

In-home Care or Nursing-home Care Beneficial for Patients with Alzheimer's disease

Abstract

Alzheimer's disease is the most common cause of dementia that results in brain-cell degeneration. The report includes some questions that one should answer to the self in order to properly examine whether one's family member(s) suffering from Alzheimer's disease must be admitted to nursing-home or should be taken care of at home. In other words, this report mainly focuses on whether care provided at home or nursing-home could be more advantageous for the patients with Alzheimer's disease. The report also includes some data on the population of patients with Alzheimer's disease in Malaysia.

*Keywords:* Alzheimer's disease, in-home care, nursing-home care.

**Description of the issue**

Alzheimer's disease is the most common and prevalent cause of dementia among the people of old-age group (American Alzheimer's Association, 2011). With increasing progression of stages (See Appendix) and the absence of cure, Alzheimer's disease has not only become a major health-concern but also a very heavy economic and social burden worldwide (Lancioniet el., 2009). Therefore, 'care' must be taken into consideration when it involves patients with Alzheimer's disease more specifically.

Care is a multidimensional phenomenon (Fjelltun, Henriksen, Norberg, Gilje & Normann, 2009). Furthermore, care is a very challenging domain in the field of medical and health sciences. Care becomes even more crucial when it involves care for patients in nursing-homes who have Alzheimer's disease because they would be the sufferers of behavioural disturbances as well as cognitive-deficits (Morse, Bottorf, Neander & Solberg, 1991).

**Reasons for requirement of increasing care for patients with Alzheimer's disease**

There are about 27 million people worldwide are affected by Alzheimer's disease. This figure is expected to rise by up to one million annually (Lancioniet el., 2009). A written statement by American Alzheimer's Association, (2011) indicated that four percent of patients with Alzheimer's disease are under 65 years old, six percent are 65 to 74 years old, 45 percent are 75 to 84 years old and 45 percent are 85 years old or older.

Due to the rapid increase in the number of patients with Alzheimer's disease all over the world and in Malaysia (See Figure 1), the most important challenge faced by health services today is to form a highly comprehensive system of care for these patients, be it in-home care or nursing-home care.

**A few questions to consider before making decision to admit the patient in nursing-home care or making him/her stay with family members.**

1. Will I be able to afford the cost of nursing-home care treatment?

Family members need to consider the cost before making the decision to send the patient to nursing-home for care. According to the research conducted by Care Matters (2014), the cost for staying in a nursing home is RM 1,200 to RM 2,600 a month for basic care services in a semi-private room, while a private room is about RM 2,650 to RM 3,500 a month. This could increase financial burden on the patients' family members.

2. Will it be convenient for my family members and myself to visit our relative(s) with

Alzheimer's disease often? (If the decision is to admit him/her in nursing-home care setting)

Compared to Western countries, presently, there are not many nursing-home centers available in Malaysia, that could look after the patients with Alzheimer's disease (more specifically).

Certain centers only provide day care for the patients. This would mean that family members need to consider the daily transportation for the patient from home to the center and vice versa. If the family decides to admit the patient to the center, they would have to consider the distance (whether it is convenient to pay visit to the patient frequently).

3. Which type of center is suitable for patients with Alzheimer's disease?

Family members are encouraged to explore carefully in selecting which type of center would be the best for the patient with Alzheimer's disease. There are two main types of centers and the main difference between the two is: one is with medical services and the other is without medical services. Centers with medical services provide health care professionals such as medical doctors and nurses. Centers without medical services and health care professionals only provide the basic needs for the patients which is less suitable for the patient with Alzheimer's disease.

4. What stage of Alzheimer's disease is the patient in?

Depending on the Alzheimer's patients' progression of the disease (See Appendix), the burden of the caregiver could vary across each stage of the Alzheimer's disease. For example, a patient with Alzheimer's disease who is in the later stage, where assistance is required for daily living situations might need more assistance from the caregiver than a patient in the earlier stages. Therefore, this increases the burden of the caregiver, leading them to higher levels of stress and less quality of sleep (Ferrara et al., 2008).

5. Are we emotionally prepared to be separate from our family member(s) who has/have Alzheimer's disease?

If the family members are unprepared to be separated from their loved one(s) who is/are advised to be admitted to nursing home-care, then the family members should visit a counsellor to avoid falling into depression as a result of separation from their close family member(s) with Alzheimer's disease.

6. Are we emotionally prepared to take good care of our family member(s) who has/have Alzheimer's disease at home?

Knowledge and training is required to prepare the family members to look after the patient of Alzheimer's disease at home. The family members will be required to sacrifice their time, work and sleep. They must work together with each other in order to provide the best care to the patient at home or hire a health care professional for assistance.

