



Alzheimer Scotland Centre for Policy and Practice



MANIPAL
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The Experience of Advanced Dementia in India

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**Developing community capacity to provide
care for people with advanced dementia in India**

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The Experience of Advanced Dementia in India

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Project Overview

This short report is one of a series of reports arising from a study funded by the Scottish Funding Council Global Challenge Research Fund. The Project “***Developing family and community capacity to provide evidence-informed advanced dementia care, and reduce risks of dementia related elder abandonment and abuse***” was co-delivered as a partnership project between the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland, UK and the Manipal College of Nursing, Manipal Academy of Higher Education (MAHE) Manipal, India. The Project responds to an urgent development need within India to develop dementia education aligned with the Global Sustainable Development Goals. The Project objectives focus on how advanced dementia is understood and experienced, the availability of advanced dementia care education and considers the potential usefulness of an existing portable education resource known as Class in a Bag.

This short report focusses on the experience of advanced dementia in India, drawing on evidence gathered in three focus groups with family carers.

Introduction and Background

Fifty million people are living with dementia globally, and approximately two thirds currently reside in LMICs (ADI, 2015). India has approximately 4 million people with dementia, the second highest prevalence of all countries in the world. In contrast to UICs, the majority of people living with dementia live in multi-generational households in India and around 50% include children under the age of 16 (Dementia India Report, 2010) and the majority of care is provided by family members and local home nurses. However, recent demographic changes, including migration and the lack of education and training of family and home carers on how to support people with dementia means that many people with dementia are not receiving appropriate care or support, particularly as they progress to the advanced stages of the disease.

Previous research has highlighted that awareness and understanding of dementia among Indian communities is poor and symptoms of dementia are often thought to be ‘normal ageing’ or the result of possession or God’s punishment (Hossain et al. 2018). Additionally, research has shown that the burden and stress related to caring for a relative with dementia is high, resulting in reduced quality of life for carers, particularly female carers (Srivastava et al, 2016; Roopalekha, et al. 2010; Shaji et al. 2009). This leaves carers of people with dementia vulnerable to developing physical and mental health problems (Ajay et al. 2017) and people with dementia vulnerable to coercive or potentially abusive care practices as a result (Danivas, et al. 2016). Many studies acknowledge the difficult situation for both the person with dementia and the caregiver and identify the need for caregiver training and support systems within the community. However, only one study identified in our literature review has explored the potential for developing training for caregivers of people with dementia in India (Narayan et al., 2016), despite the clear need highlighted within the literature. In order to address the gap in the literature and inform the development of an education resource for family caregivers this research aimed to develop an understanding of the experiences of those living with and caring for a person with advanced dementia through focus groups in Manipal, India.

Focus Group Objectives

1. To develop a culturally sensitive understanding of advanced dementia, and description of dementia-related abuse and abandonment.
2. To gain insight into the experiences and challenges facing people living with or affected by advanced dementia.

Methods

To gain an understanding of the experiences and challenges faced by people living with dementia and those caring for them, three facilitated community conversations were carried out using a focus group methodology. The first two focus groups were carried out during the UWS staff visit to Manipal in April/May 2019. A third focus group was carried out in July 2019 by the research scholar and Prof Elsa Sanatombi Devi .

Ethical approval for the project was secured 13/3/19 from the Kasturba Medical College and Kasturba Hospital Institutional Ethics Committee (Reference IES 220/2019) and endorsed by UWS School of Health and Life Science Ethics Committee. The project also obtained Clinical Trials Registry-India registration (# CTRI/2019/04/018807)

Recruitment

There were two methods of recruitment for the focus groups. It was planned to conduct one focus group in English and the further groups in local language. Recruitment for the English language focus group used a snowball sampling approach using existing networks within the MAHE Faculty. The inclusion criteria for the English language focus group were:

- Fluent in English
- Currently caring for a family member with advanced dementia
- Able to attend a focus group on MAHE campus at specified time

Two focus groups were carried out in the local language (Kannada). Recruitment for these focus groups occurred through recruitment camps held in the village approximately two weeks before the focus group. Recruitment camps were held during a pre-existing community meeting where information about the study was communicated and potential participants were able to ask questions about the study and what would be required of them. Inclusion criteria for the local language focus groups

- Currently caring for a family member with advanced dementia
- Able to attend focus group at specified venue within the community and specified time.

Focus group schedule

A focus group schedule was developed by the team in MAHE and refined during the UWS team visit. The focus group schedule is included in Appendix 1. Focus group 1 was facilitated by the UWS and MAHE team in English. Focus groups 2 and 3 were

facilitated by the MAHE team in the local languages. All focus groups were audio recorded and transcribed by the research scholar.

