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# Social Engagement and Meaningful Activities of Persons with Dementia: Some Best Practices in Kerala

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***Abstract***

This study was conducted to explore the practical techniques and strategies identified and developed by families for caring persons with dementia which will have a wider implications in families, institutional settings, developing training modules and practice guidelines in the field of quality dementia care. It is a qualitative study using the case study pattern / design. The ambit / sphere of this study are the families of the Kottayam district of Kerala having persons with dementia, who are taken care of within the families. Purposive sampling was employed selecting six families with good care practices as samples for the case study. These families were selected by consulting doctors and social workers working in association with ARDSI (Alzheimer's Related Disorders Society of India), of the Kottayam Chapter. Primary data for the study was collected from the family members (primary caregivers) of the persons with dementia and interview schedule was used for data collection. Even though the family caregivers in Kerala are not trained for providing care they have developed their own strategies and techniques to engage persons with dementia in activities that have some personal meaning and importance. All the good practices identified have already been proved effective by the families through years of practice, so these practices can be used in various different settings of dementia care for quality results.

***Keywords***

dementia, good practices, social engagement, Kerala

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## Introduction

Population ageing is a phenomenon occurring when the median age of a country or region rises due to rising life expectancy and/or declining birth rates. Initially this factor was common in the more economically developed countries, it has in the recent times started to affect the less economically developed countries especially in Asia, Latin America and Africa (UNHDR, 2005). This has encompassed almost every country with exception of 18 countries designated as "demographic outliers" by the UN (UNHDR, 2005). UN has predicted that the rate of

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population ageing in the $21^{st}$ century will exceed that of the previous century. Given that variations in terms of the degree and the pace of these changes, the UN expects population that began ageing later, will have less time to adapt to the many implications of these changes (UNDP, 2005).

India's population too is undergoing a rapid demographic transition now, and there will be a sharp increase in the number of the aged in its population. It is only natural that this rapid demographic change is happening alongside the fast paced social restructuring that usually accompanies economic development. This makes the task of meeting the needs more challenging and an urgent one for the older people. According to the 2011 Census, the total number of older persons in India was approximately 103.8 million and is expected to cross 173 million by 2026 as the life expectancy at birth is projected to increase to 69.8 years for males by 2021-25 (from 61.6 years in 1996) and 72.3 years for females (from 62.2 years in 1996).

It is also a well recognized fact that the number of older adults who suffer from dementia has been increasing and will continue to do so over the coming years. Dementia is primarily (but not solely) an affliction of the elderly, and the prevalence increases dramatically with advancement of age and will finally include almost a third of the population almost over 85% (Mahandra, 1984). Alzheimer's disease and related dementias (ADRD) are a progressive, degenerative illness usually affecting the mental abilities, emotions, behaviour and physical functioning (Patterson et al., 1999).

Dementia can create an overwhelming burden for family caregivers, negatively affecting their physical and mental health (Burton et al., 2003). The number of persons with dementia double every five years and India will have one of the largest numbers of elders with this problem. It is estimated that over 3.7 million people were affected by dementia in the country in 2010. This is expected to double by 2030 (Shaji et al., 2010). In fact, nothing short of a three-fold rise in the number of people with Alzheimer's disease is expected to occur between 2000 and 2050 (Zimmerman et al., 2005). Since an extensive epidemiological study of dementia has not been done so far in Kerala, an exclusive prevalence data is not available. Regarding the financial liability, it is estimated that the cost of taking care of a person with dementia is about Rs. 43, 000 annually; much of which is met by the families. The financial burden will only increase in the coming years. The challenge posed by dementia as a health and social issue is of a scale that can no longer be ignored. Despite the magnitude, there is gross ignorance, neglect and scarce services for people with dementia and their families (Shaji et al., 2010).

