Pakistan Journal of Professional Psychologists Vol 6, No. 1, 2015

https://doi.org/10.62663/pjpprp.v6i1.88

Burden of Care, Mental Health and Subjective Well Being of Family Caregivers of Elderly Patients

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Abstract

This study is aimed at identifying how the burden of care of the elderly patients suffering from dementia and physical disabilities is related to mental health and subjective well-being of the family caregivers. In this study, survey research design was used and data were collected through convenient sampling from 100 caregivers of elderly patients with dementia (n = 50) and physical disability (n = 50). Four tools were used; The Caregiver Strain Index (Robinson & Price, 1982); General Health Questionnaire (Goldberg, 1978); and The Subjective Happiness Scale (Lyubomirsky and Lapper, 1999). Correlation and t-test were carried out and findings showed a significant negative correlation between burden of care and the caregiver's quality of life. The caregivers of dementia patients showed a significant decline in their mental health as compared to the caregivers of patients with physical disability; however both the groups did not show any significant difference in terms of burden of care. Significant gender differences were noted in terms of depression. Further results indicated that the caregiver's education and occupation were significant predictors of burden of care. The importance of the study lies in the fact that the findings will be highly valuable in gaining insight into

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the psychological problems experienced by the family caregivers in Pakistan.

Key words: Burden of care, mental health, family caregivers

Introduction

People usually grow old within their families. Families provide companionship and various forms of support to their elderly as an expression of love and kindness and hold a significant importance in meeting their physical and psychological demands (McCorckle, Faan & Pasacreta, 2001). The demands of care giving vary from individual to individual, however, the most common demands usually involve helping them with physical activities such as bathing or other complex activities, like reading or writing etc . The most important aim of care giving is to make the care recipient more independent by restoring his or her most functional state, both physical and psychological (Bridges, 1995, p. 13). Family caregivers or informal caregivers provide care and assistance to the care recipient without getting paid, for instance, a daughter or a son, a wife or a husband (McConnell & Riggs, 1994; Haley, 2003). The burden of care increases with the increased contact with a patient, especially when patients live with their families (Schulze & Beate, 2005; Salama & El-Soud, 2012). The responsibilities of care giving can however, give rise to difficult personal issues regarding responsibility, duty, adequacy and guilt. Close relationships can also give rise to conflicts and distress as well (Stenguard, 2002 and Qualls & Zarit, 2009).

Family dynamics are highly affected when it comes to caring for someone with a mental or physical disability, since most of the time and energy of the caregiver is invested in taking care of patients (Vitalianio, Zhang & Scanlan, 2003). The role of the caregiver gets even more stressful and burdensome when the elderly members manifest psychological problems, accompanied by a physical illness or disability. The elderly patients have diverse needs and demands which include managing medication, taking patient for treatment to hospital, assisting in daily activities and providing emotional support to the care recipient (Ostman & Hanssob, 2002). Each caregiver copes with these stressful factors differently and the burden of care also leads to financial and social burden disruptive lifestyle, causing decreased socialization (Schulz et al., 2003). Burden of care does not only affect the physical emotional and psychological wellbeing of the caregiver but also results in feelings of guilt, shame, self-blame and embarrassment on part of the caregiver (Reay-Young, 2001). Thus affecting the caregiver's physical, psychological and social functioning in a negative manner (Lauber et al, 2003; Yajima et al., 2007). Studies have reported significant associations between burden of care (especially emotional involvement, disappointment and isolation) and caregivers' sense of coherence and perceived health according to age and relationship (Andren et al, 2008). Various studies have reported that most of the caregivers are prone to suffering from depression (Larsen & Lubkin, 2009). Due to burden of care, families are very often the silent and hidden victims of some of the highly devastating diseases like Alzheimer's or Dementia, (Dura et al, 1991; Yvonne & Austrom, 2005). Research has shown that the burden of care leaves a highly negative impact on the lifestyle of caregivers. It has been found that the drastic changes in lifestyle includes an increase in stress resulting from confinement, giving up job to look after an aging member of the family, making changes in the work schedule, reduced work hours resulting in deduction of pay (Schulz et al., 2003; White-Means & Rubin, 2004 and Belle, 2006). Responsibilities of care giving, work conflict, absence at work, job turnover, missing opportunities are some other important factors underlying stress. Elevated levels of care giving stress may be a consequence of the demands of caring on behalf of a severely impaired elderly, complicated life style, and lack of effective resources and higher levels of burden perceived by the caregiver (Arai, Zarit, Sugiura, & Washio, 2002 & Schulz, O'Brien, & Bookwala, 1995).

