

## A REVIEW OF BURDEN OF CAREGIVERS OF PATIENTS WITH ALZHEIMER'S DISEASE

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### ABSTRACT

Many are still unaware of the fact that Alzheimer's disease (AD) also affects the caregivers quite significantly. Caregivers refer to people who are accountable of taking care of AD patients which provide helps with his or her daily living activities and may become a full-time commitment for the caregiver. This gives rise to a concept called caregiver burden. As these caregivers spend most of their time taking care of AD patients, most of them suffer psychologically as well as physically. Unfortunately, the risk of mental and physical impairment among the caregivers of Alzheimer's patient may cause poor quality of life to both the patients and their caregivers. In addition, due to their role and responsibilities as a caretaker, they often do not have the opportunity to seek help and advices. This review article was conducted by sieving through numerous literature and studies regarding the challenges and how to help the burden of the caregivers of Alzheimer's patients. This paper aims to give and overview, suggestions as well as to increase the awareness of the caregiver's burden.

**Keywords:** Dementia, Alzheimer's disease, caregivers, factors, interventions, care, burden

## Introduction

Alzheimer's disease is the commonest type of dementia caused by the beta amyloid protein.<sup>1</sup> The memory loss is chronic and often it is always confused with delirium which is more acute.<sup>2</sup> Many are still unaware of the fact that Alzheimer's disease (AD) also affects the caregivers quite significantly. Caregivers refer to people who are accountable of taking care of AD patients which provide helps with his or her daily living activities and may become a full-time commitment for the caregiver. This gives rise to a concept called caregiver burden. As these caregivers spend most of their time taking care of AD patients, most of them suffer psychologically as well as physically. Several studies had showed many deleterious effects on the caregivers. A Stress Process Model proposed by Leonard Pearlin identifies key variables and their relationships namely primary and secondary stressors.<sup>3</sup> The primary stressors on the caregiver are derived from either objectively from the burden the symptoms of AD itself such as memory loss, functional loss, and behavior problem or subjectively from the extent to which the caregiver feels the burdens. The secondary stressors arise from the caregivers' other responsibilities and commitments such as family and work as well as ways of managing the stress as well as coping strategies.<sup>4</sup> Unfortunately, the risk of mental and physical impairment among the caregivers of Alzheimer's patient may cause poor quality of life to both the patients

and their caregivers. In addition, due to their role and responsibilities as a caretaker, they often do not have the opportunity to seek help and advices. This review article was conducted by sieving through numerous literature and studies regarding the challenges and how to help the burden of the caregivers of Alzheimer's patients. This paper aims to give and overview, suggestions as well as to increase the awareness of the caregiver's burden.

## Factors of burden among caregivers of Alzheimer's patients

### Stress, anxiety and depression

The prevalence of the mental health disorders such as stress, anxiety and depression as well as physical illness among the caregivers are more common than we thought as depicted in Table 1. According to a study conducted among Italian caregivers, 56% of them suffered from physical illness and 32% suffered from psychological illness.<sup>5</sup> Meanwhile, another study conducted by Ferrara et al. also prove that caregiver burden is heavy, as 53% out of 200 of them claim that most of their time are spent taking care of the AD patients, and very little are spent for themselves, and they feel that their own social life is affected. It was also reported that 59% of them feel emotionally drained.<sup>6</sup> Interestingly, a research done by Argüelles, Loewenstein, Eisdorfer, & Argüelles revealed that actually many AD

caregivers misjudged these AD patients, assuming that they still have some sort of functionality. Unfortunately, this wrong perception had led to a more depressive state for the caregiver when the patients' status did not fulfil their expectation especially in bowels, bladders and toilet use issues. Support system is also very important factor. If the caregivers do not receive enough support from others, they are at high risk of going into depression due to the heavy burden and responsibilities that they have to bear alone.<sup>7</sup>

As a result of the psychological triggers, caregivers also tend to suffer from longer term physiological changes that cause the cardiovascular system to persistently respond to acute stressors for an interval of six to twelve months. This may result to the rising incidence of chronic illness such as hypertension, and increased risk of poor wound healing.<sup>8</sup> This is also proven by another study conducted by Wright whereby AD caregivers were in poorer health condition and had a higher level of depression when compared to non-AD caregivers.<sup>9</sup> As a consequence, caregivers with emotional and physical strain have a 63% greater mortality rate as compared to those without strain or non-caregivers.<sup>10</sup>

**Table 1.** Percentage of caregivers having caregiver burdens in various studies.

Caregiver burdens	Percentage of people involved
Physical illness <sup>2</sup>	56%
Psychological illness <sup>2</sup>	32%
Time spent too little on self and too much on patient <sup>3</sup>	53%
Emotionally drained <sup>4</sup>	59%

### Lack of support services

The support services are the one of the main important factor to help with the caregivers burden but sadly it is still lacking in most developing countries. With the rising incidence of AD, ageing society should be more aware of the need to give a lifelong support for both AD patients and caregivers. Among the example of support services that need to be increased are nursing service, day center, cleaning service, personal care service and home care services. The importance of the support services is demonstrated in a study in Hong Kong that revealed home care services have improved the functional condition of the elderly. The home care services provided were counseling, training, interest-raising, empowerment, and nursing talks to aid with their transient reduction in functional ability among the elderly in Hong Kong.<sup>11</sup>

However, the support service may not be used fully by caregivers who are unwilling to leave their care receiver with strangers. In addition, some caregivers are unaware of the services and some feel that their care receivers might give a lot of problems to these services because of the AD patients' behavioral and emotional problems.<sup>12</sup> In addition, Vellone et. al. revealed that in Italy, the high expenses that caregiver has to pay for these kind of services lead to the stress and burden on caregivers.<sup>5</sup> Therefore, government has to take the lead to provide public support service for a better care of the society.

