

## **Guilt and its Impact among Care Givers: Results of Survey from Teaching Hospital in Karachi, Pakistan**

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### **ABSTRACT**

**Objective:** The Care Giver aspect remains unexplored in Pakistan. This study looks at Care Giver guilt and its impact on their life and ways to overcome it.

**Methods:** A cross sectional study was conducted between July and September, 2015. A total of 400 Care Givers were interviewed. Participants were asked to fill out a consent form. Human rights were protected under the Declaration of Helsinki. Selection criteria included were age more than 18 years older and the participant was required to be a current or a former Care Giver of a family member. The demographic variables recorded include age, home town, occupation and education status. Variables included duration of care giving, current Care Giver or Care Giver in previous five years, family member who received care, whether guilt occurred due to care giving. Questions were included on ways of countering guilt and making care giving a better experience for both the care giver and the receiver. The data was entered using SPSS software. Chi-squared test was used to compare categories. P-value <0.05 was considered statistically significant. The questionnaire was administered in English and Urdu languages.

**Results:** 400 Care Givers (215 men and 185 women) were interviewed. The majority (228) belonged to younger age group (18-30 years). They were mostly single, majority students, giving/ had given care to their parents or grandparents. Most of them had or were giving care to their mothers (157) followed by father (105). The majority (256) were current Caregivers while the rest provided care within the previous five years. A significant 186 respondents reported "Guilty" feelings due to deficiencies in Caregiving and 50% felt it negatively affected their life. 108 respondents were bothered by negative thoughts arising from "Guilty" feelings and 102 shared with someone, Mother (52) being most common. 170 respondents felt "Guilty" feeling among Caregivers, arising out of deficiencies in Caregiving is inevitable. 255 respondents felt that Health Care Providers should provide support to Caregivers. 167 respondents felt that Patients realize negative impact of "Guilty" feelings among Caregivers and try to mitigate. Current Caregiver responses are compared with those who provided Caregiving over previous five years.

**Conclusion:** Significant guilt arises among Caregivers due to deficiencies in Caregiving. It is important for Health Care Providers to explore, identify and manage such "Guilty" feelings among Caregivers. Further research in this area is recommended.

**Key words:** Caregiving; Caregiver; Guilt; Patient dependency; Palliative care

## Introduction

A care giver is a person who provides assistance to someone incapacitated. It can be a husband who has suffered a stroke; father with Parkinson's disease; a mother-in-law with cancer; a grandmother with Alzheimer's disease or a son with traumatic brain injury from a car accident. Informal caregiver and family caregiver are terms that refer to individuals such as family members, friends and neighbors who provide care to their dear ones without any financial benefit. Whereas formal caregivers are volunteers or paid care providers associated with a service system. (1, 2)

Emotions in care giving, especially guilt, have not received adequate attention in the research literature, even though they are frequently observed in caregivers (3). Guilt has been described as a feeling associated with the recognition that one has violated a personally relevant moral or social standard" (4). Guilt has also been suggested as a factor contributing to depression and distress in caregivers (5) and it is considered as a main emotion for caregivers, which may exacerbate their burden. (6)

More women than men are reported as Caregivers. An estimated 59% to 75% of Caregivers are reported as women.(7,8) Other studies have found women caregivers to be involved in most difficult caregiving tasks (i.e., bathing, toileting and dressing) when compared with their male counterparts, who are more likely to provide financial support, arrange care, and other less physically demanding tasks.(9,10) A number of studies have found female caregivers to be more likely than males to suffer from anxiety, depression, guilt and other symptoms associated with emotional stress due to Caregiving.(11,12)

Guilt arises because care giving can lead to psychological and mental health deterioration. Studies consistently report higher levels of depression and mental issues among Caregivers (13) Guilt can affect one's day to day life whether it's family, social or professional life. It is believed that sharing feelings can lead to reduced guilt. While researchers have long known that care giving can have deleterious mental health effects for Caregivers, research shows that Caregiving can have serious physical health consequences as well. Studies have found that caregivers may have increased blood pressure and insulin levels, (14) may have impaired immune systems(15) and may be at increased risk for cardiovascular diseases (16) among other adverse health outcomes. While care giving can be a very stressful situation for many caregivers, studies also show that there are beneficial effects as well, including feeling positive about being able to help a disabled loved one, feeling appreciated by the care recipient, and feeling that their relationship with the care recipient had improved.(8,17)

Based on identified need, we decided to study Care Giver guilt and its impact on their life and ways to overcome it.

