



# Life Experience of Seventh-Day Adventist Church Members in Caring for Their Parents Who Suffer from Alzheimer's Dementia

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## ABSTRACT

**Introduction:** Previous phenomenological studies explain that family member faced many consequences in caring for family members with Alzheimer's Dementia at home. The consequences are in the form of the impact of financial, social and psychological pressure. Considering such consequences, families especially in Eastern cultures will continue to care for their elderly at home for reasons of compassion or retribution toward parents even though they feel frustrated and burdened. The purpose of this study is to describe the life experience of Seventh-day Adventist church members in caring for their parent who suffer from Alzheimer's Dementia. **Method:** This qualitative study is using phenomenological design. There are 3 participants are selected who are fit with the inclusion criterions: immediate family member, seventh-day Adventist church member, live together with their Alzheimer's Dementia parent who suffer at least 2 years of dementia, and agree to sign inform consent after the full explanation of the study. Data are gathered using semi structured face to face interview in participant's home setting. Data than transcribed in to word document and analyzed using Cresswel step by step content analysis. **Result:** There are five negative categories of family member experiences in taking care of their Alzheimer's Dementia parent: 1) physical abuse, 2) psychological abuse, 3) social limitation, 4) spiritual distress, and 5) knowledge deficit. It also found that there are several coping mechanism or adaptation made by family member in caring their Alzheimer Dementia parent: 1) family members are motivated to learn more about Alzheimer Dementia, 2) spiritual growth that they pray more often and surrendered to God, 3) increase understanding toward elderly. **Discussion:** Based on the result of the study, all the informants experienced pressures in all holistic aspects of life. If they are not able to cope with the pressure, illness may be arrived and made the family situation become worse. Therefore, professional health care must provide support to the family who take care of their Alzheimer Dementia parent.

**Keywords:** Life Experience; Older Adult; Alzheimer Dementia; Family Care Giver.

## INTRODUCTION

Alzheimer's Disease (AD) coomonly found in people after 65 years old. It is a brain disease that results in decreased memory, thinking, speaking abilities, and also gradually in

behavioural change. The cause of AD still unknown. However, AD is occurred due to the deposition of proteins in the brain that blocking the nutrients supplies to the brain cells. There are several risk factors that include age, genetics or family history, environments and also other factors such as smoking, hipertension, high cholesterol and diabetes can exagurate the development of AD.

In the early stages, sufferers of Alzheimer's disease will experience memory problems that are mild, such as forgetting the name of an object or place, as well as forgetting events or content of conversations that have not recently occurred. Over time, these symptoms will get worse. At an advanced stage, sufferers of Alzheimer's disease have difficulty speaking or explaining things, it is difficult to plan things, it is difficult to make decisions, often look confused, and experience changes in personality. Alzheimer's patients will experience decreased brainpower, memory, and increasingly loss of ability to control bowel movements. These things can cause patients to fall, experience malnutrition, unable to communicate, or get infected and experience various other complications.

Alzheimer's disease treatment is done to reduce the symptoms and the development of the disease. Treatment of Alzheimer's disease is the administration of drugs such as rivastigmine and psychotherapy to stimulate and relax the patient's brain. Alzheimer's disease can be prevented in several ways, for example: quit smoking, maintenance of ideal body weight, eating foods with balanced nutrition, and exercise regularly.

Dementia is overwhelming for the individual him/herself and also for the families and care giver. Many impact such as families. Many impacts such as stigmatization, barriers to diagnosis and care, and impacting careers, families and societies physically, psychologically and economically due lack of awareness and understanding of dementia in most countries (WHO, 2017). Care giver is stressed not only due to memory loss and subsequent functional decline but also because of behavioural disturbances that occur frequently in AD patients (Neugroschl & Wang, 2011). Caregivers report significantly distress due to both cognitive and behavioural changes and providing increased care for Activities of Daily Living (Association, 2010).

Despite of such overwhelming situation in caring AD, families especially in Asian culture will continue to care for their parent at home for the reasons of compassion or retribution toward parent. For this reason, it is necessary to explore life experience of family members who are caring for their AD. Sharing life experience will benefit more families and community in understanding the development of the disease, increase awareness of prevention

and management of AD. Therefore the main objective of this study is to reveal the life experiences of family members who care for their parent who suffer from AD at home.