### Dementia: History

The term "dementia" was probably coined in the first century A.D. For the next millennium it was generally quite ill-defined and often used (along with delirium) to refer to insanity in general (Lipowski, 1981; Mahandra, 1984). It is also likely that no real distinction was made between dementia and the changes in cognitive function associated with normal aging (Mahandra, 1984). Early in this century, the term "organic psycho syndrome" was used by Bleuler to refer to a set of behavioural manifestations of chronic diffuse cortical damage. The behavioural manifestations involved decrements in memory, judgment, perceptual discrimination and attention, emotional liability, and defective impulse control (Lipowski, 1981). This was essentially the classification adopted by the American Psychiatric Association (APA) in the early editions of its *Diagnostic and Statistical Manual of Mental Disorders*. Specifically, the DSM-II defined "organic brain syndrome" as a "basic mental condition characteristically resulting from diffuse impairment of brain tissue function from whatever the cause," and it manifested behaviourally as an impairment in orientation, memory, intellectual functions, judgment, and affect (Lipowski, 1981). In this classification, brain dysfunction resulted in a single behavioural syndrome, regardless of the etiology and site of neuropathology (Lipowski, 1981).

### Medical Model of Dementia

Dementia as a clinical syndrome is characterized by global cognitive impairment, which represents a decline from previous level of functioning, and is associated with impairment in functional abilities and, in many cases, behavioural and psychiatric disturbances. Several formal definitions exist, such as that of the ICD-10:

> 'a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capability, language, and judgment. Consciousness is not impaired. Impairments of cognitive function are commonly accompanied, occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. The syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.'

There are a number of conditions that cause the symptoms of dementia. Alzheimer's disease (AD) accounts for around 60 per cent of all cases; other common causes in older people include cerebrovascular disease (vascular dementia [VaD]) and dementia with Lewy bodies (DLB) (accounting for 15–20% of cases each). In some cases of young onset, frontotemporal dementia (FTD) is also a common cause, second only to AD. Numerous other causes exist, including other degenerative diseases (for example, Huntington's disease), prion diseases (Creutzfeldt-Jakob Disease (CJD)), HIV dementia and several toxic and metabolic disorders (for example, alcohol-related dementia). Dementia also develops among 30–70 per cent of those people with Parkinson's disease, depending on duration and age (Aarsland et al., 2003). The distinction between Parkinson's disease dementia (PDD) and DLB lies in the relationship between motor and cognitive impairment. If dementia precedes, or occurs within 12 months of, motor disorder, DLB is diagnosed (McKeith et al., 1996); otherwise the convention is to use the term PDD.

### Symptoms, Presentation and Patterns of Illness

Alzheimer's disease (AD) usually manifests itself with loss of memory, especially for learning new information, reflecting disturbances in the function of the anatomical sites (medial temporal lobe and the hippocampus), which are the primary focus of pathological change. Later in these illness the other higher cortical functions (for example language, praxis and executive function) become affected and behavioural and psychiatric disturbances are seen. These have been referred to in literature in a number of ways, including behavioural and psychological symptoms of dementia (BPSD), challenging behaviour, neuropsychiatric symptoms and, more recently, behaviour that challenges. Such symptoms commonly include depression, apathy, agitation, disinhibition, psychosis (delusions and hallucinations), wandering, aggression, incontinence and altered eating habits. These are important because they are the frequent symptoms, which are often difficult to manage and cause great distress to individuals and care takers. They are stronger predictors, more than cognitive impairment of both carer stress (Donaldson et al., 1997) and entry to institutional care (Bianchetti et al., 1995). Sometimes AD can manifest itself initially as a behavioural disturbance, language disturbance or praxis but these may also be manifestations of other causes of dementia.

Frontotemporal dementia usually comes to the forefront with language disturbance and/or behavioural difficulties (either disinhibition or apathy), whilst DLB is characterized by recurrent visual hallucinations, fluctuating cognitive disturbance and motor features of parkinsonism. Associated features in DLB are falls, disturbances of consciousness, autonomic dysfunction and rapid eye movement (REM) sleep behaviour disorder (McKeith et al., 2005). Vascular dementia (VaD) can occur after an acute vascular event (for example, a stroke) or subacutely and insidiously with progressive attentional and executive/planning problems, gait disturbance and apraxia, reflecting 'subcortical' frontostriatal dysfunction due to vascular pathology. Focal neurological signs are common (and their presence is required in some diagnostic criteria) just as in the changes of brain imaging, including cortical infarcts, multiple lacunae and extensive white matter change. Behavioural challenges are also common in VaD, with depression and apathy most frequently seen as part of it (O'Brien et al., 2003).