## Materials and Methods

A cross sectional study was conducted between July and September, 2015 at a teaching hospital in Karachi. A total of 400 Care Givers were interviewed. Participants were asked to fill out a consent form. Human rights were protected under the Declaration of Helsinki. Selection criteria included were age more than 18 years older and the participant was required to be a current or a former Care Giver of a family member. The demographic variables recorded include age, home town, occupation and education status. Variables included duration of care giving, current Care Giver or Care Giver in previous five years, family member who received care, whether guilt occurred due to care giving. Questions were included on ways of countering guilt and making care giving a better experience for both the care giver and the receiver. Questionnaire was a bilingual questionnaire and it had one open ended question. The data was entered using SPSS software. Chi-squared test was used to compare categories. P-value <0.05 was considered statistically significant. The questionnaire was administered in English and Urdu languages.

## Results

400 Care Givers (215 men and 185 women) were interviewed. The majority (228) belonged to younger age group (18-30 years). They were mostly single, the majority students giving/ had given care to their parents or grandparents. Most of them had or were giving care to their mothers (157) followed by father (105). The majority (256) were current Caregivers while the rest provided care within the previous five years. (Table 1)

A significant 186 respondents reported "Guilty" feelings due to deficiencies in Caregiving and 50% felt it negatively affected their life. 108 respondents were bothered by negative thoughts arising from "Guilty" feelings and 102 shared with someone; Mother (52) being most common. (Table 2-A)

170 respondents felt "Guilty" feeling among Caregivers, arising out of deficiencies in Caregiving is inevitable. 255 respondents felt that Health Care Providers should provide support to Caregivers. 167 respondents felt that Patients realize negative impact of "Guilty feelings" among Caregivers and try to mitigate. (Table 2-B)

Tables 3, 4-A and 4-B (pages 8-10) compare respondent's responses of current Caregivers with those who provided Caregiving over previous five years.

We asked the Caregivers three ways to reduce care giver guilt. Common responses included improving quality of care, sharing responsibilities and feelings, professional help, financial and family support, using spiritual support including praying and reading Holy Books. Another interesting response was psychotherapy which we believe can be an important and very helpful way of countering guilt.

Table 1: Socio-demographic characteristics of study participants (n=400)

Variable	Frequency	Percentage
<b>Age</b>		
18-30	228	57
31-40	44	11
41-50	69	17.3
51-60	47	11.8
61-70	12	3
<b>Gender</b>		
Male	215	53.8
Female	185	46.3
<b>Marital status</b>		
Single	236	59
Married	164	41
<b>Care status</b>		
Current	256	64
Past five years	144	36
<b>Duration of Care Giving</b>		
Less than 6 months	122	30.5
6 months to 3 years	69	17.3
More than 3 years	209	52.3
<b>Occupation</b>		
Employed	183	45.8
Unemployed	9	2.3
Housewife/student	208	52
<b>Education</b>		
Up to primary	19	4.8
Matric & intermediate	180	45
Graduate	116	29
PG	85	21.3

Table 2-A: Individual responses of Participants on “Guilt” among Caregivers (n=186)

Questions/Responses	n	%
<b>Guilt feelings affecting life negatively?</b>		
Yes	93	50
No	74	39.8
Not sure	19	10.2
<b>Suffer from anxiety and depression due to guilt?</b>		
Yes	98	52.7
No	69	37.1
Not sure	19	10.2
<b>Recurrent negative thoughts about Guilt bother you?</b>		
Yes	108	58.1
No	63	33.9
Not sure	15	8.1
<b>Do you have shared your “Guilt” feelings with someone?</b>		
Yes	102	54.8
No	74	39.8
Not sure	10	5.4
<b>If “YES” then you have shared “Guilt” feeling with ?</b>		
Father	25	13.4
Mother	52	28
Spouse	39	21
Sibling	50	26.9
No response	20	10.8
<b>Has sharing your “Guilt” feeling has made you feel better?</b>		
Yes	109	58.6
No	42	22.6
Not sure	35	18.8
<b>Have you sought professional help to relieve your “Guilt” feelings?</b>		
Yes	34	18.3
No	133	71.5
No response	19	10.2
<b>Has there been a reduction in “Guilt” feeling with time?</b>		
Yes	99	53.2
No	56	30.1
Not sure	31	16.7
<b>Area of your life adversely affected by your “Guilt” feelings?</b>		
Family life	67	36
Professional life	37	19.9
Social life	41	22
Other	30	16.1
All	11	5.9