### **Nursing-home Care for patients with Alzheimer's disease**

#### **Advantages of nursing-home care for patients with Alzheimer's disease**

In Malaysia nowadays, the trend of transformation in the family structure from expanded family to nuclear family is taking place very rapidly (Hew, 2003). Together with economic changes from underdeveloped to a developing country (Lai & Yap, 2004) it also leads to the growing tendency to require mothers or females in the family to work in order to support the household financially. Without realizing, this results in an increase in the tendency to transfer elderly to nursing-home care centres, as doing so, will help to relieve some burden of the family members.

Modern lifestyle involves fixed-hours of work for adults and study for children, which leads to lack of time for resting. Furthermore, taking care of Alzheimer's patients is time-consuming (Wilks, Little, Gough & Purlock, 2011). Having Alzheimer's patients for nursing-home care allows family members to have more rest and thus reduce negative effects on health, such as lack of sleep (Ferrara et al., 2008).

According to the study by Cheung (2005), nursing-home care centres provide beneficial services such as counselling, developing interests, training and group activities for the patients with Alzheimer's disease. Patients also attend nursing talks that would help them to improve their functional ability and learn to cope to live along with the disease (Cheung, 2005). Furthermore, in nursing-home, the patients with Alzheimer's disease that belong to the older-age group will also meet other patients of their own age group. Hence, they will find companionship and would not feel lonely and isolated (Berkman & Glass, 2000). They will be able to communicate with each other and understand each other better, since they are the sufferers of the same diseases.

In addition, nursing-home also provide higher security for patients with Alzheimer's disease, as they have higher number of caregivers present in the environment compared to that in home-setting. Patients in the later stages would start wandering around without being able to remember where they came from. Thus, the number of caregivers available to look

after for the patients is very important. Meanwhile, studies have also shown that patients received right nutrition and care from the nurses at nursing-home centers, which could help in reducing the severity of the disease (Hua-Chen, 2013).

### **Disadvantages of nursing-home care for patients with Alzheimer's disease**

While talking of patients, especially in the case of people with severe brain diseases such as Alzheimer's disease, there are numerous challenging situations that the health-care professionals or caregivers in nursing-home centres have to deal with in their day-to-day work. These difficult tasks have been identified as physically and emotionally exhausting (Morgan, Semchuk & Stewart, 2002) for the professional caregivers. The workloads given to caregivers were also considered as heavy, both psychologically and physically (Fjelltnun, Henriksen, Norberg, Gilje & Normann, 2009).

Maslach, Jackson and Leiter (1996) discussed that having intense involvement with patients becomes a stressor for staff, which can lead to burnout. In addition, another research done by Norbergh et al. (2006) stated that the staff from 11 nursing homes showed unfavourable attitudes towards the patients and had dissatisfaction in their job.

Furthermore, some studies have even found that most of those patients who died in the early years at the nursing-home, were sicker and their health was declining faster when they arrived. However, a study published in the year 2000 found that declining health didn't provide a complete explanation, since some patients in seemingly good health died soon after they were admitted (McCurry et al., 2009).

This suggests something about the nursing-home care centers placement itself, which includes the disrupted and weakened relationships with family and friends, infections caught from other patients, or insufficient care provided to the patients with Alzheimer's disease by the professionals in nursing-home centers.

### **In-home Care for patients with Alzheimer's disease**

#### **Advantages of in-home care for patients with Alzheimer's disease**

Eighty percent of care provided at home is delivered by family members (American Alzheimer's Association, 2011). These family caregivers may range from spouses, relatives, friends and in some cases when affordable, even healthcare personnel such as doctors and nurses. A home setting may make the patient feel better due to the presence of his/her family members.

In some cultures that are collectivistic like Malaysia, having the patient under in-home care setting will lead to having less emotional guilt within the family members. This is because they would be able to avoid the guilt-feeling of 'abandoning' their family members(s) who is or are patients of Alzheimer's disease. This is because collectivistic cultures value their families more (Sokolovsky, 1997).

According to Jay Sokolovsky (1997), in collectivistic cultures, usually the younger generations are responsible to look after their older family members. Failure to do so will lead to feelings of shamefulness and guilt for the younger family members. Moreover, Jay Sokolovsky (1997) also mentioned that living harmoniously with the family members, represents 'good old age'. This further means a lot to the elderly patients with Alzheimer's disease as they might feel they are being valued highly by their family members.

Furthermore, Nijboeret el., (2000) added that caring for one's own elderly family member will lead to a sense of satisfaction for a variety of reasons, such as fulfilling a parental obligation, or caring for a loved one.

#### **Disadvantages of in-home care for patients with Alzheimer's disease**

The permanent care that is given to the patient with Alzheimer's disease may produce high-levels of stress and increase financial-burden as the family members will have to pay the

health care professionals or assistants that could provide care services at home (Sansoni, 2002).

