

Problems Faced by Caregivers of Alzheimer's Patients

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Care giving is a difficult task especially when it involves physical or mental retardation, and it leaves marked negative impact on primary caregivers. Alzheimer is one such ailment where the patient is totally dependent on others for each bit of their life, so the care giving of Alzheimer patients become more burdensome. The aim of this research was to examine the burden and difficulties of caregivers dealing with Alzheimer's patient, especially those living at home. Case study method was employed for this research. Eight caregivers were selected purposively, and content analysis was used to examine their perspective regarding burden and challenges. In the assessment of content, the gathered qualitative information was analyzed in a deductive manner. The results of the analysis showed that caregivers face daily challenges in terms of physical and psychological health issues, social support and resources, family conflicts, crisis, and criticism. The outcomes further elaborated that due to different roles and responsibilities as caregivers they face both positivity and negativity in their lives which in most cases leads them to religiosity. The results of this study can add to positive social change by contributing to the development and implementation of programs that may take into account considerable differences in future.

Keywords. Alzheimers, caregivers, content analysis, conflicts, crisis, and criticism, Deductive

Caring is considered very demanding and involving task both physically and emotionally. Caregivers are defined as "concealed patients because of their high rate of depression and anxiety along with burden of care (Montine et al., 2012). The burden on caregivers

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is described as a multidimensional response to healthcare experience in personal, economic, physical, psychological, and financial strains (Kasuya & Meguro, 2010). Family support, particularly regular visits from other family members and the existence of a powerful social network correlates to a reduce burden on caregivers (Parks & Novielli, 2003). According to Coetsee (2007), care can be recognized as providing exceptional care and can extend over a long period of time. Caregiving also often requires significant investment in time, resources, and finance; often entails difficult tasks, and can be exhausting both mentally and physically.

Alzheimer's disease (AD) is a progressive disorder that causes brain cells to waste away and die, symptoms include mild memory loss in beginning leading to inability to carry out conversation and daily activities. Parts of brain that are involved in controlling thought, memory and language are affected by this disease (Center of Disease Control: CDC, 2020). AD slowly reduces the ability of people to perform their cognitive tasks and normal daily activities (Włodarczyk, Brodaty, & Hawthorne, 2004). Patient independence gradually gets restricted as the severity of AD prolongs. In all complicated and fundamental daily operations, patients need assistance (Pfeffer, 2004). They generally remain in bed at the last point of the disease because they are unable to move and have trouble remaining in contact with the environment (Klimova et al., 2015). Because the patient becomes totally dependent on the caregiver and because of long-term nature of the condition, care slowly becomes exhaustive. The role of caregiver increases with the severity of the disease cycle. Excessive responsibilities lead to caregiver burnout growth. Many factors have an impact on AD patient caregivers' sense of burden. These variables may vary from caregivers' personality characteristics, patient functional constraints, obstacles and networks of assistance (family support, friends, and acquaintances), their level of care and their quality of life.

Most often, caregivers with excessive burden are females, people with low social status, elderly individuals, and individuals with low educational levels. Certain factors that influence the feeling of burden are: tension, financial or personal constraints and even the relation before and during the disease between the caregiver and the patient (Rachel & Turkot, 2015). It is difficult to care for elderly Alzheimer patients. As a result of daily care needs, including changing, bathing feeding, day to day assistance and household work, care givers frequently fail to address their own needs sufficiently (Neumann & Dias, 2013). All these are directly the responsibility of the primary caregiver.

While, everyone plays a significant role in care, it is evident that the primary caregiver is responsible more for offering care and attention (Ricoeur, 2016). By contrast, secondary care providers can perform the same roles as primary care providers but they are not responsible for decision-making on the same scale. Secondary care providers replace primary care providers for a short period of time and normally perform specific tasks such as shopping, patient transport assistance, pension collection and bills of payment.