Table 2-B: Individual responses of participants on guilt among Caregivers (n=400)

Question	Yes	No	Not sure
Do you feel "Guilty" for not being able to provide care?	186 (46.5)	173 (43.3)	41(10.3)
Do you agree "Guilt" out of deficiencies on part of care giver is inevitable?	170(42.5)	123(30.8)	107(26.8)
Health care providers should provide support to Caregivers for anticipated "Guilty" feelings?	255(63.8)	69(17.3)	76(19)
Do you agree that family support reduces "Guilt" among Caregivers?	304(76)	45(11.3)	51(12.8)
Do you agree that that best Caregiving can be provided by close family members?	250(62.5)	129(32.3)	21(5.3)
Do you agree that Professional Caregiving cannot replace Caregiving provided by family members?	232(58)	121(30.8)	47(11.8)
Satisfaction out of providing Caregiving to close family member outweighs guilt arising due to deficiencies?	259(64.8)	60(15)	81(20.3)
Patient receiving Caregiving is aware of the "Guilty" feeling that arises in care giver during care giving and tries to mitigate it?	167(41.8)	111(27.8)	122(30.5)

**Discussion**

The results of this study are consistent with those of previous studies suggesting the relevance of guilt in care giving outcomes. We have found associations between guilt and important outcome variables such as depression, negative impact on life suggesting a significant relationship between guilt feelings and caregiver distress.

Men constituted the majority of the caregivers in this study. This is in keeping with the tradition of the area where male relatives constitute the majority of caregivers as they are the sole bread earners in our society in the majority of the families and take care of their family. On the contrary in past studies women Caregivers are usually more involved than male Caregivers in the roles in assisting and nurturing all family members, besides the care recipient. Given that women usually perceive more responsibility for caring for all family members, they are likely to be more vulnerable to guilt associated with the perception that they are neglecting other relatives due to care giving. In fact, women Caregivers have been found to report more role conflict, more caregiving costs and more interference with family and leisure time than do men (18).

In our study, 186 individuals experienced guilt during their care giving period. One possible explanation is the additional burden of providing for the needs of other members of the family by the male Caregivers leading to increasing guilt while taking care of their dear ones.

It was observed in our study that the majority of the care givers was single and was in their student life enrolled in universities for graduation or post graduation degrees. About 45 percent of our Caregivers were employed. It is believed that good income and socioeconomic status can have lesser guilt feelings in care giving.(19) One possible explanation for a low prevalence of guilt feelings can be the proximity and type of emotional relationship between Caregivers and the loved ones before the process of integration and adaptation to Caregiver role(20).

Guilt feelings are bound to have a negative impact on daily life which is apparent by observations in our study. About 93 Individuals in our study declared guilt feelings to be negatively affecting their lives. They suffered from anxiety and depression due to guilt feelings.

Regarding the relationship between higher levels of burden and the lower educational or expertise level of the Caregivers often link feelings of anxiety and distress that impact negatively on the care delivered, as well as in caregiver’s own health. (21)

Our study demonstrates that family support and sharing guilt feelings will have a positive influence on care givers. Only 34 care givers from the 186 who had guilt feelings said they would want a professional intervention in dealing with guilt. This aspect is an alien concept in our society. Caregiving issues tend to be kept within family circle. More than half care givers believed that best care giving can only be provided by close family members and professional support cannot replace it. Our society is a family oriented society with joint family systems.