Participants

Participants in the three focus groups were all involved in caring for a family member with dementia. All of the participants were carers for people of an older generation, parents, and grandparents. This included both biological parents and in-laws. Table 1 outlines the numbers of participants in each focus group.

Table 1 – focus group participants

	Focus group 1	Focus group 2	Focus group 3
Number of participants	9	9	9
Gender (m/f)	9 female	7 male/2 female	9 Female
Language	English	Kannada	Kannada
Length of focus group	119 minutes	29 minutes	47 minutes

Data analysis

The focus groups were audio recorded, transcribed and where necessary were translated to English. Analysis of the focus groups was carried out using framework analysis (Ritchie & Spencer, 2002). An initial familiarisation of the data involved reading and re-reading the transcripts from focus groups 1 and 2 and listing, highlighting and noting the key ideas and themes in the data. The second stage was to develop an initial thematic framework used to index sections of the data, which are pertinent to each theme within the framework. The indexing stage was carried out by LR and AJW. Following this, data were charted, and final themes were agreed as described below.

Findings

The analysis resulted in three interlinking themes, with subthemes as outlined in Figure 1 and explained in more detail below.

Conditions of caring

In understanding the experiences of family carers of people with advanced dementia, the focus group participants described bio-psycho-social and cultural conditions which shape their care experiences. These are explored in more detail below.

Biological conditions

The biological symptoms of dementia as experienced by the individual and the family carer plays an important part in shaping the caring experience for participants. This subtheme relates to the common symptoms of dementia which were experienced and that family carers expressed they have problems addressing in their daily care routine.

This included concerns related to the fundamental needs of the individuals, including eating and drinking, going to the toilet, washing and dressing.

He cannot go to the bathroom.....he cannot get up.... cannot walk.....and even cannot call. (P2, FG 2)

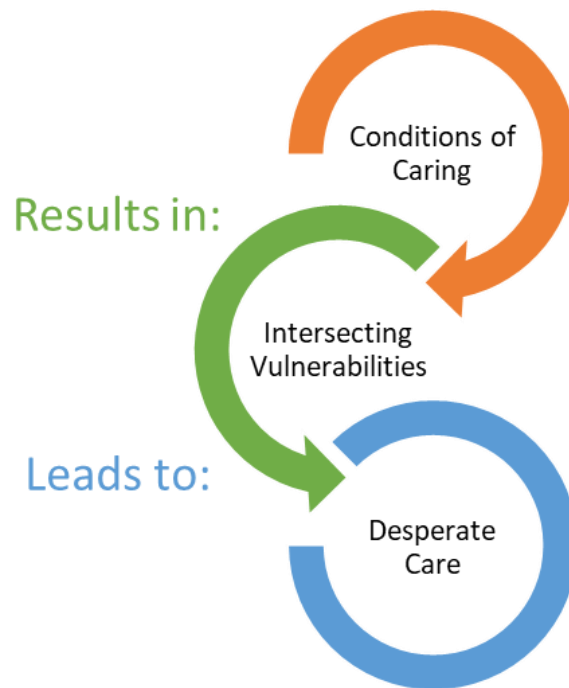


Figure 1: Focus group themes

Psychological conditions

Additionally, caregivers spoke of concerns relating to psychological factors. Again, these are related to the symptoms of dementia and common co-morbidities but also the burden and stress experienced by family caregivers caring for a person with dementia. This included concerns about mental health, notably depression and suicidal thoughts of the person with dementia and those in a caring role and increased stress on family members.

Sometimes I feel very sad so...even after having a degree, I am sitting at home and looking after her. (P6, FG1)

My mother had depression and she was thinking of committing suicide (P4, FG1)

Social and cultural conditions

The final subtheme explores the social and cultural circumstances that the participants are caring for family members with dementia in the advanced stage. This includes prescribed gender and family roles within society and the social support structure (or lack of) available to support people living with dementia. The majority of focus group

participants were female and although the majority spoke of male relatives helping with some aspects of the care, it was clear that as females, there was a cultural expectation that they should take on the caregiver role. The participants spoke of caring out of a sense of duty and responsibility.

We are doing our duties and responsibility, if they are satisfied, we are also satisfied (P4, FG2)

For some, this meant that they had to sacrifice their own ambitions and careers in order to take on the caregiver role.

I wanted to do PhD nursing, things went very good I was selected but I couldn't join the..... course my husband said that it is not possible for you to join the course either you have to sacrifice you PhD or else we have to put my mother to the old age home. (P6, FG1)

Additionally, there was conflict between caring for older relatives with dementia and caring for children. Multi-generational households are traditional in Indian culture, however some of the participants expressed concern and specific challenges with a recent cultural shift to a nuclear family model where children move away from home leaving older parents living alone.

