



## **Alzheimer Scotland Centre** for Policy and Practice



**MANIPAL**  
ACADEMY of HIGHER EDUCATION  
*(Deemed to be University under Section 3 of the UGC Act, 1956)*

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

### Executive Summary

Short Report Series Number 1  
July 2019

Funded by

Scottish Funding Council Global Challenges Research Fund 2018-19

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

## Executive Summary

### Project Team

Professor D Tolson<sup>1</sup>, Professor E Sanatombi Devi<sup>2</sup>, Dr L Ritchie<sup>1</sup>, Dr A Jack-Waugh<sup>1</sup>, Dr V Binil<sup>2</sup>, J Henry<sup>2</sup>, CS Martis<sup>2</sup>, Dr A George<sup>2</sup>.

<sup>1</sup>The University of the West of Scotland, UK.

<sup>2</sup>Manipal College of Nursing, Manipal Academy of Higher Education. India.

### Contents

<b>Project Summary</b> .....	3
<b>Permission and Access</b> .....	3
<b>Objectives and Deliverables</b> .....	3
<b>Working Methods</b> .....	3
- <b>Findings and Outputs: Evidence Review</b> .....	4
- <b>Findings an Outputs: Current Services and Public Health Data</b> .....	4
- <b>Finding and Outputs: Experiences of Advanced Dementia</b> .....	5
- <b>Findings and Ouptuts:Dementia and Advanced Dementia Education Mapping</b> .....	6
- <b>Findings and Ouptuts: Co-Design Activities and Class in a Bag</b> .....	7
<b>Key Findings and Next Steps</b> .....	7
<b>References</b> .....	9

### Reports in this Project Series

**Report Number 1.** Executive Summary: Developing community capacity to provide care for people with advanced dementia in India

**Report Number 2.** Scoping Dementia Services and Public Health Data in India

**Report Number 3.** Mapping advanced dementia education provision in India against a best practice interprofessional learning framework

**Report Number 4.** The Experience of Advanced Dementia in India

## Project Summary

There are 4 million people living with dementia in India and an urgent need to establish dementia education and care aligned to the Global Sustainable Development Goals. Advanced dementia within India is a hidden problem, which places individuals and their sometimes-young carers at high risk of poverty and other inequalities. There is an immediate need to develop practical and theoretical understanding among practitioners, policy decision-makers and the public about advanced dementia alongside an understanding of advanced dementia related abuse and abandonment. This mixed method project has begun to explore the experiences and vulnerabilities of people affected by advanced dementia, to establish the principles to inform culturally sensitive dementia education linked to care. The project has included community conversations to gauge views on the potential to adapt the UWS-Class in a Bag (CIAB) as a brief educational intervention to accelerate dementia awareness and community /family based dementia care capabilities.

## Permission and Access

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 approval extends from 12/3/19 to 11/3/20.

## Objectives / Deliverables

1. Develop a culturally sensitive definition of advanced dementia and description of dementia-related abuse and abandonment.
2. Gain insight into the experiences and challenges facing people living with or affected by advanced dementia.
3. Identify key skills for family caring underpinned by contemporary best evidence, including the *Palliare* Best Practice Statement for advanced dementia care (developed from a K2 Erasmus + project).
4. Agree design, implementation and evaluation principles based on the 'examine, empower and enact framework' (UNDP 2018) for a culturally sensitive prototype of a portable community education resource based on state of the art UWS-Class in a Bag-Dementia.

## Working Methods

Professors Tolson (UWS) and Sanatombie (MAHE) adopted a co-principal investigator model with distributed responsibility among the core team. Desk-based research has been undertaken at a distance and fieldwork has been undertaken on site in Manipal. The short term appointment of a graduate Research Scholar has enabled us to reach into non-Hindi speaking village communities. Two weekly team Skype meetings with an emphasis on knowledge sharing and mutual support has maintained momentum. An intensive week of public engagement and data collection activities was complete in April, with the UWS team working in Manipal.

Methods used to collect data included:-

- review of research literature (objectives 1-2)
- desk based research to map local services and access public health data (objective 1)
- focus groups to explore the experience of family care giving (objective 2)
- educational gap analysis (objective 3)
- community co-design conversations and user acceptability questionnaires exploring relevance and cultural sensitivity issues of an existing research based training resource UWS-Class in the Bag-Dementia (objective 4).