Researchers have found that men and women differ in terms of responsibilities and burden associated with care giving and thus the impact of burden of care on both the genders may also be different (Robins, 1982). Gender also appears to be a salient predictor of caregiver burden. It has been found that female caregivers suffer from more psychiatric disorders as compared to male caregivers. Female caregivers are also much more likely than male caregivers to report being anxious or depressed, or experiencing lower levels of life satisfaction (Yee & Schulz, 2000). While women report comparatively higher burden of care, conflicting roles and strain, women are more likely than men to carry on with the care giving responsibilities over a longer period of time as compared to the male caregivers. Women are less likely than men to obtain assistance from others while providing care and there is less likelihood for female caregivers to indulge in preventive health behaviors, such as relaxation, exercise and taking proper medications while care giving as compared to male care givers (Larsen & Lubkin, 2009).

To conclude, the compendium on family care giving to elderly patients with dementia and physical disability, reveals that burden of care adversely impacts the caregiver's emotional, physical, and mental health, quality of life and subjective wellbeing. It has also been noted that more women as compared to men serve as caregivers to the mentally or physically impaired elderly and thus their mental health is at a greater risk than men (Doornbos, 1997). In England, the National Health Services (NHS), provides nurses to the families to take care of patients; moreover, they usually have special day care centres for patients where care is provided to them regardless of the availability of any of the family members. But in Pakistan, family members are mostly the principal caregivers who have to do all the duties and this is why the life of the caregiver in Pakistan is more affected in terms of mental and physical health. Anyhow, this issue is a less explored area of research in our country, so this study was conducted to get an insight into this.

Objective

To assess how the burden of care of elderly patients with dementia and physical disability relates to the mental health and subjective well-being of their family caregivers.

Hypotheses

- There would be a significant negative relationship between the burden of care of elderly patients with dementia and physical disability and subjective well-being of their family caregivers.
- The mental health and subjective well-being of the female caregivers would be significantly higher as compared to the male care givers.
- The mental health of the family care givers of dementia patients would be significantly higher as compared to the family care givers of the patents with physical disability.

Methods

Research Design

Cross Sectional Survey Research Design was used in this study.

Participants

Data were collected from 100 caregivers (50 caregivers of patients of dementia and 50 caregivers of physically disabled elderly patients) from four hospitals in Lahore, by using convenient sampling technique. The age range of participants was 18 to 70 (M = 38.73, SD = 10.873). The demographic information about the participants comprised of name, age, gender, social class, education, occupation, marital status and relationship with the elderly patient.

Operational Definitions

Burden of Care. A stress that results from care giving and refers to how much the caregivers feel about their physical and psychological health, financial or economic status has been negatively affected (Robinson & Price, 1982).

Mental Health. Defined as not merely the absence of a psychological problem; rather it is a condition of complete psychological stability and wellbeing (Goldberg et al, 1978).

Subjective Well-being. It refers to how an individual perceives and assesses his or her happiness and satisfaction with life and includes an overall sense of emotional, physical and psychological health and wellbeing (Lyubomirsky & Lapper, 1999).