Sleep quality in family caregivers of patient with Alzheimer's disease might not always be sufficient. Family caregivers are often awakened by their care-recipients at night which contributes to the family caregivers' sleeping issues, and because of this, family members find themselves sleeping better when they take breaks from taking care of the person with Alzheimer's (Ferrara et al., 2008). Furthermore, studies have also shown that family caregivers' sleep problems continue even after the Alzheimer's patient has moved out of the home or died (McCurry et al., 2009).

When relating the stress that a family caregivers of a person with Alzheimer's experiences, it can be said that the stress is powerful. The stress is so powerful that the research studies that had been found show that family members of Alzheimer's patients have an association with decreased wound healing mechanisms, poor immunity and cardiovascular issues such as higher blood pressures (Ferrara et al., 2008). Furthermore, Ferrara et al., (2008) added that this is when the burden of taking care of someone becomes an issue for the family caregivers and it is reflected physiologically.

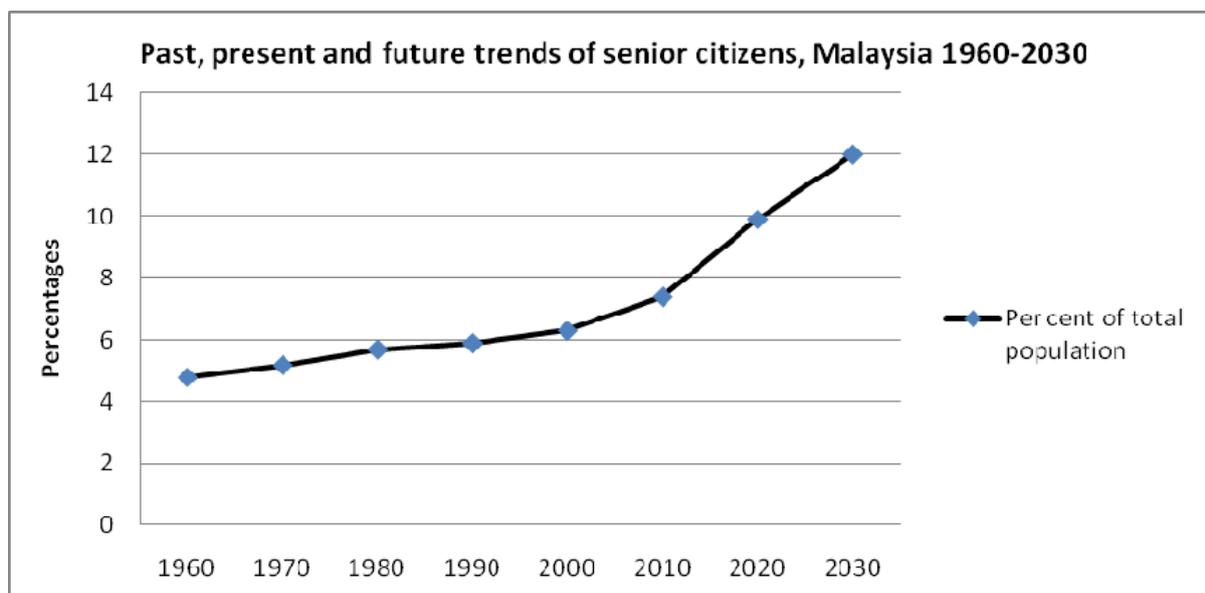
Family caregivers must often deal with a variety of long-term and disabling physical and behavioral problems associated with Alzheimer's disease. The typical cognitive changes of Alzheimer's disease are frequently accompanied by equally disturbing behavioral dysfunctions (Stolley, Reed & Buckwalter, 2002). Family caregivers are often unprepared to cope with the trauma of caregiving, mainly because of their lack of knowledge (Stolley, Reed & Buckwalter, 2002). Hence, there is a need to educate family caregivers about Alzheimer's disease.

Person with Alzheimer's not only forgets, but mostly is not able to recall the past and this creates a burden on their caregiver (Grant et al, 2002).

### Statistics on patients with Alzheimer's disease in Malaysia

According to the Alzheimer's disease foundation Malaysia, it is estimated that there are currently about 50,000 people with the disease in the country. However, most of them have not been diagnosed.

The reason why most of the Alzheimer's patients have not been diagnosed is because their relatives think that the symptoms that are being displayed are a normal part of 'aging' process and those symptoms are mistaken as 'normal forgetfulness'. Thus, they do not find it necessary to seek for medical advice.



*Figure 1.* The figure above shows the increasing trend of different types of dementias, including Alzheimer's disease in Malaysia. The source of the image is the 'Department of Statistics of Malaysia'.

