

Caring for the Caregivers: A Review

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ABSTRACT

Background: Caregiving of a person with Alzheimer's disease can be a stressful for the caregivers at many levels. Management of Alzheimer's disease is mainly driven by the needs of the persons with the disorder which are carried out by the caregivers. Most often, the needs of caregivers become a secondary concern leading to significant burden on them. Hence, it is pertinent to incorporate their emotional wellbeing when designing psychosocial interventions in the management of persons with Alzheimer's disease. **Objectives:** To review relevant literature: 1) to understand the impact of caregiving of a person with Alzheimer's disease on their caregivers and, 2) to study the different psychosocial interventions for caregivers of persons with Alzheimer's disease. **Methods:** The databases searched for the current review are PubMed and Google Scholar. Twenty-five articles were reviewed. **Result:** Caregivers face significant level of distress and burden during the process of caregiving. The level of anxiety and depression is found to be directly correlated with burden among the caregivers. Inability to cope with the situations affects caregiving. Psychosocial interventions like psychoeducation, coping strategies, supportive therapy, relaxation therapy are found to be beneficial. Home based, tailor made intervention is more effective than a clinical based intervention. **Conclusion:** Psychosocial interventions for the management of persons with Alzheimer's disease should incorporate the psychosocial issues and needs of caregivers. Their stress should be addressed for effective management of persons with Alzheimer's disease and better caregiving experience.

Keywords: Caregiving, Persons with Alzheimer's disease, Stress, Burden, and Coping

Alzheimer's disease is a degenerative neurological disorder where a person can gradually becomes totally dependent on the caregivers. It is one of the common causes of Dementia. Persons with Alzheimer's disease face difficulties related to memory, judgment, decision making, and performing daily activities in the initial phases. As the condition progresses the symptoms also start to worsen. Depending on the stage of the disease, persons with Alzheimer's disease require a minimal to full assistance. As the symptoms worsen and the disease progresses caregiving demands also increase.

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Caregiving is a process where a family member looks after the person with Alzheimer's disease and is usually regarded as a caregiver. Informal caregivers are the family members who take care of the day to day activities of a person with chronic illness. They provide assistance and support to the person. They are family members who are primarily involved in taking care of a person with Alzheimer's disease. They are usually a spouse, adult children, or daughter/son in laws. Traditionally in India, elderly parents are assisted by their adult children. It is usually considered as the duty and responsibility to take care of the parents when they get old and dependent.

Taking care of a person with Alzheimer's disease can be extremely exhausting and stressful for most. Caregiving can impact the caregivers in different ways. Caregivers are an integral and the most important part of the caregiving team. Their role of caregiving is often taken for granted and their needs and stresses are hardly addressed in the psychosocial intervention for persons with Alzheimer's disease which tends to focus primarily on symptom management and home based care. Caregiver wellbeing fosters better caregiving experience and input for the Persons with Alzheimer's disease. It is hence important to understand their needs and design an appropriate psychosocial intervention for the family caregivers.

The main objectives of this study were to identify the impact of caregiving on the caregivers and to understand the different psychosocial intervention for the caregivers.

METHODS

Search methods

The databases searched for the current review were PubMed and Google Scholar.

Studies which fulfilled the following criteria were included:

- Studies related to the caregiving issues of a person with Alzheimer's disease and psychosocial interventions for caregivers of persons with Alzheimer's disease.
- The outcome of the studies on caregiver's care focusing on enriching mental health, management of stress and coping strategies.
- Studies employing qualitative, quantitative or mixed methods. Studies published in English language. Manual screening was done to list out the studies according to the inclusion criteria. Twenty-five articles were reviewed.

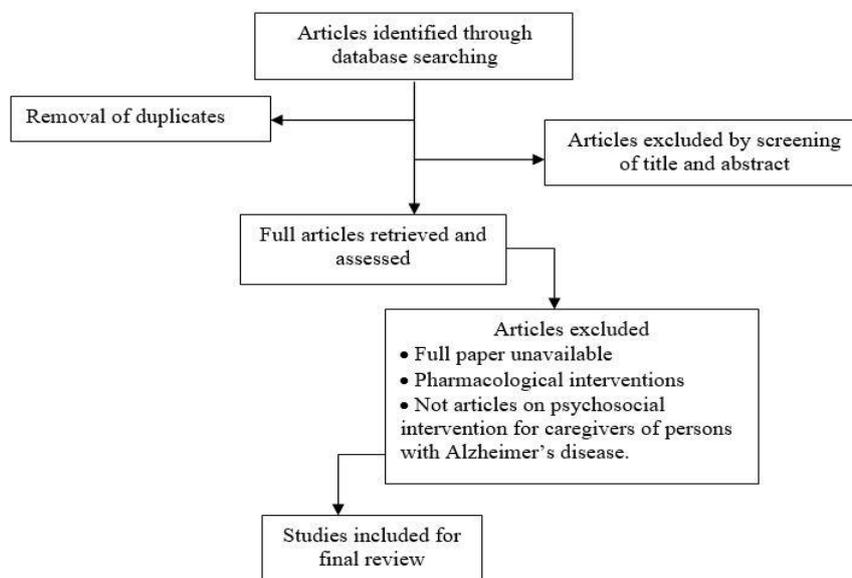


Figure:1 Review flow chart- Selection of articles

RESULT AND DISCUSSION

The studies reviewed were broadly categorized into two sections, namely the impact of caregiving on family members and psychosocial intervention for caregivers.