Literature Review

Caregiver burden has been identified as the challenges faced by family members who are caring for the elderly or disabled people (Andren & Elmstahl, 2008; Vellone et al., 2012). The role of caregivers can be broken down into an objective and subjective dimension. Objective stress identifies the effects of Alzheimer's disease for individual behavioral and physical changes, as well as the events related to adverse care experience. The subjective dimension addresses the caregiver's emotional and psychological implications, such as anxiety and depression (Mahoney & MacSwan, 2005). Caregivers experience a feeling of grief on a daily basis that can be distinguished from depression. Grief happens when there is a threat to a person's security and security within a partnership (Ott, Sanders, & Kelber, 2007). At the same time, caregivers often experience a sense of loss when assuming the new role of caregivers.

Because of the caretaker's responsibility, they confront problem mentally, physically and medically and as a result become a subordinate patient of Alzheimer's and dementia care recipient. Considering the adverse effects of Alzheimer's disease on caregivers and other disorders, knowing the risk factors that influence the guardian's well-being and health is essential. Dementia patients have a fourfold greater likelihood of anxiety than non-caregivers and two folds of antidepressant therapy. With more depressive manifestations, larger amounts of stress are recognized (Wimo et al., 2013).

Spousal caregivers for dementia can suffer from mental disability and additional risks to the development of dementia (Norton et al., 2010). Possible factors attributing greater psychological danger are psychosocial, cognitive, and physiological (Vitaliano, Murphy & Young, 2011). Moreover, risk of depression, social isolation and instability, may lead to intellectual decline (Vitaliano, Murphy & Young, 2011). Sleep disturbance, sleep disorder or sleep loss can also occur in care givers (Cupidi et al., 2012) along with difficulties in

daily home routine, constraints in social life and changes in sleep patterns (Thommessen et al., 2002). But social support may decrease the burden of psychological and non-psychological illness (Jiang et al., 2016), prevent social isolation and solitude (Thompson et al., 1993), and encourage social integration and interpersonal relationships.

Gallant and Connell (2003) discovered that care is linked to insufficient practice, sleep loss, and weight gain or loss. Sansoni et al. (2004) research showed that 56% of caregivers had energy loss, weight fluctuations, and insomnia. The physical impact on carers taking care of a dementia patient is considered to be highly stressful and potentially harmful physical health problems (Mahoney & MacSwan, 2005; Vitaliano et al., 2003). This situation may lead care givers to increased consumption of alcohol, an unhealthy diet and consumption of tobacco (Suinn, 2001). Haley et al. (2004) suggests that care may influence the immunity of caregivers.

Caring for an Alzheimer's patient, however, can trigger mental, psychological, and physical issues. In most cases of Alzheimer's disease, at least two people are affected; the person and caregiver (Mannion, 2008). AD has a stronger impact not only on patients' quality of life but also on patient families and caregivers. AD causes physical illnesses and mental health problems among caregivers. Whilst AD is a chronic disorder, the burden can be minimized by collaboration between the health care provider, the public, social institutions, nurses and secondary health care providers. This study was conducted in order to analyze the extent of burden of Alzheimer's caregivers and to establish the relationship between selected parameters and burden feelings.

Objectives

1. To identify the problems and challenges faced by Alzheimer patients' caregivers.
2. To determine the impact of Alzheimer patients on the lives of caregivers.
3. To identify the aspects of care giving in caregivers life.

Method

A qualitative, descriptive study was conducted by the researcher. Qualitative description (QD) is a label used in qualitative research for studies which are descriptive in nature, particularly for examining health care and nursing-related phenomena (Polit & Beck, 2009).

Sample

Eight AD patients' family caregivers were chosen. Purposive sampling technique was used to identify the study sample. The purpose behind using this technique was to collect data only from caregivers of Alzheimer patients. All participants were primary caregivers of the Alzheimer patients. The participants include one male and seven females, the reason behind such selection is that only these participants were willing to participate in research. Moreover, in Pakistani household the females are entrusted to take care of the elderly, that is why, there were women as primary caregivers. The data was collected in person by researcher and audio recording and hand written notes were taken.