Instruments

The Caregiver Strain Index (CSI). The Caregiver Strain Index is commonly used to trace the families with potential concerns regarding caregiving. The scale consists of 13 items which asses the stress resulting from caregiving. The test is divided into the main domains of that are physical, social, employment, financial and time. Higher level of strain is indicated if there are seven or more positive responses to the items on index. The instrument can be used to assess caregivers of elderly patients, belonging to any age group. Seven or more positive responses represent the need to assess the caregivers more deeply and to propose proper intervention. The Internal consistency reliability of the scale is 0.86 and construct validity of the scale is correlated with the physical and emotional health of the caregiver as well as the views regarding the context of caregiving (Robinson, 1983; Thornton & Travis, 2003).

General Health Questionnaire (GHQ-28). The General Health Questionnaire (GHQ) assesses the current mental health of an individual by asking whether or not the respondent has recently experienced a particular behavior or symptom. Every item is rated on a four point scale (As cited in, Montazeri et al, 2003). General health questionnaire is the most commonly used assessment tool for mental wellbeing. It was developed as a tool to assess people who are prone to fall a victim to psychological disorders. GHQ assesses the mental health problems which are most common such as somatic complaints, anxiety, depression and social withdrawal. The GHQ is available in various versions consisting of 12, 28, 30 and 60 items. The version of GHQ containing 28 items is most widely used. Reliability coefficients of the scale range from 0.78 to 0.95. The GHQ-28 shows a high correlation with the Hospital Anxiety and Depression Scale (HADS) (Sakakibara et al, 2009) as well as with other assessment tools for depression (Robinson & Price, 1982). The General Health Questionnaire is easy to administer and score. It can be scored in many different ways which can be important in providing multiple measures for outcomes (Goldberg et al, 1978). In the current study, the Urdu translated version of GHQ-28 was used.

The Subjective Happiness Scale (SHS). The SHS is aims at assessing one's subjective wellbeing and comprises of only four items. Among them, two items require the respondents to characterize themselves using both their own rating and ratings which are relative to their friends. The remaining two items offer brief descriptions of happy and unhappy person and require the respondents to mark the degree to which each item describes them. The SHS has high internal consistency. The scale has high convergent and divergent validity. Good to excellent reliability has been shown by test-retest and self/peer correlations. According to various samples which have been studied, the reliability coefficient has been estimated to be between .73 and .87. The scale has high convergent and divergent validity. The responses are scored on a 7 point scale. The lowest score that one can possibly get is 0 and the highest is 60. The scale assesses the levels of happiness or the intensity of happiness of a certain individual. The highest happiness score is 7. The average score runs from about 4.5 to 5.5. If an individual scores below 5.5, then he or she is less happy as compared to an average individual. A person scoring less than 4 may be required to be assessed for depression (Lyubomirsky & Lapper, 1999).

Procedure

After the approval of the Board of Studies (BOS), an official letter for data collection was obtained from the department and was delivered/ posted to the concerned hospitals. The data was collected from three hospitals in Lahore. On getting permission from the heads of the said institutions informed consent was taken from the participants who were the care givers of patients with dementia and the caregivers of patients with physical disability. A debriefing about the study was given to the participants. They were assured about the confidentiality of the data obtained from them. Data were then analyzed with the help of SPSS 16.

Results

The first hypothesis was that there would be a significant negative relationship between the burden of care and subjective wellbeing of family caregiver's, for which correlation analysis was applied and the results show a significant negative relationship between burden of care subjective well-being of family caregivers ($r = -.37$, $p< 0.01$).

The second hypothesis of the study was that there would be significant gender differences in terms of mental health and subjective wellbeing for which t-test for independent samples was applied and the results are shown below in table 1.

Table 1

Means, SD and t-values of Scores on Mental Health and Subjective Well-being of Male and Female Caregivers (N=100)

Variables	Group	N	M	SD	*t(98)*
Mental Health	Men	50	16.88	2.74	3.82*
	Women	50	19.98	5.02	
Subjective Well Being	Men	50	10.40	2.60	0.54
	Women	50	10.10	2.94	

Note: * $p < .05$

Both the groups of men caregivers and women caregivers showed significant differences in terms of mental health, but no significant differences were found in subjective wellbeing. Mental health of the female caregivers was affected more as compared to the male caregivers.