Impact of caregiving on family members

Taking care of a person with Alzheimer's disease can be a stressful experience (Cheng et al., 2013). The level of psychological distress is usually high among them and they are usually considered as "*The invisible second patients*" (Brodaty et al., 2009).

A family caregiver of a person with Alzheimer's disease has to assist in almost all their activities of daily living. These activities include dressing, feeding, bathing, toileting, etc. (Schulz et al., 1994). There are various cognitive impairments and behavioural issues among the persons with Alzheimer's disease which creates stress and burden among the caregivers as they have to handle these too. Caregivers also experience grief, helplessness and hopelessness.

The caregivers' experiences stress and burden as they have to carry out multiple responsibilities. A person with Alzheimer's disease becomes dependent on the caregivers because of which the process of caregiving becomes all the more stressful which can even lead to mental health conditions like anxiety, depression, etc. (Merlo et al., 2017). As the disease progresses the person becomes more and more dependent on the caregiver. As the dependency increases the level of assistance required also becomes more. They may require assistance in their daily activities like bathing, grooming, toileting, eating, etc. The caregivers may also have their own personal needs which someone becomes secondary for them as they have to give full-time assistance to the person.

William et al., (2013) has defined caregiver burden as negative physical, mental, emotional, social and economic consequences of providing care. Grabher (2018) stated that the impact of Alzheimer's disease and the process of caregiving are multifaceted.

Robinson et al. (2001) identified few indicators which were found to be significantly correlated to the problem behavior associated with impact on caregiving. The indicators are namely "increased restrictions on caregivers activities, decline in physical and emotional health, increased costs, and provoking nature of the person with Alzheimer's disease".

The process of caregiving is associated with a range of negative psychological and physical symptoms as well as financial strains and social isolation. These symptoms may lead to a high level of burden for the caregiver. Factors such as age, socio economic status and strategies of coping influences the level of burden. Attributes of person with Alzheimer's disease, like the level of behavioural disturbances and their cognitive functions also influences the level of burden (Beinart et al., 2012).

There can be different sources of stresses for the family members. These sources can be related to the following: Demographic stress, work related stress, time- related stress, physical and emotional stress (Grabher, 2018). It becomes difficult for the caregivers to adjust their own work schedule with accommodation of the caregiving responsibility. Caregivers may have to even give up their careers or may retire early. When a primary caregiver has to fulfill other demands at one time she or he may require a substitute for caregiving. But finding a substitute for caregiving can be challenging. The caregivers also face physical and emotional distress. These physical and emotional distress

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constitutes various factors. There may be feelings of anger, fatigue, loneliness, embarrassment, guilt, etc. Different people have different ways of handling their stresses. For some becomes difficult to handle their stresses and emotions. Caregiver may experience different consequences of caregiving like being socially isolated. This can further lead to mental health issues related to depression, and also difficulty to take care of oneself (Gonzalez et al., 2014).

The behavioural problems of the persons with dementia have a significant indirect effect on the level of depression among their caregivers. Moreover, behavioural problems and dependency on completion of the activities of daily living have positive and a direct effect on the caregiver's depression (Ondee et al., 2013).

The health-related quality of life is inversely associated with the dependency level of the person with Alzheimer's disease and the caregiver's age. The health related quality of life is lower than that of the general population of the same age and gender (Lopez et al., 2006).

Psychosocial interventions for caregivers

Researchers have spoken about multi component interventions. In a study conducted by Mittelman et al. (2004) on the long term effects of counseling and support on the symptoms of depression which was examined among the spouses of the patients with Alzheimer's disease. A well designed psychosocial intervention has shown effective result in reducing depressive symptoms among the caregivers of persons with Alzheimer's disease (Sorensen et al., 2002).

Pinquart et al. (2006) suggest that multi component interventions reduced the level of stress. Psycho educational interventions, cognitive behavioural therapy, supportive therapy were found to be effective interventions. Gonzalez et al. (2014) came up with a multi-component intervention. The intervention which was developed constituted elements related to problem identification, problem solving skills, setting priorities and decision making. This intervention was found to be effective among the caregivers.