Table 1

Demographic Characteristics of Care Givers of Alzheimer Patients

| Participants Sex | Age | Relation with patient | Qualification |
|------------------|---------|-----------------------|---------------|
| Male | 50years | Son | Masters |
| Female | 32years | Daughter in law | M.Phil. |
| Female | 81years | Wife | B A. |
| Female | 52years | Wife | Intermediate |
| Female | 40years | Daughter | Masters. |
| Female | 80years | Wife | Matric. |
| Female | 27years | Daughter in law | M.Phil. |
| Female | 52years | Wife | Matric. |

The demographics mention Table 1 indicates that all the care givers were educated and from different age groups but most striking age group was 80 plus because usually in this age people themselves need care but two of our participants were providing primary care to AD patients.

Procedure

First of all a semi structured interview protocol was formulated by reviewing the literature, discussions with supervisor, and co-supervisor in detail regarding psychosocial stressors of caregivers and coping strategies. Researcher conducted 8 semi-structured interviews for data collection. Participants were contacted in hospitals, clinics and on recommendation of other participants. The researcher obtained prior approval from head of Neuro department Allied Hospital Faisalabad, Neuro Surgeon Faisal Hospital Faisalabad, and Alzheimer Association Lahore before conducting the research and asked for their cooperation in contacting caregivers. Informed consent was drafted in

simple Urdu and English languages. The participants were guided about their privileges of privacy, confidentiality, and all necessary information about the study that it will not be the cause of any physical, emotional, professional, personal and psychological harm. The participants were ensured that information given by them will not be shared with anyone in any way and the identity of any particular participant will not be revealed. The research was designed and conduct with all recognized ethical and scientific laws, principles and standards given by American Psychological Association (APA) and Higher Education Commission (HEC) Pakistan.

Researcher interviewed the individuals at their recommended place according to their possibility and availability. The researcher ensured ethical considerations before the interview started, each member was briefed about the nature of research and the worth of their involvement in research work. Approval for the recording of their interview was taken from the participants. There were no supports of any assistant so researcher took notes of interviews and also tried to note body language of caregivers. All 8 case studies were set according to feasibility and accessibility of participants. Each case study interview took different time from minimum 40 minutes to maximum 90 minutes. During the interviews some of the questions were based on predefined research questions but some questions were explained according to the caregiver's understandings. During interviews researcher faced some problems and hurdles for example one of the participant asked to come to her school for interview but when researcher reached there, she refused to record interview. Researcher requested her again and again then she asked to come to her mother's home. One of participant was interrupted again and again due to patient's needs. After collecting data, all interviews were transcribed by the author. Content analysis was used to evaluate discourses, following four steps: original text reading, distancing, structural analysis, deeper understanding and appropriation (Kripendorff, 2004). For this, researcher endorsed deductive content analysis approach with preconceived themes along with their frequencies.

Results

The data of eight caregivers of Alzheimer's patient was analyzed by using content analysis. Researcher extracted common themes and converged into major themes. Themes generation from transcript of interviews was initially done by researcher and one of her assistant and then for cross checking and validation supervisor and co supervisor also reviewed the themes.

Table 2

Major Themes and Sub-Themes Extracted from Transcribed Data From Care Givers of Alzheimer Patients

| Major Themes | Sub Themes | Frequency |
|--|---|--|
| Physical and Psychological Health Issues | Depression Stress Feeling of hopelessness Lack of self-esteem/self-respect Anger Insomnia Burden Fatigue Fever Headache Loss of appetite Physical health disturbed | 09 05 03 02 04 02 11 08 05 06 01 04 |
| Roles & Responsibilities` | Overloaded with work Responsibility for feeding, bathing & changing Household chores Look after kids and everyone Struggling/ Hardworking | 03 07 02 01 01 01 |
| Religious Inclination | Religious strengthen Devotion towards Allah Offer prayers | 04 03 08 |
| Positivity | Hope Faith | 01 03 |
| Lack of social support | People complain instead of appreciation Social burden | 13 09 |
| Limited Social life | Lack of social life Difficulty in social mobility Social isolation Criticism by people | 02 01 02 01 |
| Family conflicts | Marriage bond affected Home disturb | 09 08 |
| Struggling life | Compromising relation Loss of self Financial hardships Become second patient | 06 02 07 01 |
| Negativity | Dark future Feel empty | 02 01 |

Table 2 illustrates the major findings identified from caregivers. Caregivers must face a lot more issues that may start from their health.