My husband and me both are working so suddenly if the caregivers leaves it becomes extremely difficult.....that is the major problem when the family is nuclear, if it is a joint family somebody will be there when we re urgently in need. (P9, FG1)

Culturally and socially, there is an expectation that families, and in most cases, women, provide the care for people living with dementia. Although there are options to have paid care in the home, there is a lot of stigma and distrust around this and the costs of hiring paid carers are high making it difficult to sustain for any length of time.

They are not professional caregivers, they are like other helpers at home, someone who comes as on earning basis, they do not really understand towards the depth they have to take care or in what way they actually have to look at. (P1, FG1)

The combination of the bio-psycho- social and cultural conditions of caring for a family member with dementia appeared to create a challenging situation for many of the participants. This created vulnerability for the person with dementia and for the family carer. This will be discussed in the next theme.

Intersecting Vulnerabilities

The conditions described above appeared to create a situation which resulted in both the family caregiver and the person with dementia being in a vulnerable situation. The stories told by the participants showcase intersecting vulnerabilities in the participants' situations. The vulnerabilities of the person with dementia and the family caregiver are different but intersect, reflecting the reciprocal cared for/ care giver relationship.

The lack of health and social support and infrastructure for families supporting people with dementia result in the burden of care falling on the family and in many cases, one

or two family members. The financial cost of accessing medical care is high, as is the cost of employing a home nurse to provide basic care.

I asked many caregivers they charge around 15000-20000 rupees and all that also is very costly. Our salary that is staff nurse salary is around 14000 to 20000 then instead of that it is better unless and until I get a person who is cost effective for me it is better for me only to take care. (P6, FG1)

Additionally, there is no formal training for home nurses and there is a lack of trust in their ability to look after a family member with dementia. Participants in the focus group spoke of the assumption that employed home carers could not adequately care for their family members because they did not love the person and were only interested in picking their wages. There was a feeling that only family members, because of the pre-existing relationship based on love and trust were able to provide support with the fundamental care required by family members with advanced dementia.

With that we have to show lot of love to these types of dementia patient. When we show them love automatically they will start listening to us. (P3, FG3)

However, there was a recognition from some participants in the English language focus group that love was not enough and there was a clear need for training for family carers to be able to provide the specialist care required by a person with advanced dementia.

Even if we just love our dear ones, love cannot help all the times it needs special care. (P1, FG1)

In contrast, the participants in the local language focus groups did not identify a training need to be able to provide specialised care. They felt that because they were caring for a loved one, they would do what was required to care to the best of their ability and did not want external involvement or training.

To give care to the patient I don't think we need any extra training.....Suppose they have diabetes and hypertension, in that case we require some knowledge otherwise, if there is only dementia and if we think about us too in that situation... we may be able to take better care of our loved ones. (P1, FG3)

This situation creates vulnerabilities for both the family carer and the person being cared for with advanced dementia. The lack of external support for family carers increased the burden of care and associated stresses of trying to manage caring with other responsibilities putting them at increased risk of physical and mental illness. This was recognised by many participants as a vulnerability of the caring role.

The caretaker also has the risk of going for depression.... and I was very much worried my sister in law that time and because of my job I couldn't take of my mother to my house. (P4, FG1)

This in turn creates a vulnerability for the person with dementia who risks losing their care and support if their family member is ill, particularly in a nuclear family.

I am also from a nuclear family and when we all went out to study and work. Just my father and mother were there, after that my father passed away. (P1, FG1)

Additionally (for some) the lack of awareness that advanced dementia is a complex condition which requires specialist skills and training in order to provide care and support for a family member creates a further vulnerability for both.

I think as age advances everybody gets this type of problem so this is my thinking towards dementia. (P4, FG3)

I don't think training is required as we do not give any special care to the patient. (P8, FG3)

The final factor which creates an intersecting vulnerabilities is the focus group highlighted a number of misconceptions and social stigma around dementia, including the causes of dementia and the care needs and abilities of a person with dementia. This then prevents families from seeking medical or social support when they need it as families were not willing to accept the diagnosis.

I had called all my family members and told that grandmother is in this stage and now it is a high time for us to go to the doctor so fixed the appointment with the doctor after I fixed the appointment with the doctor my family member did not talk to me. (P5, FG1)

The intersecting vulnerabilities identified from the focus groups put both the family carer and the person with dementia at risk of poor health and wellbeing. The result of these vulnerabilities is discussed in the final theme below.

Desperate care

Desperate care captures the care experience of the person with dementia and the care practices family caregivers adopt. Due to the care conditions and the resulting vulnerabilities these could be considered to have the potential to be considered abusive, coercive or neglectful. However, when discussing these care practices, it was clear that family caregivers feel that they have no other choice in order to cope with their situation and that they are the result of desperation.