## Findings and Outputs

### 1. Evidence Review

The aim of the literature review was to develop a critical understanding of advanced dementia care experiences and challenges faced by individuals, families and local community services in south East Asia. Following the completion of the rapid review of the literature, it was apparent that there was sufficient literature on the topic, which could form the basis of a manuscript for a peer review journal. As such, the team agreed to adopt a scoping review methodology following a collaboratively prepared review protocol. The approach for the scoping review was underpinned by Arksey and O'Malley's (2005) five-stage framework, which adopts a rigorous process of transparency, enabling replication of the search strategy and increasing the reliability of the study findings. Initial database searches carried out using the search terms [dementia, OR Alzheimer's disease OR cognitive impairment OR memory impairment] AND [care OR support OR community OR home care OR institutional care OR caregivers OR abuse OR neglect OR abandonment OR vulnerability OR hardship] limited to articles published in the past 10 years (since 2009) and based in India or countries in South East Asia identified 174 articles. These were screened for relevance to the aim of the search by title (removed 126 articles) and then abstract (removed 29 articles). This resulted in 19 articles included in the scoping review. The review confirms that there is a dearth of information about the experiences of caregivers of people with advanced dementia. However, the literature that is available establishes that family members carry the burden of care for people with dementia in India. As such, family carers are more likely to experience high levels of stress and illness and are likely to engage in coercive behaviours that could result in physical or psychological harm to the person with dementia. Additionally, the literature highlights the lack of understanding of dementia among caregivers for people with dementia and the absence of training or support for family carers.

**Output:** A literature review that we aim to publish in a peer-reviewed journal.

### 2. Current Services and Public Health Data

The World Health Organisation (WHO), Global Action Plan on the public health response to dementia, proposes that countries develop national dementia action plans with targets for increased dementia public policy, awareness, prevention, diagnosis, care and treatment and research (WHO 2017). Alzheimer's and Related Disorders Society of India (ARDSI) ([www.ardsi.org](http://www.ardsi.org)) is leading on stakeholder consultations to inform the development of a country action plan for India. Currently, available data on dementia in India is of varied quality and may underestimate the scale and complexity of dementia-related needs, vulnerabilities and

hardships. It was not possible to locate a definition of advanced dementia from scrutiny of local policy or service documents, and there does not appear to be differentiation in reporting the stage of illness progression at the time of a person's diagnosis. The absence of detailed data makes it impossible to determine the scale of need arising from advanced dementia, although local practitioners suggest that the condition is often advanced when individuals or family seek help. The concept of dementia treatment gaps, focused mainly on medication is gaining in popularity and gaps as high as 90% have been reported even in relatively prosperous areas such as Kelara and Goa. Dementia Care and Information Centres do exist in some areas, but provision is patchy. We were unable to locate reliable data on service usage or demand for dementia care from inpatient, outpatient or community services or camps (outreach clinics). As far as we could determine, there is no dementia specific care infrastructure in Manipal or surrounding areas or accessible recording of dementia-related abuse. There is no discernable dementia training or dementia education for health or social care professionals or for family carers in Manipal and the Udipi District.

**Output:** Sub report Series Number 2.

### 3. Experiences of Advanced Dementia

To gain an understanding of the experiences and challenges faced by people living with dementia and those caring for them, two facilitated community conversations were carried out during the UWS visit to Manipal. These community conversations used a focus group methodology. Focus group 1 was conducted in the English language and involved nine participants. All of the participants were female and caring for a family member with dementia in an urban environment. The second focus group was conducted in Kannada, the local language of the area. There were 11 participants (6 male; 5 female) in this focus group, all family carers of people with dementia living in an urban area. A third focus group with 8 women from local villages, all caring for a relative with advanced dementia was undertaken in the local Kannada language.

The focus groups were audio recorded, transcribed and were necessary 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 emerging from 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 was charted, and final themes were agreed as described below.

The analysis highlights the biopsychosocial (cultural) conditions created through the experience of living with dementia and caring for someone with dementia in Manipal. This resulted in intersecting vulnerabilities for both the person with dementia and the family carer, putting them both at risk of harm, abuse or poor wellbeing. Social and cultural conditions highlight the importance of family support and the cultural expectations of families to care for the older generations. However, the experiences of the caregivers revealed that stigma of dementia and lack of understanding or support often result in the burden of care falling on one family member – often this is a daughter in law who has a cultural duty to care for her parents-in-law. The biological conditions result from the impact of the disease on the individual and the symptoms that present from these. Finally, the negative psychological impact on both the person with dementia and the family carer was highlighted through reported incidences of depression, suicidal thoughts, stress and loneliness. The combination of these conditions appears to result in increased vulnerabilities of both the carer and the person with dementia – it is at the intersection of these vulnerabilities that result in an outcome of 'desperate care'.