The third hypothesis of present study state that there would be significant differences between dementia caregivers and caregivers of patients with physical disability in terms of burden of care and mental health, for which t-test for independent samples was applied and the results are shown below in table 2.

Table 2

Means, SD and t-values on Burden of Care and Mental Health of Care Givers of Dementia and Caregivers of Patients with Physical Disability

Variables	Groups	n	M	SD	*t*(98)
Burden of Care	Dementia	50	12.08	0.75	1.68
	Physical Disability	50	11.74	1.21	
Mental Health	Dementia	50	20.74	2.72	6.31*
	Physical Disability	50	16.12	4.41	

Note: *p <.05

Both the groups i.e., caregivers of patients with dementia and caregivers of patients with physical disability did not showed any significant difference in terms of burden of care. However, the caregivers of patients with dementia showed a significantly poorer mental health as compared to the caregivers of patients with physical disability.

The findings of this study indicated a highly negative correlation between burden of care and the caregiver's quality of life. Male and female caregivers showed significant gender differences in terms of mental health. The caregivers of patients with dementia showed a significant decline in mental health as compared to the caregivers of patients with physical disability; however both the groups did not show any significant difference in terms of burden of care.

Discussion

The first finding showed a highly negative correlation between burden of care and quality of life and this finding is consistent with earlier Western findings. For example, Gronfeld, et al, (2004) found that the quality of life of the caregiver is affected by four major characteristics of the caregiving situation, i.e., high care giving demands, psychological distress, loss of physical health for the caregiver and interference with life styles. Depression, anxiety, and a feeling of burden can be the consequence of the emotional toll of care giving (Doornbos, 1997; Maurine & Barmann, 1990). Similarly, Miura, Arai and Yamasaki (2005) noted that there was a significant negative association between the burden of care and quality of life, especially in relation to mental health. Another study revealed that poor family relationships, low earning and burden of care were linked to low quality of life among caregivers (Hughes, et al, 1999). In a study conducted by Ekwall, Sivberg and Hallberg (2005) it was evident that there was a significant relationship between loneliness, limited social network and decline in quality of life of family caregivers; who face increased stress and strain because of their participation in care giving activities and were more likely to have higher morbidity and mortality than caregivers who report little or no difficulty providing care to the patient. Similar results have been found by study of Schulz and Beats (1999). Researchers have also shown that caregivers can suffer from physical ailments as well as anxiety and depression, strain in marital relationships, restrictions of roles and activities, and diminished physical health (Given et al, 2004 & Haley et al., 2001).

The second finding of the research revealed significant gender differences in terms of mental health of caregivers which is in line with Western findings. For example, Given and Given (1991) noted poor physical and mental health among wife caregivers than husband caregivers, and daughter caregiver than a son caregivers. A study conducted by Elmahdi (2011) indicated that prevalence of psychiatric disorders were reported to be higher in wives as compared to husbands, which may be attributed to the difference in their appreciation of the care giving situation and their responsibility towards the individual in need of care. Both the genders, i.e., men and women differ in terms of responsibilities and burden associated with care giving and thus the impact of burden of care on both the genders may also be different .As compared to men, women were more likely to assume the care giving role across the lifespan, but men who are 75 years of age or older are more likely to be caregivers than the comparable age group of women. In a longitudinal study conducted by Zarit et al (1986) it was found that initially wife caregivers reported more subjective burden than did husband caregivers. However, no significant differences were found two years later. The researchers speculated that the wives adjusted their coping style to a more instrumental approach that the men adopted from the beginning (Robins, 1982 & Yee & Schulz, 2000). Gender also appears to be a salient predictor of caregiver burden as noted by Larsen and Lubkin (2009). Research related to dementia and non-dementia care giving have found that in contrast to male caregivers, increased levels of burden are experienced by the female caregivers (Awad & Voruganti, 2008).