We are family members we love them a lot, things can happen in such a way that it can render to abuse probably. (P1, FG1)

Examples of desperate care relate to supporting family members with advanced dementia with the fundamentals of care; eating, drinking, washing and going to the toilet. There were examples spoken about where coercion was used to ensure that family members felt that they had provided care to their loved one before going to work or engaging in other tasks such as looking after children.

It is not like regularly we restrain when we are near here. We just leave her alone, when we ya... to use washroom, when we are away from home. We have no other way. (P5, FG1)

Additionally, participants spoke about the use of physical restraints to reduce risk and to ensure that their family member was safe. Examples such as tying a person with dementia to a chair on the porch or locking the bedroom to ensure they couldn't fall or wander off. Despite an awareness that these practices were potentially abusive, the participants spoke of having no other option due the increasing burden of the caring and other responsibilities such as employment or childcare.

She will be sitting out in the veranda the whole time we have to put up the fan on for her and it is too difficult my mom should monitor both the children and her we have to put cloth around her body we have to put it to the chair [so she doesn't fall] (P5, FG1)

Finally, there were a number of participants who spoke of issues relating to loneliness and a feeling that keeping their family members away from society was the best thing for them. This resulted in increased loneliness for the people with dementia, as well as the family caregivers. Although beyond what would be considered the fundamentals of care, the lack of social support and isolation of people with dementia described could have negative consequences for those experiencing it.

With this problem you can't socialize and you can't have normal relationship with people around. (P2, FG1)

It is clear from the focus groups data that the experience of living with and caring for a relative with advance dementia in Southern India produces a set of difficult challenges for families. Families often do not understand dementia and improvise the best they can with the intention of protecting their family member with dementia. The training needs identified in the English language focus group included general awareness raising, specific support with the fundamentals of care, communication and the need for trained third party carers and day services. However, it is worth noting that the local language focus groups did not feel there was a need for training. This may be because the English language focus group participants had a wider knowledge of the healthcare system and many were qualified nurses who had insight into what was available. The participants in the local language groups were not qualified and may not have had the knowledge to identify their own training needs.

Discussion and recommendations

The findings of the focus groups confirms that the experience of caring for a person with advanced dementia in India can result in difficult circumstances for both the person with dementia and the family caregiver. As such there is a lack of understanding of the needs of the person with dementia, and for many caregivers, a lack of awareness of their own education needs in their caregiving role. The caregiving situation is a result of the cultural and social expectations and understanding of the caregiving role combined with the biological and psychological symptoms of dementia. This combined with the lack of support and reluctance to access support out with the family makes both the person with dementia and their caregiver vulnerable to further physical and mental health problems. These vulnerabilities combine and results in acts of desperate care which have the potential to harm or be perceived as harmful to those living with dementia.

The findings of the focus group have begun to help us to understand the experience of caring for people with advanced dementia in India, however there are some limitations to these findings. Although attempts were made to ensure that the views of carers from different experiences and backgrounds were represented, the majority of the data in this analysis was drawn from the English language focus group. As the participants could speak English and all worked in some capacity at the university, many within the School of Nursing, it can be assumed that these participants were well educated and had some knowledge about dementia and the research process. In contrast, the focus groups conducted in the local language did not last long and participants appeared reluctant to share their full experiences. This may be due to cultural relations and class structures within the community. Future research should take into account the cultural context and explore ways to ensure inclusivity in the research process and enable equal participation from all participants.

However, the data from focus groups 2 and 3 did indicate that caregivers have similar experiences to those expressed in focus group 1 but as indicated in the analysis, the main difference was the caregivers awareness and identification of their own training needs. This may be reflective of the concept 'you don't know what you don't know' (White et al., 2018). The role of caregiving is often so intense and there is little time for reflection between tasks that carers adopt coping strategies to survive. This is reflective of our focus group findings and highlights the need for education and awareness interventions for family caregivers.

In conclusion, the focus groups have identified the caring conditions of family carers for people with advanced dementia in India. These conditions combine to create intersecting vulnerabilities for both parties which can result in caregivers adopting desperate care practices which have the potential to harm the people they are caring for. As such there are a number of recommendations arising from this work package:

- There is a need for education resources for family carers which provide practical advice and support for caring for family members with advanced dementia
- There is a need for dementia awareness raising within the community to enable family carers to feel supported within their local networks.
- There is a need for culturally sensitive resources which acknowledge current 'desperate care' practices in a non-judgemental manner
- There is a need for future research to adopt culturally sensitive research methods which enable participants to engage fully in the research process.

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