### Social Model of Dementia

While the clinical model of dementia presented above describes the changes occurring within the brain, the way that dementia affects a person in day-to-day life will vary from one individual to the other. For many years, people with dementia were written off as incapable, regarded as little more than 'vegetables' and often hidden from society at large. During the 1980s and 1990s, there was a move away from regarding people with dementia as incapable and excluding them from society, and towards a 'new culture of dementia care', which encouraged looking for the person behind the dementia (Gillard, 1984; Kitwood, 1997; Kitwood and Benson, 1995). People with dementia could now be treated as individuals with a unique identity and biography and cared for with greater understanding.

Building further on this work, others (notably Marshall, 2004) have advocated that dementia should be regarded as a disability and framed within a social model. The social model, as developed in relation to disability, where understanding disability is not as an intrinsic characteristic of the individual, but as an outcome produced by a social process of exclusion. Thus, disability is not something that exists purely at the level of individual psychology, but is a condition created by a combination of social and material factors including income and financial support, employment, housing, transport and the built environment (Barnes et al., 1999). From the perspective of the social model, people with dementia may have an impairment (perhaps of cognitive function) but based on their disability results they are often treated by, or excluded from, society. For people with dementia, this model carries some important implications, for example:

- The condition is not the 'fault' of the individual.
- The focus is on the skills and capacities the person retains rather than loses.
- The individual can be fully understood (by his or her history, likes/dislikes, and so on).
- The influence is recognized of an enabling or supportive environment.
- The key value is endorsed of appropriate communication.
- Opportunities should be taken for rehabilitation or re-enablement.
- The responsibility to reach out to people with dementia lies with people who do not (yet) have dementia (Gilliard et al., 2005).

## Social Engagement and Involvement in Meaningful Activities

There is evidence that engagement in meaningful social activities is related to quality of life for individuals residing in long-term care facilities (Gonzalez-Salvador et al., 2000; Hagen et. al., 2003). For example, participation in activities such as music, exercise, or cooking is associated with less depression, better cognition, mobility, and balance, and lower mortality rates (Kiely et al., 2000; Koh et al., 1994; Marsden et al., 2002; Mitchell and Kemp, 2000; Turner, 1993). Further, allowing the concerned person's choice in activity programming is associated with their involvement (Hedley et al., 1994). It is often a challenge, however, to involve persons with dementia in activities and for them to be able to inform the caregiver of their preferences. This challenge may be especially notable in residential care/assisted living (RC/AL) facilities, which have become a predominant provider of long-term care. RC/AL facilities are non-nursing home residential settings that provide or arrange supportive and health care services for individuals who require assistance with daily activities (Kane and Wilson, 1993). Traditionally, they differ from nursing homes in that they promote a more social model of care (e. g., resident autonomy and choice in a home-like environment). Further, this social model of care, to which activity involvement clearly relates, is important to enhance the quality of life of persons with dementia (Dobbs, 2004; Mitchell and Kemp, 2000; Zimmerman et al., 2005). Given the difference in the RC/AL philosophy compared to nursing homes, these residents may have, and their families may expect them to have, higher activity involvement than residents in nursing homes (after adjusting for functional, cognitive, and health status). Thus, it is useful to understand resident involvement in activities to both facility care well as to the resident involvement, both generally and separately, for each type of setting. A scrutiny of the findings related to activity involvement, assessment for and availability of activities, and what types of resident and facility characteristics are associated with activity involvement may provide useful suggestions to improve care.

Persons with dementia have the opportunity to maintain and enhance their sense of dignity and self-esteem by engaging in meaningful social interactions throughout the day, every day. Caregivers require training and support to understand how to help PwD (Person with dementia) achieve this goal. Both formal and informal activities provide the PwD and the caregiver a sense of security and enjoyment. Formal activities are those that are typically found on the community activity calendar (classes, parties, discussions); informal activities are everyday interactions (a chat with a friend, a walk down the hall, a soothing bath). Meaningful activities are carried out by the foundation of dementia care because they help residents maintain their functional abilities and can enhance their quality of life. Every event, encounter or exchange between residents and staff is a potential activity. For example, dining is a meaningful opportunity for socialization, enjoyment, satisfaction and self fulfilment. Access to personal space and opportunities for free time to relax are essential elements for enhancing quality of life. There are three care goals in this area according to Alzheimer's Association USA. 1) To offer many opportunities each day for providing a context with personal meaning, a sense of community, choices and fun. 2) To design interactions to do with — not to or for—the resident, and 3) To respect resident preferences, even if the resident prefers solitude.