Present research also aimed to determine difference in terms of burden of care and mental health of both care givers of dementia and non-dementia patients. The results revealed that care givers differs significantly in terms of their mental health but not different in their experiences as burden of care. The findings are similar to the findings of prior studies which suggest that dementia caregivers experience more negative effects, such as high anxiety and depression, as compared to non-dementia caregivers as a consequence (Moritz, Kasl & Berkman, 1989; Hooker et al., 1998). As care giving is very stressful job therefore, dementia caregivers usually report to have given up pleasurable activities or not having much time for other family members. Moreover, dementia caregivers have also been found to report significantly higher physical, emotional strain (more likely to experience/express anger) and mental health problems as compared to non-dementia caregivers (Scultz & Martire, 2004). Another study revealed that caregivers of patients with dementia spent significantly more hours per week in the provision of care as compared to non-dementia caregivers therefore, experienced greater caregiver strain as well as physical and mental problems, employment complications, sparing time for themselves and other members of the family (Ory, Hoffman, Yee, Tennstedt & Shulz, (1999). Studies targeting the elderly with disability have shown that the amount of care provided; increases the likely hood of burden, psychological and emotional strain in caregivers which is also found to be significantly linked with the severity of physical and psychological symptoms of the care recipient (Abramson & Dunkin, 2004: Elmahdi, 2011; Horowitz, 1985; Navidian, Kermansaravi, Rigi, 2012; Yurtsever, et. al., 2013).

Conclusion

This study was conducted to assess mental health problems and burden of care faced by the family caregivers of elderly patients in Pakistan. The findings revealed that the burden of care experienced by the family caregivers of elderly patients leaves a negative impact on their mental, physical and emotional health that adversely effect their quality of life as well as their subjective wellbeing. It was found that the mental health of female caregivers is affected more by the burden of care as compared to the mental health of male caregivers. The caregivers of patients with dementia showed a significant decline in mental health as compared to the caregivers of patients with physical disabilities. Both the groups of male and female caregivers revealed significant gender differences in terms of mental health problems. Female caregivers are more prone to suffer from anxiety, depression and social withdrawal as compared to the male caregivers. The present results are similar to the western findings that have yielded similar results. There are a number of factors i.e., the intensity of care giving; gender differences, types of tasks performed during the care giving process, relationship of both the caregiver and the care recipient, assistance and support from members of the family, personal characteristics of caregivers and the demands and obligations of care giving in specific cultures which affect care giving and the resulting stress.

Implications

The study gives an insight in understanding how burden of care affects the caregiver's mental and physical health as well as quality of life and subjective wellbeing in Pakistani society. These findings can help the mental health professionals to devise certain support and self-help strategies as interventional devices which will help the caregivers to take a better charge of their own health and well being. Furthermore findings of the study are valuable and helpful for health professionals to understand emotional problems, subjective complaints and functional impairment in the caregiver's psychiatric assessment for which they can devise therapeutic interventions. Moreover, present study findings are helpful in motivating the social support networks and encouraging caregivers to make use of these helpful facilities in coping with the problems of patient care, adapting to their roles and providing relief from isolation (by sharing news, interacting their friends/neighbors, discussing problems/feelings which may all help relieve the stress of caring for a patient). Findings of study are very important in the sense as they will be helpful in devising sufficient information pack to be provided to the families of elderly patients regarding support and practical assistance through psycho-educational programs. And last but not least providing social support to caregivers will decrease the use of nursing homes, which have very high costs.

Limitations and Suggestions

The study has been conducted on a relatively small sample of 100 caregivers of only two types of elderly patients suffering from dementia and physical disability. Accordingly, a future study should be conducted on a larger sample, preferably covering more cities in Pakistan, and on family care givers of other types of elderly patients as well so that the findings can be more generalized. A cross cultural comparable study can also be conducted to see the differences in terms of burden of care and mental health of family caregivers of elderly patients. Furthermore, in relation to present study variables the effectiveness of support and mental health interventions on adjustment and quality of life of caregivers should also be studied to better meet the caregivers' mental health needs.

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