According to the Alzheimer's disease International report, the prevalence of the disease and other dementias in Malaysia in 2005 was 0.063 percent and the annual incidence rate was 0.020 percent (Chan, 2005). It is estimated that this figure will rise up to 0.126 percent and 0.454 percent in 2020 and 2050 respectively (Chan, 2005).

With its rapid growth and morbidity, it ranks the second on the burden of disease in the entire Asia-Pacific Region, compared to sexually-transmitted diseases (STDs) (excluding AIDS), malaria and breast cancer (Bruce & Paterson, 2000).

### **Concluding Statements**

On the whole, due to the rapid growth and morbidity of Alzheimer's disease worldwide and in Malaysia, it becomes very crucial to examine whether in-home care or nursing-home care would be more suitable for the patient. From the report, it could be seen that the advantages of nursing-home care outweigh the advantages of in-home care.

Nursing-home care placement helps to reduce the direct care obligations on family caregivers. However, it does not necessarily reduce the family caregivers' distress of being away from their family member(s) with Alzheimer's disease, mainly due to separation from one's own family member(s), especially in collectivistic cultures like Malaysia, and also due to the financial burden (Sansoni, 2002) of admitting the family member(s) with Alzheimer's disease at nursing-homes.

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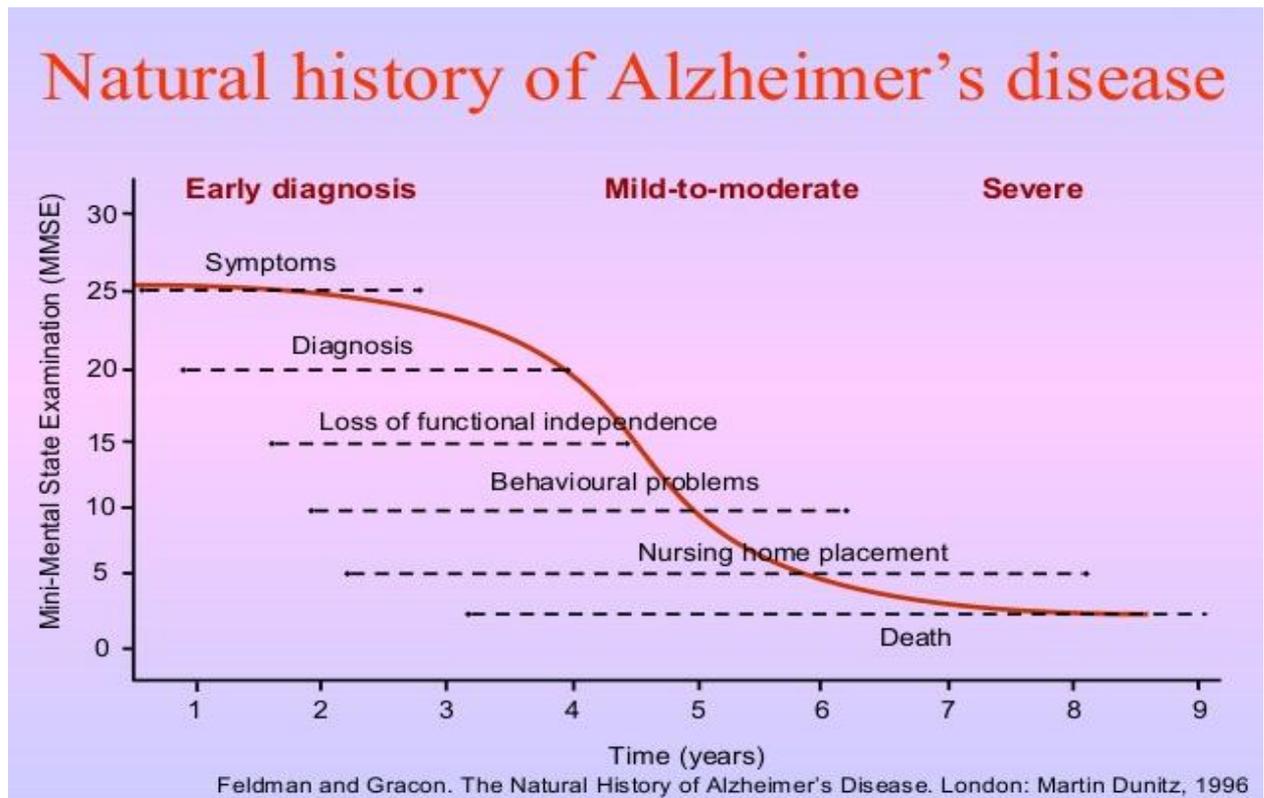
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## Appendix



*Figure 2.* The figure above displays the progression of Alzheimer's disease over the course of years. It begins from early stage, showing some symptoms and keeps progressing until the end stage which finally results in death.