### Poor sleep

With the burden of taking care of AD patients for long hours, many caregivers lack rest and subsequently sleep quantity. Moreover, their sleep quality is usually interrupted by their care-receiver at night. Unfortunately, the sleep problem among caregivers persisted even after the care recipient passed away or moved out of the house as shown by a study done by McCurry and his colleague. The study also showed that the less social support the caregiver received, the poorer the sleep quality. A poor quality of sleep will lead to a lower quality of life among the caregivers, and further exacerbate the psychological problem they suffer from the caregiver burden.<sup>13</sup>

### Interventions on burden of caregivers of Alzheimer's patients

Despite the increasing prevalence of Alzheimer's disease, the studies on the caregivers of person with Alzheimer's are still lacking. We have found a holistic approach on the possible interventions to lift up the burden of the caregivers. Table 2 illustrated the summary of the interventions that will be described further.

**Table 2.** Interventions on burden of caregivers of Alzheimer's patients.

Interventions	Description
Occupational therapy	Coping behavior and supervision methods
Spiritual Therapy	Strengthen the intrinsic belief system among the caregivers
Behavioural interventions	Interactive sessions of problem solving and critical thinking techniques
Effective coping strategies	Problem solving skills, decision making techniques and techniques to deal with attitude problems of the Alzheimer's patients

### Occupational therapy

Occupational therapy is a customized therapeutic intervention to improve the AD patient's ability to perform daily activities with their limited cognitive ability. A study done by Graff had focused on the outcome of occupational therapy to both dementia patients and their caregivers. The study aimed on intervening with caregivers' behavior by including coping behavior and supervision methods in his occupational therapy, while for the patients, therapy was aimed at cognitive and behavioral interventions. The occupational therapy was shown to have a success in reducing caregiver burden and enhancing patient's quality of life.<sup>14</sup>

### Spiritual therapy

The challenging task of caring for patients with Alzheimer's disease may be reduced with the use of spiritual therapy that strengthens the intrinsic belief system among the caregivers. A study done Beuscher & Grando revealed that spirituality can help in coping with early stage Alzheimer's disease. These respondents were brought up to use prayers ever since childhood, and prayers was found to be comforting and have granted them hope.<sup>15</sup> Various studies have shown that spirituality works as a very effective resource for them to cope with the disease too. According

to Kirkland & Mcilveen, therapeutic advantages of spirituality in patient and their caregiver includes to make sense of a situation and to have approval and acceptance. Besides the benefit from spiritual therapy, it is practical, easy and economical.<sup>16</sup>

### Behavioural interventions

Another approach to reduce the caregiver burden is through behavioural interventions. Based on a study done, behaviour interventions could improve the negative behavioural symptoms as well as reducing psychological-related problems such as anxiety and depression.<sup>4</sup>

With the advances of technology, behavioural interventions can also be performed virtually. This was proven by a research regarding the trial of 'Mastery over dementia' which was awarded with the Alzheimer Disease International (ADI) award for the 'most promising psychosocial intervention for people with dementia or their caregivers' 2010. 'Mastery over dementia' comprises of 8 sessions of internet interventions with a professional counselor which includes interactive sessions of problem solving and critical thinking techniques.<sup>17</sup>

Intriguingly, telephone intervention is another approach of tackling with behaviour problems among caregiver. In 2013, the efficacy of virtual behavioural intervention were also shown by a research by Tremont et al. with the development of a telephone intervention named 'Family Intervention: Telephone Tracking- Caregiver (FITT-C)'.<sup>18</sup> It was performed by well-trained therapists via telephone regarding knowledge about dementia, emotional support and coping strategies. However, in another study, a tele-support between 5 caregivers per group for an hour per week only have minimal benefits.<sup>19</sup> This could be due to lacked of a well-trained therapists or counselor to guide them, has been demonstrated in the previous research. However, this approach is very cost effective and more studies should be done to explore its benefits.

### Effective coping strategies

Coping strategies may vary between caregivers. Engagement and disengagement strategies are two broad categories of coping strategies.<sup>20</sup> However, disengagement strategies which disengaged the caregivers from the person or the surrounding transaction have clinically significant mental health effects such as anxiety and depression.<sup>21</sup> This was also supported by a study conducted by Raggi, Tasca, Panerai, Neri, & Ferri whereby the severity of caregiver burden has association with their disengagement strategies such as having avoidance behavior and problem-focused approach, rather than problem solving. These studies aimed at proposing modified coping strategies in order to reduce caregiver distress and burden.<sup>22</sup> A psycho-educational intervention by the work of Beinart and his research team had aimed at educating the caregiver with effective coping strategies in terms of problem solving skills, decision making techniques and techniques to deal with attitude problems of the Alzheimer's patients.<sup>23</sup>

### Conclusion

In conclusion, handling Alzheimer's patients who has impaired memory, thinking and behaviour is far harder than

said or seen. Caring for these patients' falls on the shoulders of family or relatives as one has to continuously need to attend the needs of the patients. It does not only impose a great burden on the patient but it also involves the caregiver as well. This indirectly causes a lot of mental, social and health effects on the caregivers. A combination of interventions for these caregivers to ease their burden would be greatly needed to give a better quality of life for both patients and their caregivers. These, includes psychosocial and occupational therapy that would prepare caregivers to not be emotionally or physically drained. In future, we recommend more studies to be considered by researchers such as on factors of dementia patient's caregivers that contributes to burden or caregiver's burden and their effectiveness in caring dementia patients. Government has to take the lead to provide public support service for a better care of the society.

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