## **METHODS**

This qualitative study is using phenomenological approach. Population is family that have AD parent at home. Sample are recruited through snowballing method and selected by using inclusion criterions: immediate family member, Seventh Day Adventist (SDA) church member, live together with their AD who suffer at least 2 years of dementia, and agree to sign inform consent after the full explanation regarding the purpose and benefit of the study. Data are gathered using semi structured face to face interview. All the participants are dwelling in Bandung and member of SDA church. All the data are collected in Bahasa Indonesia. Data are collected until data were saturated or no new information was obtain from participants. Data are transcribed in to word document and analyzed using Cresswel (2016) step by step content analysis.

## **RESULTS**

The life experience is emerged in five dimensions of holistic live: Physical dimension, psychological dimension, social dimension, spiritual dimension, and intellectual dimension. Several subcategories are discussed within each category using verbatim quotes where possible.

### **Physical Dimension**

Family care givers experienced physical violence committed by AD sufferers. However as a Christian care givers they had never committed or retaliated to violate their AD sufferer. Care givers understand that the sufferer did not realize what he is doing at that time due to kognitive impairment.

*“I was thrown with stone and other objects. One time, I was kicked and thrown againts the wall. It is so painfull and I have suffer for these, many times. I questioned God” what happen with this man? Then I realize that he doesn't know what he did anymore. He really knows nothing”.*

Family care givers also experienced difficulty in sleeping and decreased in length of sleep hours due to sufferer’s behavior. AD parents are often awoken in the middle of the night. Asked for many question and make noise.

*"I can't sleep due to noise and snoring. Wow, I also need to sleep thou, so I slept in the other room and check him one time in midnight and I went to slept again. "In the nights he often banged the door at 2 to 3 AM. After this I could not sleep anymore until morning (she stood up while demonstrating the location of their bedroom, bathroom, living room and bedroom of AD older adult)"*

### **Psychologically Dimension**

Family care givers experienced many negative psychological impact from abusive behaviour of sufferer included stressed, suffered, and angry. Care givers are sad, shocked and cried of being not recognized by the parents. Most of all, they are worried of what other people think about them and mixed with the feeling that the neighbour do not understand their condition. They are afraid that AD sufferer may hurt other people in their location. Care givers often upset because of AD sufferers are difficult to handled and managed. More over, she said it is a dilemma. As addition care giver try frighten the AD sufferer and hoping he will obey their command.

*"Yes of course it's sad. I'm just surprised, he becomes like this. He did not recognize me anymore. It was like the first time I returned home. I was shocked". "I cried and my tear drops when he hit me and I said, he did not know why he did it"*

*"We also afraid that he might hit others, then we have to be responsible for his harsh behaviour".*

*"We experienced a prolonged dilemma between giving sedatives or not. Sedatives weaken him but give us peace of mind and away from people's talk behind our back. Until now it's a dilemma. When sedatives are given, he sat and remained silent. He seem no longer alive human being. Really dilemma! Finally, we stop the sedatives"*

*"sometimes we raised our voice, angry and screaming, shouted, and scared him and said Oh, police, please, this gentleman is rude to me. Oh! Police please!" "one time I took the saxophone box and I want to hit him after run away from his room"*

Despite of all unpleasant experiences. Care giver try to understand and accept their parent condition and cultivate caring and patience behavior.

*"But what can we do? We have to face the reality. This is the reality. We have to accept".*

*"We really learn to be patience. "Yes, we are hurt, but we realized that he did not understand his behavior"*

### **Social Dimension**

In social dimension caregivers experienced social restriction and withdrawn from others. This condition due to AD sufferer are very demanding, jealous and also afraid of being talked by others.

*"He wants to be accompanied continuously. He is extraordinary jealous and not allowed me go out side the house. I have no friends to talk there".*

*"Sometimes people see me as a person who do not like social activities. Only a few people understand. I'd rather stay at home".*

There are some positive things felt by the informants because they can provide social support to the elderly. Although care giver have negative feeling about their neighbour they received social support also from a neighbour and church member".