Psychoeducational approach can be divided into three stages- theoretical information, practical training in realistic situations and optimising the care is response to the patient. Psychoeducation is a tool that helps in reducing burden among the caregivers and increase their well-being (Dumont et al., 2016).

Ostwald et al. (1999) mentioned that an interdisciplinary psychoeducational approach is important to provide education to the caregivers and the persons with Alzheimer's disease. This should be a combination of Information and behavior management training with a focus on family support system. The intervention conducted here extending the practical skills of the caregivers so that they can deal with different tasks on a day-to-day basis. Communication among the family members and their cooperation was also one of their focuses. They found a moderate-to-significant reduction burden among the caregivers after the intervention.

Merlo et al. (2017) came with the concept of Alzheimer Cafe. It is an approach aimed at helping persons and caregivers deal with the condition. It is a concept be created where the caregivers were educated about the symptoms of Alzheimer's disease, they discussed their issues, sharing of their experiences, basically an attempt to make the disease more acceptable to the person affected by it and their caregivers.

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In a study conducted by Ducharme (2014) on psychoeducational intervention for family caregivers, the authors have emphasized on not only providing education to the caregivers but they also stated the importance of stress management and self care.

A home based intervention for patients with Dementia and their caregivers is found to be effective addressing the elements of optimising physical health and function, providing support to the caregivers and maintaining a better quality of life (Gitlin et al., 2010).

Lingler et al. (2016) mentioned that problem solving intervention specifically designed for management of medication is effective. In their intervention they focused on 7 areas namely caregivers responsibilities, problems in administering medicines, preventing medicine errors, information about the medicines, resources in the community, contingency and the changes in the intake of medication.

DiLauro et al. (2017) in their study on hospital-based Dementia support program, they mentioned three major themes in order to help the caregivers to help the persons with Alzheimer's disease to participate in leisure activities. The themes are namely "recognizing and acknowledging changes, making sense of the changes and conflicts and embracing changes and forging ahead". This study basically discussed about the how mutually shared participation in leisure activities can be a caregiver's support.

Dias et al. (2008) mentioned about the effectiveness of a home based program to support the caregivers of persons with dementia in developing countries. The intervention which was provided during this study was based on two principles. The first principle was to utilise health and human resources which were locally available. The second principle was that the intervention had to be a community and home based as it was found that most of the people with dementia and their families had a lot of difficulties in order to access the public health services. The main aim of this study was to improve the level of awareness and knowledge among the family caregivers regarding dementia, to provide emotional support, to increase their resources for caregiving and to improve the caregiving skills for the family caregivers. It was found that the home based intervention led to significant improvements in caregivers mental health and perceived burden.

A systematic review study was conducted by Selwood et al. (2007) on the effectiveness of psychological interventions on the caregivers of people with dementia. Immediate and long term efficacy of the different types of psychological interventions for the mental health of the caregivers of the persons with Alzheimer's disease were carefully analysed. Behavioural management therapy at an individual level was found to be very effective for alleviating caregiver's symptoms of stress. Education regarding dementia, behaviour therapy, supportive therapy, coping strategies was found to be effective at an individual level rather than at a group level.

An intervention for the caregivers should include providing education about Alzheimer's disease, understanding the symptoms of the person, and anger and frustration management (Robinson et al., 2001).

The most common coping strategies used by caregivers of persons with dementia are confronting coping, distancing, seeking social support and self controlling. Dementia can lead to serious consequences on families particularly on the primary caregivers (Chakma et al., 2016).

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Conveying information regarding the illness, ways of controlling tension and stress, and strategies to handle the persons with Alzheimer's disease is a very crucial step in working on the wellbeing of the caregivers. The intervention which is to be provided to them should not be only information based, but incorporating other elements like problem solving, cognitive restructuring, etc. is also necessary (Carrasco et al., 2009).

Thus, it is very important to develop a culturally appropriate intervention which can be provided using the existing resources such as supporting the families in performing their roles as caregivers (Dias et al., 2009).

CONCLUSION

Caregiving is a very demanding task. The caregivers have to be continuously involved with caregiving. The routine of the caregivers is basically restricted to their caregiving responsibilities. The demand of caregiving limits the caregiver from performing her/his personal activities (Schulz et al., 1994).

It is significantly evident from the articles that caregivers face a lot of distress and burden during the process of caregiving. It becomes all the more difficult for them when they are unable to cope with the situations. Certain psychosocial interventions like psycho education, coping strategies, and supportive therapy are found to be beneficial for them. Researches also suggest that a home based intervention is more effective than a clinical based intervention.

The number of people with Alzheimer's disease is predicted to increase in the coming years and the caregiver's responsibilities will also increase. Thus it is important to have a cost effective intervention plan for the caregivers in order to support them. A multi component intervention can help them tremendously. This paper shows the different psychosocial interventions for caregivers of persons with Alzheimer's disease.

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Conflict of Interest

The author(s) declared no conflict of interest.

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