## Design and Methods

The major objective of this study was to identify good techniques and strategies developed by each family in taking care of persons with dementia based on different conditions of the family such as age of the person with dementia, behavioural patterns, nature of the disease, other age related physical problems, environmental factors, economic conditions, educational and vocational status of other members, including the total number of family members. One of the six specific objectives of this study was to explore the good practices to engage persons with dementia in activities that will have a personal meaning to them.

Each family has a unique system of caring for persons with dementia. So a case study method is employed for this study. The objectives of this study demands an in-depth study of each family and every minute technique and strategies developed by them are explored in this study. This is a qualitative study, regarding the good care giving techniques and strategies developed by families themselves which so far have not been scientifically studied and recorded properly. The area of this study are the families of Kottayam district having persons with dementia, who are cared for by the families themselves. The researcher employed purposive sampling. He had identified six families with good care practices as samples for a detailed case study by consulting doctors and social workers working in association with ARDSI (Alzheimer's Related Disorders Society of India), Kottayam Chapter. Primary data for the study was collected from the family members (primary caregivers) of the person with dementia and an interview schedule was used as the tool for data collection. Data analysis and interpretation was done using the methods of qualitative researches like acoustic recording and transcription. These interviews were recorded using the audio recorder. Based on the transcription, the case history of each patient was formulated and interpretations were made from it.

## Results

Those cases with relevant and good visible practices are the ones given the priority care area for 'making these persons with dementia engage in some meaningful social activities' and only these are included in this article. So only five cases are being discussed here briefly. Specifically identifying only those e social activities that have a personal meaning to the person with dementia (PwD) is an important task for the family which demands some skills from the caregivers. So the primary caregiver and his strategies are given focus in these case studies.

**Case 1**

Mrs. A is a 40-year-old housewife, who is the primary caregiver of her mother-in-law having dementia. Her husband is a shop keeper working in a vegetable shop. She has two children (girls), both school going students, studying in 9th standard and 6th standard. Only she will be there at home during the day time to take care of the patient, since her husband has to go for work and children have to go to school.

The grand mother is 73-years-old and she started showing symptoms of dementia at the age of 68. At the onset of the disease, she had a severe wandering tendency. She went out of the house and walked to distant places without any orientation. She woke up early in the morning between 3 and 4 am and went out, saying that she was going to church. She had a tendency to clean the premises of the house with the broom until the broom got damaged. Once she fried fish using kerosene instead of coconut oil. After that incident she was not allowed to cook. When she was asked to stop cooking and entering the kitchen, she became emotional and cried for hours. It might be because, she may have enjoyed cooking and she was famous for her skills in cooking. She became hyper active and destroyed a sewing machine and a chair. She took all the objects including the learning materials of children and hid it somewhere. All these behavioural problems led the family to consult a doctor and thus she was diagnosed as having Alzheimer's disease. Presently she is calm, speaks less, most of the time simply sits on a chair in the sit-out, occasionally walks along the bed room and sit-out. If we ask her a specific question she will respond, but it may not be the correct answer to the question.

This person with dementia (PwD), once busy with all the household chores and having frequent interaction with neighbours and relatives, the family realized and identified that it was difficult for her (PwD) now to be always confined inside the house. Hence, Exit seeking was a frequent tendency. The family members consciously gave several opportunities to her (PwD) to go outside the house with random monitoring. The grand children too have an important role to play in the monitoring. They take the PwD to the nearby house of their relatives; assist her (PwD) to walk along the road and nearby premises. The presence of children was found to be very useful in making the person engage in activities. The children make the grandmother (PwD) engage herself in games and they continually motivate her (PwD) to participate in it. It was noticed by the family members that their presence makes the person happy and comfortable. The positive impact on persons with dementia- both cognitive and affective, created by the presence of children opens doors for further studies and experiments.