*"... I have prayed, and grateful there is a friend. Someone who helped me, he visited us, he is deacon".*

*"I've tried to give support to my dad, maybe that's the spirit that I have".*

*"I belief that not everyone understand what I have been through because they don't experience it. So if someone starts advising me, I realy ignore them because I keep thinking that they don't understand how I feel. They must experience it first in order to understand what happen to me. There is only one person that I like to listen because she took a good care of her mother in-law who suffer from AD in the past seven years".*

### **Spiritual Dimension**

In spiritual dimension, Care givers expressed both pleasant and unpleasant experiences. They described their positive spiritual outcomes that they pray more frequently and surrender all to God. They believed that prayers will strengthen them. This positive outcomes are discovered by their statement:

*"I surender all to God whatever will happen next.*

*"I always pray, please God give me patience so I can go through this difficult time. I belief that You know what is best, for him." You have the purpose to strengthen me by giving me this test"*

*"If not by the power of God I will be sick and stroke" I suffered but He comfort me"*

*"I must thank God". He is woderful".*

*"I hold his hands and said, Let us pray. Jesus loves you, he is able to heal you. I often cry in my prayers".*

As members of the Seventh-day Adventist there is also the spiritual pressure experienced by the family care givers. Among them are embarrassed and lazy to go to church. Ask God why this happened to them. Besides that, they feel guilty because they have to do things that should not be done on Sabbath day like washing and drying clothes because AD parent suffer from bed-wetting

*"...bed linen and clothes are often wet and and smel. So, even in the sabbath day I have to wash and dry the bed linens and clothses. I am affraid that church member saw me and I say some of them may not understand my situation. They might said that I should not wash and dry on sabbat day"*

### **Intellectual Dimension**

There is lack of knowledge experienced by family care givers. It is expressed as follow:

*"... I don't really understand what it is. What I know is difficult to communicate, rudeness and seem he saw manythings"*

*".. I am lucky that I am a nurse. Otherwise I do not understand what is this". There are families also said thhis, 'bring him to a shaman. They said that there is a demon in him. Probably from their ancestors. He is talking with some one here, look. They named and suggested manything for curation and to cast out the demon. As a nurse I do not believe it. As medical person I understand what happen is hallusination as he often hears something and sees something.*

There is positive impacts of knowledge deficit that forced the family care givers read more literatures about Alzheimer's. They described it as follows:

*"... So what to do with Alzheimer's? so I find out by read, read, and read. Before I do not know about Alzheimer's but now I know what will happen next to him"*

## **DISCUSSION**

As can be seen in Figur-1 that family care giver expressed their unpleasant experience in all dimensions of holistic live. However it is also expressed some pleasant experiences in psychological dimension (caring, understanding, and more patience); in social dimension that they receive social support from neighbors and deacon from church; in spiritual they pray often

and surrender all to God; and lastly in intellectual dimension there is motivation to learn more about Alzheimer’s Dementia. Therefore, the discussion of this study is divided into two parts, namely unpleasant and pleasant themes.