Whether it is psychological or physical it is certain that they are the sufferers. Caregivers are often facing issues and become a second patient. But this has a positive impact regarding religious implications.

Table 3

Frequency of Occurrence of Major Themes Among Care Givers of Alzheimer Patients

| Major Themes | f | % |
|--|-----|------|
| Physical & psychological health issues | 65 | 40.1 |
| Roles & Responsibilities | 15 | 9.25 |
| Religious Inclinations | 14 | 8.64 |
| Positivity | 04 | 2.46 |
| Lack of social support | 22 | 13.5 |
| Limited social life | 06 | 3.70 |
| Family conflicts | 23 | 14.1 |
| Struggling life | 10 | 6.17 |
| Negativity | 03 | 1.85 |
| Total | 162 | 100 |

Table 3 depicts the frequencies and percentages of major themes. The outcomes revealed the majority of burden caregivers faced are physical and psychological health issues. Than family issues are the major obstacles. After these, lack of social support, roles and responsibilities and religious inclination occur. They are struggling with their life, has limited social life and this ends up on both positivity and negativity.

Discussion

The present study was conducted to examine caregivers' problems and burden they faced while taking care of AD patient. The first theme, physical and psychological health issues depict following sub themes i.e., depression, stress, feeling of hopelessness, lack of self-esteem/self-respect, anger, insomnia, burden, fatigue, fever, headache, loss of appetite, diabetes and disturbed physical health. The results are supported by a previous research that was conducted by Gallants and Connell (2003) and it was found that caring for AD patients was associated directly with loss of sleep along with loss of appetite issues among caregivers. Włodarczyk et al. (2004) study indicates that the disease impacts not only the general health-related quality of life of the patient but also the primary caregiver's quality of life. Caregivers report greater rates of pressure, anxiety, and distress relative to non-caregivers for people with Alzheimer's (Pinquart &

Sorensen, 2003; Sorensen et al., 2008). Another study by Covinsky et al. (2003) supported the present results by concluding that the most common psychosocial impacts of caring are depressive symptoms in care givers (Cuijpers, 2005). Researchers have reported caregiving has adverse effects on the physical health of caregiver (Mahoney et al., 2005; Vitaliano et al., 2003). Sansoni et al. (2004) reported that 56% of caregivers reported loss of energy, change in diet routine along with insomnia.

The second theme was roles and responsibilities which indicated dual burden, workload, household chores, struggling and hardworking and responsibilities of every task. Thies (2004) supported the current results that caretaking becomes a 24-hour task. Melo (2010) also reported same views referring to caregivers' duties towards patient, home and other family members.

The third major theme depicts the religious inclination and positivity, while figuring out the problems, the participants revealed that this situation moved them towards Allah. They offer prayers regularly and have positivity with hope and faith that everything goes smooth and sound. They got attraction towards religion and Allah. Their own faith got strengthened. The results are supported by previous findings. Tedrus et al. (2020) reported in their study that religiosity of caregivers was correlated with that of the AD patients. Heo (2009) suggested that religiosity plays an important role in decreasing caregiver burden and depression, and it facilitates coping with the stressors of care giving (Rammohan, Rao, & Subbakrishna, 2002).

The fourth theme was lack of social support and limited social life, which shows that caregivers are not getting any support, their social life, social mobility and time for friends and family gets limited. The previous literature supported the present results. Thommessen et al., (2002) reported difficulties in daily home routine, constraints in social life and changes in sleep patterns of care givers along with disruption in lifestyle and reduced socialization reported by Schulz et al., (2003). Research has reported that caregiving university relatives are more prone to problems in adjustment and difficulties in social relations (Kazmi & Muazzam, 2017).