Table 3: Participant's responses on Care Giving

Question	Current N (%)	Past 5 years N (%)	P-value
<b>Caregiving provided to?</b>			
Father	63 (24.6)	42(29.2)	0.335
Mother	103(40.2)	54(37.5)	
Spouse	23(9)	6(4.2)	
Grandparents	44(17.2)	30(20.8)	
Others	23(9)	12(8.3)	
<b>Do you feel guilty for not being able to provide required care?</b>			
Yes	122(47.7)	64(44.4)	0.579
No	106(41.4)	67(46.5)	
Not sure	28(10.9)	13(9)	
<b>Guilt out of deficiencies is inevitable?</b>			
Yes	115(44.9)	55(38.2)	0.342
No	73(28.5)	50(34.7)	
Not sure	68(26.6)	39(27.1)	
<b>Health care providers should support Caregivers in addressing their guilt?</b>			
Yes	165(64.5)	90(62.5)	0.992
No	43(16.8)	26(18.1)	
Not sure	48(18.8)	28(19.4)	
<b>Do you agree that family support and sharing reduces guilt?</b>			
Yes	190(74.2)	114(79.2)	0.132
No	27(10.5)	18(12.5)	
Don't know	39(15.2)	12(8.3)	
<b>Best Caregiving is provided by close family members?</b>			
Yes	150(58.6)	100(69.4)	0.091
No	92(35.9)	37(25.7)	
Not sure	14(5.5)	7(4.9)	
<b>Professional help cannot replace Caregiving by close family members?</b>			
Yes	141(55.1)	91(63.2)	0.112
No	79(30.9)	42(29.2)	
Not sure	36(14.1)	11(7.6)	
<b>Satisfaction of providing Caregiving outweighs guilt due to deficiencies?</b>			
Yes	166(64.8)	93(64.6)	0.631
No	41(16.0)	19(13.2)	
Not sure	49(19.1)	32(22.2)	
<b>Patient is aware of "Guilty" feelings in Caregiver and tries to mitigate it?</b>			
Yes	112(43.8)	55(38.2)	0.11
No	62(24.2)	49(34.0)	
Not sure	82(32.0)	40(27.8)	

Table: 4-A: Guilt and its Impact on Care Givers

Question	Current N (%)	Past 5 years N (%)	P-value
<b>Does "Guilty" feeling negatively affect your life?</b>			
Yes	62 (50.8)	31 (48.4)	0.201
No	51 (41.8)	23 (35.9)	
Don't know	9 (7.4)	10 (15.6)	
<b>Do you suffer from anxiety and depression due to guilt?</b>			
Yes	69 (56.6)	29 (45.3)	0.253
No	43 (35.2)	26 (40.6)	
Don't know	10 (8.2)	9 (14.1)	
Question	Current N (%)	Past 5 years N (%)	P-value
<b>Do recurrent negative thoughts bother you that arise from Guilt?</b>			
Yes	74 (60.7)	34 (53.1)	0.465
No	40 (32.8)	23 (35.9)	
Don't know	8 (6.6)	7 (10.9)	
Question	Current N (%)	Past 5 years N (%)	P-value
<b>Do you share "Guilty" feelings with anyone?</b>			
Yes	64 (52.5)	38 (59.4)	0.665
No	51 (41.8)	23 (35.9)	
Don't know	7 (5.7)	3 (4.7)	

Strength of our study included participants from diverse regions all over from Pakistan, with the majority from Karachi. And we had a full range of age groups ranging from 18 year olds to more than 60. Limitations included that our focus was not a particular disease or ailment. We recruited all Care givers who were giving care to their family members whether for diabetes, hypertension or an elderly having decreased mobility at home.

### Conclusion

Significant guilt arises among Caregivers due to deficiencies in Caregiving. It is important for Health Care Providers to explore, identify and manage such "Guilty" feelings among Caregivers. Further research in this area is recommended.

### References

1. Fradkin, L.G. and A. Heath. Caregiving of Older Adults. Santa Barbara: ABC-CLIO, Inc., 1992.
2. McConnell, S. and J.A. Riggs. A Public Policy Agenda: Supporting Family Caregiving in Family Caregiving: Agenda for the Future, ed. M.A. Cantor, San Francisco: American Society on Aging, 1994.
3. 1-Yaffe, M. J. (1988). Implications of caring for an aging parent. Canadian Medical Association Journal, 138, 231-235.
4. Kugler, K. and Jones, W. H.(1992). On conceptualizing and assessing guilt. Journal of Personality and Social Psychology, 62, 318-327
5. Spillers, R. L., Wellisch, D. K., Kim, Y., Matthews, B. A. and Baker, F. (2008). Family caregivers and guilt in the context of cancer care. Psychosomatics, 49, 511-519.
6. Brodaty, H. (2007). Meaning and measurement or caregiver outcomes. International Psychogeriatrics, 19, 363-381.