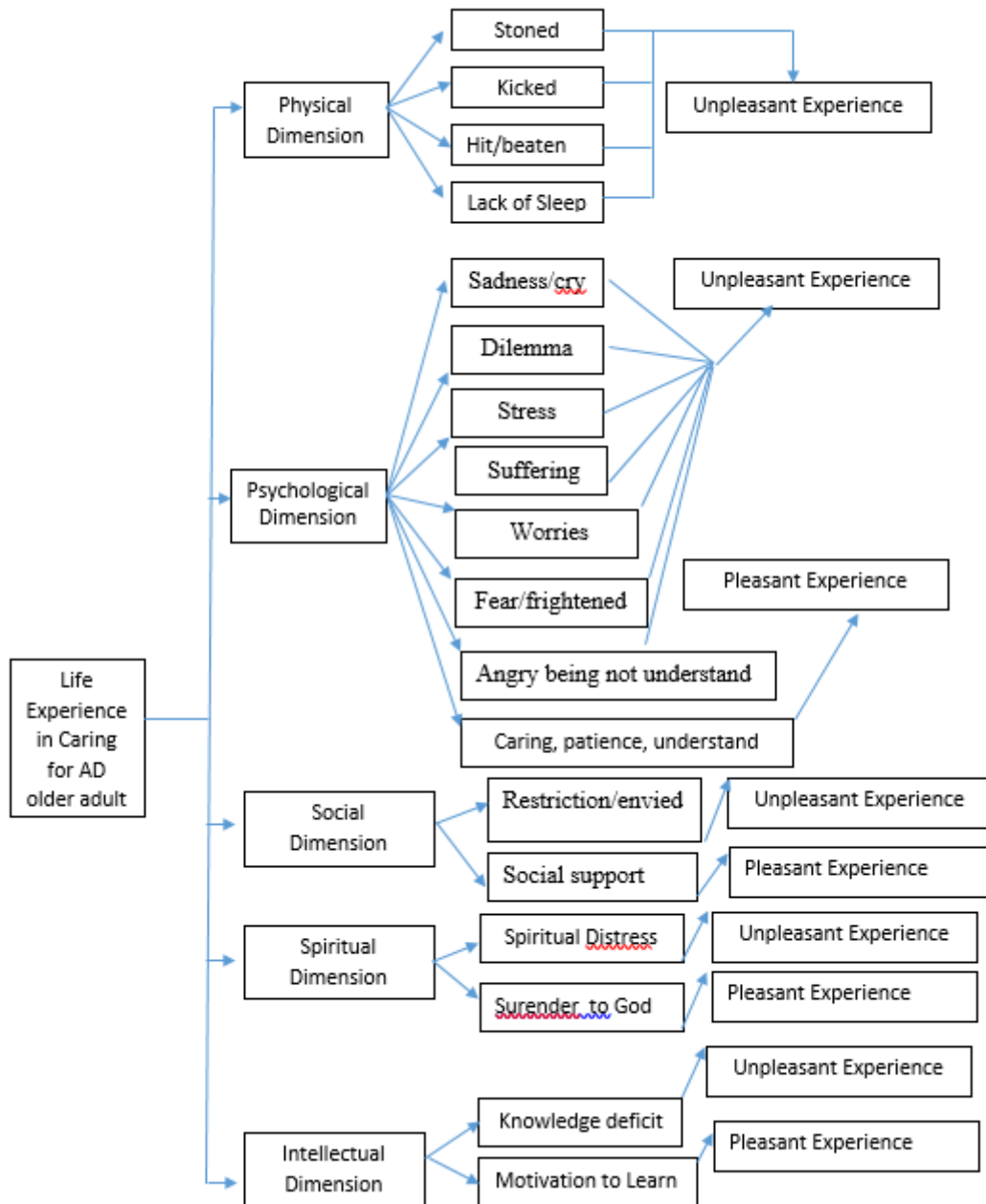


Figure 1. Categories and Subcategories of Families Experiences

### Unpleasant Experience

Most of the sufferers perform abusive behavior. Physically, care giver is stoned, kicked, hitted/bitten by Alzheimer’s sufferer. This situation can be explained that Alzheimer’s

Dementia manifested of structural brain damage. The collection of symptoms includes the loss or decline of intellectual functions (including among them the functions of thinking, orientation, understanding, arithmetic, learning capacity, language, and consideration) and memory so severe that it causes dysfunction of daily life. Because of this disorientation, the elderly with Alzheimer's dementia have difficulty controlling their anger responses such as shouting or loss of consciousness which can then lead to physical violence against the family (Qualls, Zarit Steven, & Honn, 2009). People with dementia often show some disruption and changes in daily behavior (behavioral symptoms) that are disruptive (disruptive) or non-disruptive (non-disruptive) (Volicer, Hurley, & Mahoney, 1998).

Sleep disorders are also experienced by family care giver due to the noise caused by Alzheimer's sufferers. This is consistent with the results of previous studies in which care giver is often literate and ultimately unable to sleep soundly. Care giver stated that need to take sleeping pill in order to be able to sleep soundly (Widyastuti, 2011).