**Case 2**

Mr. B is 67-year-old retired Indian Navy officer, who is the primary care provider for his wife who is at the primary stage of dementia. She is a retired primary school teacher of 65-years-old. She started showing symptoms two years back and was diagnosed with primary stage of dementia. She forgets the names of the close relatives while talking about them. Sometimes she forgets the recipe of the food items while preparing food. The wife and the husband are staying alone in a house. Their only son and his family stay abroad. The family hired a housemaid; she comes twice in a week and does the major household work. Other daily work such as cooking and cleaning are done by the husband and wife together. Being in the early stages of the disease, there were no serious difficulties and symptoms.

Both the husband and wife have a good relationship; mutually understanding and supporting each other. While cooking, the PwD forgets the ingredients needed and confuses it with the recipe of some other items, which creates anxiety. So they prepared a hand written recipe book describing the preparation method and ingredients needed for all the items they cook and placed it openly in the kitchen. This has increased the courage and confidence of the PwD when she enters the kitchen.

The awareness among the other family members about the importance of making the PwD engaged in an important activity is a positive factor in providing quality care. The family where the husband consciously organized all the necessary facilities and made it available for the wife (PwD) to keep her engaged when she was diagnosed in the early stages of dementia, is a good modal. Both the husband and wife are mutually supportive and do all the household work together, including cooking. Cooking is a productive activity which provides satisfaction and ample opportunity to be engaged and to interact with other members (applicable only for early stages of dementia).

They watch TV programmes, especially spiritual programmes on religious channels, read news papers and religious magazines together. The moral support and presence of the husband in all the interested activities of the person having dementia is worth commendation. The PwD is noticed to be very comfortable in the husband’s presence. The love and affection shown by the husband is the true motivation for the person with dementia to continue with her interested activities. In this family, the caregiver employs a supportive care giving strategy which has been found to be very effective in keeping the patient comfortable, confident, engaged and free from confusions due to mild cognitive impairment and memory lose.

**Case 3**

Mrs. X is a 42-years-old house wife, who is the primary caregiver for her father-in-law having dementia. She was a school teacher and now she has resigned from her job to take care of her father. Her husband is a journalist and has been working for a newsdaily for the past seven years. She has three children, one of them studying in the degree college another for, plus two and the third one is in the 9th standard. Now the family comprises of six members, father, mother, three children and the grandfather who is having dementia.

The PwD is 66-years-old and he started showing symptoms of dementia at the age of 60. He is a botany degree holder and had worked as a lecturer for 30 years. After his retirement he was actively involved in social activities. He was the member of a resident association and was actively participating in many social services. He was also the member of a local public library. Reading was the happiest hobby for him. He loved to spend his free time with the children and he used to teach them also. Slowly he started showing symptoms of dementia. He started behaving like the children. He loved to spend all the time with the children and even tried to play cricket with his grand children. He developed a strong desire for chocolates. He suffered from loss of sleep and he seemed to be restless throughout the night. He forgot the alphabets and so began miss reading the newspaper. His manners deteriorated, and he often stuffed his mouth with food, often choking at the dining table. He insisted on eating food from his plate in a specific manner, often with his hands. The family decided to consult a doctor and he was diagnosed as having Alzheimer’s disease.

Towards the later stage, day to day activities became difficult. Over the months his short-term memory deteriorated. Severe gastrointestinal problems including diarrhoea led to dramatic weight loss. Depression was increasing. He spent most of his time on the bed.

Mrs. X, the primary caregiver and the daughter in-law of the person with dementia, resigned her job to take care of the patient. Only she was at in the home during the day to take care of the patient.

The family gave strong support to the patient. All the members tried to be with the patient and make him comfortable. They started giving more attention to him. They also made some environmental changes in the home. Firstly, they shifted him to a room opposite to a garden which provided more light and air circulation. The family tried to give some physical activities to him to keep him occupied (PwD). In the evenings they would make him walk around the garden. The grand children would speak to him and help him speak about his interested topics. He likes to hear stories, so the children would play an important role in it. The caregiver would read the newspaper loudly for him. The family would go for a monthly outing with him. The usual places of the outing was the park and a school ground near the house. This was found to be an interesting activity that made him happy and energetic.