The fifth major theme depicts family conflicts indicating that caregivers face hardships in relations, affected marital bond, disturbed home environment and financial crisis. This was supported by previous studies for example Rachel and Turkot (2015) reported economical and personal constraints, increased personal problems (Schulze & Rössler, 2005; Salama & El-Soud, 2012)and that close

relations can further give birth to distress and conflicts as well (Stengard, 2002; Qualls & Zarit, 2009) and it even escalates if patient is living with his or her family.

Last theme extracted, illustrate the struggle and negativity in the life of caregivers. They face issues regarding their health, family and social life, criticism from others, reduced self-esteem and respect. They feel themselves like a second patient. Results are in accordance with previous findings. Research has reported that family members of AD patients experience many types of feelings, including sadness, discouragement, aloneness, anger, and hope, as well as fatigue and depression (Mace & Rabins, 2011).

Most of the researchers that have been conducted in reference to caregiver are mostly done in western countries. Current study has been conducted in reference to Pakistan since most of research studies in Pakistan were focus on the patient rather than the problems of the caregiver. Mostly work in Pakistan has been conducted on caregivers of different diseases but specifically no more work has been done on Alzheimer. Current study has highlighted psychosocial issues of caregiver of Alzheimer's disease patients.

Limitations and Recommendations

Like every study current study has certain limitations as well, while interpreting research results was that the group of study was too small because it was a qualitative research. The sample size has been very limited, so it is necessary to generalize the findings cautiously (Polit & Beck, 2001). A broader sample of Alzheimer caregivers is suggested for future studies. In addition, cultural-specific studies will promote awareness of how Alzheimer's treatment takes place among the population and provide insight into influence of culture on caregivers' needs. Moreover, because AD care can be performed over many years, longitudinal studies should be performed to understand more clearly the long-term effect of AD on caregivers. In this field it is necessary to explore the perspective advantages of qualitative research.

The sample was restricted to only from Lahore and Faisalabad, Therefore, future study could be designed to collect data from all cities of Punjab or Pakistan to explore more variability and diversity in the response. The qualitative data was collected only from volunteers. In future, appropriate screening tool could be used for the selection of participants. The present study did not specify the mental and physical health issues of caregivers. So, the future study could be planned by specifying these to explore impact on family relationships

and life style. There is small sample size, especially, due to the stigma of old age disease reference to Pakistani culture in future quantitative research could be conducted with large sample.

Implications

Current study can aid the psychologists in constructing such provisional strategies of self-help that can aid the caretakers of AD in taking control of their own well-being in a good manner. In addition, findings of current study could aid in better understanding of emotional problems, functional impairments and personal grievance during psychological assessment of care providers. This could also aid in constructing therapeutically intervention. Present study is helpful as it motivates networks of social support and encourages caregivers to utilize such helpful facilities in dealing with the patient's care taking problems, adjusting in their roles and providing help from isolation (by sharing news, intermingling with their friends/neighbors, conversing on problems/feelings which might help in relieving all the stress of they face while taking care for patient. These findings are very important as they will help in construction and relaying of acceptable information to the families of patients regarding functional assistance and support via psycho-educational programs.

Conclusion

Long life leads to higher risk of developing dementias such as Alzheimer's, which require care in patients' homes, which lead to modifications in many families' daily lives. The physical and psychological health of caregivers suffers, as they must fulfill their roles and responsibilities. Their social life becomes limited and in addition to that they must face family issues and lack of social support. Caregivers due to undue burden, not only struggle with their lives, but it also gravitates them turn towards religion. This burden along with negativity, somehow also brings positivity in their lives. Care for an Alzheimer patient requires caregiver to learn and experience another person's sufferings, frequently disguising their own pain and needs. In addition, the coexistence with an Alzheimer's patient requires that caregiver, pay their full attention to the patient and forget their own personal life. It is a common practice that in such tiring and hectic responsibility there might be some missing care related chunks which brought criticism on part of secondary care givers which makes problems even tougher and complicated for primary care givers which further enhances their problems, but religion connects them to the positivity and hope.

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