In psychological dimension, family care giver also experienced distress which is characterized by crying. Crying is one of the symptoms of stress and also as a right response in term of stressful situation (Simbolon, 2015). Treating the elderly with dementia is not easy. Even for some people this job isn't even fun (WHO, World Report on Violence and Health, 2002), even an activity that has a very high stress level (Biggs, Phillipson, & Eastman, 1994). Care givers who experience high stress can commit violence in the elderly. It is found that there is significance relationship between stress levels with violent behaviour (Yuliawati & Handadari, 2013). Care giver or family member must able to recognize the signs of distress, depression and risk factors for their depression include patient depression, severity of behavioural disturbance and perceived burden (Watson, Lewis, Moore, & Jeste, 2011). By recognizing these things, it is easier to find suitable stress management that fit with their condition.

Another psychological pressure is dilemma. Dilemma is expressed in term of between giving or not giving the sedative to parent. There is feeling guilty if sedative is given because it's weaken the parent. There is worry if sedative is not given. They afraid and frightened that their parent may hurts others. A dilemma is a general term that refers to a difficult condition, namely the emergence of a problem that offers two possibilities, both of which are equally impractical to accept. The best way to cope with dilemma in this situation is to seek perspective. Care givers should ask family conference if possible. Reviewing the issue with the family often bring a new perspective. The family members may offer some influence and aid in addressing the moral dilemma. At the very least you will have a much more clear understanding and the



decision is made in a team and not personal. This strategy will help family care giver to alleviate their feeling of guilty.

In addition, angry and not being understood are another expression of psychological symptoms of psychological pressure. The care givers are angry when the Alzheimer's parent did not understand their command and instruction. In previous study is found that angry is identified in most family care giver. Feeling angry with elderly because of the changes experienced by the elderly both changes in the personality of the elderly and changes in the behavior of the elderly (Widyastuti, 2011). In one research suggested that the experience of caring for the elderly with dementia can be provokes anger, ambivalence and emotions that are unstable because of changes that are occur in the elderly (Miller, 2004).

Socially, most of the care giver stated that they are hesitated go outside. Alzheimer's sufferer can not be left alone at home. Care givers are restricted to stay at home to accompany her/him. In previous phenomenology study also found that care givers must stay 24 hours at home and they loss contact with friends and other families (Widyastuti, 2011). This result is also is suitably supported by cross sectional studies that caregivers of the elderly with dementia will experience social disorders (Adam, McClendon, & Smith, 2008).

### **Pleasant Experience**

Psychologically, care givers experience pleasantly that they are care for the elderly become more patience and understand about the Alzheimer's sufferer condition. Caring attitude appeared that they interested in their parents and care for them seriously and continually (Anonymous, What is good health care, 2019). Alzheimer's Association emphasize that patience is one among 10 ways to help family living with Alzheimer's (Anonymous, 2019). Understanding means sympathetically aware of the parents feelings; tolerant and forgiving their harsh behavior.

Socially, care givers are very grateful for social support. Social support came from their neighbor and church member such as deacons. This support is in term of home visits. They are given advise and listened to their complaints and feelings. Previous studies has shown the benefits of social support such as improving the ability to cope with stressful situations; alleviating the effects of emotional distress and promote lifelong good mental health. Lack of can lead to isolation and loneliness (Clinic, 2019).

Spiritually, all care givers pray more for their parents' health and ask God for help to provide patience and strength in dealing with their parents. They surrender completely to God. Previous

study revealed that appropriate spiritual live among family care giver facilitate their coping and meeting the purpose and meaning of the moment experienced (Rocha, et al., 2018).

Intellectually, family care giver curious to learn more how to deal with their Alzheimer's Dementia parents. Alzheimer's association suggested 10 ways to help a family living with Alzheimer's. One among them is that the family should educate themselves what is the effect living with Alzheimer's family at home (Anonymous, 2019).

To conclude, all the informants experienced both unpleasant and pleasant experiences. They must be able to weight between pleasant and unpleasant experiences. If pressure is to high they must seek help to cope with the pressure. Otherwise, suffering to long pressure will cause illness. It will make the family situation become worse. Therefore, professional health care must provide support to the family through education by giving them knowledge and understanding and train them how to provide a good care of their Alzheimer Dementia parent at home and also how to manage their unpleasant experience.

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