**Case 4**

Mrs. C is a 56-year-old house wife, who is the primary caregiver of a person with dementia who is 89-years-old. The patient is the mother in-law of Mrs. C. There are five members in that family—Mrs. C, her three girls and the patient. Her first daughter got married, the second one is studying, and staying in a hostel and the third daughter is going to school and stays with the mother. No information about her husband is available, because she did not want to discuss about him and got emotional when she was asked about him. So now she and her daughter together provide care to his mother.

The patient has been showing symptoms of dementia for the last two years. Sometimes she shows aggressive behaviour. She uses abusive words towards the caregiver, spits on her, and throws away food. She remembers several minute details of events of her younger years, but has little knowledge about the later years. She was a good singer, a person with a sense of humour and a spiritual orientation. She remembers old love songs, rhymes and devotional songs which she sings occasionally. She studied up to the 4th standard and has good general knowledge. Now she is very talkative, speaks very loudly , will respond to all questions which may be provocative and aggressive at times. The patient has seven children, two girls and five boys. Her husband died 10 years ago. Now she is staying with the wife/ the daughter -in law of her third son.

The PwD sings old songs and comic rhymes which she had sung in her younger days. When the children ask her for more songs, and motivates her she responds at times. The possibilities of art can be used effectively for engaging the patients. One who has an interest in art will have that interest at all her stages of life; even dementia seems to have minimum control over it. The opportunity provided by the family to the patient to interact and to be social is an important factor. In this family, the patient is in a room where there is a window which opens to a private road. She can see the neighbours passing through the road with whom she was friendly earlier. Whenever she sees someone, she calls them and talks to them (may be meaningless talk). Neighbours are ready to come close to the window and talk to her. This is an activity which she enjoys.

**Case 5**

Mrs. D is a 49-year-old school teacher who is the primary caregiver for her mother in-law of 90 years. She is a qualified teacher (BA, BEd. ) working in a nearby school. There are seven members in this family—father, mother (PwD), her husband and three children. Father is 92-years-old; he is still healthy and has no much physical problems. Husband is an officer working in the employment exchange. Two children are working in Bangalore and the younger daughter is studying in school. Thus two children are not available to the family but the other members are present.

The mother started showing symptoms of dementia at the age of 87. She has no formal education and was a house wife. She was diagnosed as having dementia at the age of 88. She has some past memories and her present behaviour has some link with her past. She wants to go out (exit seeking) for feeding hens, goats and pigs. Now these animals are not in the house. There is a busy road just in front of the house. So the family placed a spilt layered door facing the room towards the courtyard. The lower layer will be closed and it prevents her from going outside. But she can watch travellers and vehicles from the top portion of the door which is kept open. She was very religious and was very keen in observing all the important religious days and festivals.

Religious practices provide room for keeping the patient engaged. The PwD had a habit of reading the Holy Bible before the onset of the disease. So the Bible was placed beside the cot and she reads it occasionally, even though the caregiver doubts whether she understands any of the material she reads. The observation of important days and festivals provides the person with dementia an opportunity to interact with others and it makes her more social and engaged. Since the PwD had a habit of observing all the important days, both religious and traditional festivals like Onam and Christmas; the family provides special attention to her so as to remind the PwD of those days by encouraging and facilitating her to observe these se days. They celebrate it with the purpose of making the grandmother (PwD) happy and the family identifies it as a cheerful experience and a meaningful activity for their grandmother.

## Conclusion

The personal meaning of activities is usually associated with the earlier experiences of life the person with dementia had in, his/her vocational history and educational background. One, who was very active and independent in their 'pre-dementia' stage /life, may find it difficult to adjust to the 'present' controlled life situations. A person with dementia is capable of finding meaning in the 'present' life situations and can also derive significance and importance in it if the caregiver recreates situations from their past history.

The family caregivers in Kerala are not trained for providing care; but they have developed their own strategies and techniques to provide maximum comfort to the patient. The findings of this study have a peculiarity that, all the good practices so far identified have already been proved effective by the families through their years of practice. A trial and error mechanism has already been applied by the families in each care giving strategy. The good, that has emerged and the relevance found in these specific situations should be used to find some universal applicability, therefore it would be worthy to study it universally.

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