Table 4-B: Guilt and its Impact on Care Givers

Question	Current N (%)	Past 5 years N (%)	P-value
<b>With whom you have shared "Guilt" feeling?</b>			
Father	18(14.8)	7 (10.9)	0.067
Mother	38(31.1)	14(21.9)	
Spouse	19(15.6)	20(31.3)	
Sibling	31(25.4)	19(29.7)	
No response	16(13.1)	4(6.3)	
<b>Does sharing "Guilt" feeling make you feel better?</b>			
Yes	69(56.6)	40(62.5)	0.483
No	27(22.1)	15(23.4)	
Don't know	26(21.3)	9(14.1)	
<b>Ever sought professional help to resolve "Guilt" feeling?</b>			
Yes	26(21.3)	8(12.5)	0.294
No	85(69.7)	48(75.0)	
Don't know	11(9.0)	8(12.5)	
<b>Has "Guilt" feeling reduced with time?</b>			
Yes	65(53.3)	34(53.1)	0.826
No	38(31.1)	18(28.1)	
Don't know	19(15.6)	12(18.8)	
<b>"Guilt" feelings arising from deficiencies of caregiving negatively impact you?</b>			
Family life	43(35.2)	24(37.5)	0.959
Prof life	24(19.7)	13(20.3)	
Social life	29(23.8)	12(18.8)	
Other	19(15.6)	11(17.2)	
All	7(5.7)	4(6.3)	

7. Health and Human Services. Informal Caregiving: Compassion in Action. Washington, DC: Department of Health and Human Services. Based on data from the National Survey of Families and Households (NSFH), 1998.

8. The Henry J. Kaiser Family Foundation (KFF), Harvard School of Public Health, United Hospital Fund of New York, and Visiting Nurse Service of New York. The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective. Menlo Park: KFF, 2002.

9. National Alliance for Caregiving and AARP. Caregiving in the U.S. Bethesda: National Alliance for Caregiving, and Washington, DC: AARP, 2004.

10. Metlife Mature Market Institute. The Metlife Study of Sons at Work Balancing Employment and Eldercare. New York: Metropolitan Life Insurance Company, 2003.

11. Yee, J. L., and R. Schulz. 2000. Gender differences in Psychiatric Morbidity among Family Caregivers: A Review and Analysis. *The Gerontologist* 40:147-164.

12. Navaie-Waliser, M., A. Spriggs, and P.H. Feldman. 2002. Informal Caregiving: Differential Experiences by Gender. *Medical Care* 40:1249-1259.

13. Schulz, R., A.T. O'Brien, J. Bookwala and K. Fleissner. 1995. Psychiatric and Physical Morbidity Effects of Dementia Caregiving: Prevalance, Correlates, and Causes. *The Gerontologist* 35:771-791.

14. Cannuscio, C.C., J. Jones, I. Kawachi, G.A. Colditz, L. Berkman and E. Rimm. 2002. Reverberation of Family Illness: A Longitudinal Assessment of Informal Caregiver and Mental Health Status in the Nurses' Health Study. *American Journal of Public Health* 92:305-1311.

15. Kiecolt Glaser, Ja., and R. Glaser. Chronic Stress and Age-Related Increases in the Proinflammatory Cytokine IL-6. In proceedings of the National Academy of Sciences, 2003.

16. Lee, S, G.A. Colditz, L. Berkman, and I. Kawachi. 2003. Caregiving and Risk of Coronary Heart Disease in U.S. Women: A Prospective Study. *American Journal of Preventive Medicine* 24: 113-119.

17. Beach, S.R., R. Schulz, J.L Yee and S. Jackson. 2000. Negative and Positive Health Effects of Caring for a Disabled Spouse: Longitudinal Findings from the Caregiver Health Effects Study. *Psychology and Aging* 15:259-271.



18. Ingersoll-Dayton, B. and Raschick, M. (2004). The relationship between care-recipient behaviors and spousal caregiving stress. *The Gerontologist*, 44, 318-327.
19. Jacobi CE, van den Berg B, Boshuizen HC, Rupp I, Dinant HJ, van den Bos GAM. Dimension-specific burden of caregiving among partners of rheumatoid arthritis patients. *Rheumatology(Oxford)*. 2003;42:1226-33.
20. Fonseca NR, Penna AFG, Soares MPG. Ser cuidador familiar: um estudo sobre as consequências de assumir este papel. *Physis Rev Saúde Coletiva*. 2008;18(4):727-43.
21. Gratão ACM, Vale FAC, Roriz-Cruz M, Haas VJ, Lange C, Talmelli LFS, et al. The demands of family caregivers of elderly individuals with dementia. *Rev Esc Enferm USP [Internet]*. 2010 [cited 2012 Mar 22];44(4):873-80. Available from: <http://www.scielo.br/pdf/reeusp/v44n4/03.pdf>