsibility to take care of their older family members who nursed and brought them up. About one-fourth (23.4 percent) female and 7.4 percent male caregivers were of the view that families could look after their elderly better than the purpose-built institutions. It is important to note that 11.7 percent of the female caregivers reported that their respective male spouses were a great source of emotional support. The respondents were of the view that families should not send their older people to old homes; it is traditional obligation of the children in a society like Pakistan.

Although family caregivers were facing various problems, majority of the caregivers were not willing to send their elderly to old homes. Perhaps it could be the reason that formal agencies have taken fewer initiatives for building institutional facilities for the elderly in Pakistan.

Table 14 Percent distribution of caregivers who were not willing to send their older family members to old homes by gender

	Reasons for not willing to send older family members to old homes					
Gender	**Families provide better help**	**Spouses are of emotional support**	**Care-giving obligation**	**Old homes are not safe for females**	**Old people are source of guidance/assets**	**Total**
Male	7.4	0.00	10.6	3.2	1.1	**22.3**
Female	23.4	11.7	27.7	5.3	9.6	**77.7**
Total	**30.9**	**11.7**	**38.3**	**8.5**	**10.6**	**100.0**
N	**29**	**11**	**36**	**8**	**10**	**94**

Source: Ahmad 2010

Discussion

Demographic transition is characterized with epidemiological transition. There is increasing prevalence of chronic ailments as population ages. Family members are

closely involved in providing care to their chronically ill older individuals at home in countries which lack formal caregiving facilities/institutions. Unpredictable nature of serious chronic conditions (such as cancer, stroke and heart diseases) poses challenges to the family caregivers providing assistance in a number of activities. In the face of insufficient formal services (such as professional home care, respite care and day care centres for chronically ill older people) informal caregivers bear the burden of care. The present study investigated experiences and problems of informal caregivers in urban Lahore.

Informal caregiving varied by gender, age and relationship to the care recipient. Female caregiver bore disproportionate burden of caregiving across the six survey sites in Lahore. More than four-fifths of the care-givers were either daughters-in-law or daughters of care-recipients. The significant number of caregivers was aged ≤30 years and from lower socio-economic strata of Lahore. It indicates that caregiving might have certain implications for those in the prime labor force age group.

A substantial proportion of female caregivers experienced stress more frequently compared to those of males due to poor sleep and incontinence of chronically ill older family members. The level of stress was significantly associated with the work status of the caregivers (Chi-square value 39.8, P≤0.022). Working caregivers were more stressed than those of non-working because they had to take time off the jobs to provide care to their impaired older family members. The significant proportion of caregivers expressed the need for special health care services for chronically ill older people to ease the burden of informal caregivers.

Conclusion

Informal caregivers, particularly females bear the burden of caregiving in terms of physical, emotional and financial stresses. Informal caregivers need formal support and counseling services. Day care and community centres should be established to provide respite to the informal caregivers. Health professionals should recognize the important role of informal caregivers while making health care decisions. Educational programs should be launched to help support the informal caregivers. Social workers and NGOs should be involved to provide counseling services to family caregivers to better care their frail and disabled older family members. Since many informal caregivers take time off the job, family-friendly policies should be worked out to ease the family caregivers.

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Biographical Note

Dr. Khalil Ahmad is working as Assistant Professor in the Institute of Social and Cultural Studies (ISCS), University of the Punjab, Lahore-Pakistan