The theme of desperate care encapsulates care given to people with dementia, such as restraint, close monitoring and isolation, which is a result of the lack of support infrastructure and is delivered by family carer because they have no other option, despite knowing that there is a potential for physical or psychological harm.

**Output-** Sub Report Series Number 4 reports the findings of the focus groups, and a manuscript will be prepared for a peer reviewed journal.

## 4. Dementia and Advanced Dementia Education Mapping

The aims of the work package were to: collect baseline information on accredited nursing and community education, social policy, curricular guidelines, rights and values-based practice and best practice guidelines which focus on nurse and community education on advanced dementia in India and internationally. From the data, to carry out a gap analysis and identify the gap between 'what is happening' and 'what should be happening'. From the findings, the team was to make recommendations for the partnership approach to developing a culturally relevant education framework for nurses and community members to address the knowledge and skills gap identified.

Data was gathered using the following methods and sources:

- Discussion meeting with Manipal faculty staff during the Manipal field trip
- An internet search of the education recommendations of international guidelines on advanced dementia; WHO, ADI, India.
- A short review of papers on nurse education and advanced dementia in India
- An Internet-based search of; nursing curricular content, programmes available which focus solely on partially on advanced dementia, community education on advanced dementia.
- Relevant findings from the focus group research.

A team of three undertook the data gathering using the Dementia Palliare Best Practice statement as the framework to organise, analyse and present the data (Holmerova et al 2016; Tolson et al 2017). Two team members gathered information about 'what is happening', and one team member collected data about 'what should be happening'. The summary report highlights progression to a Dementia plan for India and the support for education and development a national plan would stimulate, is slow to progress. Using the Dementia Palliare Best Practice statement as a benchmark with the Indian Nursing Council curriculum guidelines and Manipal College of Nursing course content as examples, the team found advanced dementia was absent in undergraduate and postgraduate curriculum. Teaching and learning activities concerned with health and social care of people living with dementia as a whole was scarce, again across undergraduate and postgraduate programmes.

The WHO global dementia plan, the recommendations from ARDSI and the findings of this project provide the signposts for the way forward in dementia education for the health and social care workforce and communities in India. Increased awareness of the rights of people living with dementia is guided by the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and the Mental Health Act (India) (2017) is a priority for integration into education, practice and communities. There is potential for collaboration with the India Council of Nursing to influence future nursing curricular to include critical recommendations from the WHO Global plan on Dementia and the ARDSI. Family caregivers, through their participation in the focus groups, have illuminated the need for education on the biopsychosocial impact of

dementia on their family members and effective person-centred solutions to every day caring experiences.

**Output-** Sub Report Series Number 3 reports on the dementia education mapping.

## 5. Co-Design Activities and Class in a Bag

An existing UK version of the UWS-Class in a Bag (CIAB) containing resources for both adults and children to learn about dementia were provided for the project team in Manipal. The UWS team demonstrated the CIAB content and approach to MCON faculty members and to student nurses. Field notes were taken to capture initial reactions and views on the learning resource and approach. Two faculty members (ES & VB) undertook a short introductory CIAB training session to better understand the concepts and to become familiar with the facilitators instruction manual. User acceptability was further explored using structured questionnaires to capture the views of 20 practitioners following a demonstration tutorial.

What we found was that the CIAB approach was thought to offer a practical and engaging way for practitioners, community and family to become dementia aware and gain some insight into the experience of dementia. The low technology version of an actual bag containing artefacts that could be handled, illustrative photographs and other items including stories and a facilitator manual had more appeal than a digital version. The popularity of the low tech version was simply that the 'hands on' method was accessible and allowed opportunity for the facilitator to adapt to the group that were participating in a CIAB learning session. It was highlighted that the design brief would need to take account of the weight of the bag for transporting, durability of materials for use in a warm climate mindful of seasonal rains. A further consideration was how the bag itself and contents might be cleaned between uses.

Specific items that would need a local and culturally relevant replacement were identified and it was noted that items/images appropriate for both rural and urban living would be required. For example, local clothing items would be more meaningful for rural living, and western styled items would be recognisable in cities and so on. Choices would also be important in the photographic images to allow the facilitator to select the most relevant images of, for example, appropriate cooking equipment for the particular group. Different ways to capture and convey illustrative stories were also thought important particularly for community education and dementia education with children. In addition, due to gendered identity it would be important to have some materials that were unisex, but also some examples specific for men and others for women.

**Output:** A Design Brief has been prepared however the report is currently embargoed.

## Key Findings and Next Steps

1. Our evidence review (rapid review and scoping review of the literature) confirms that there is a dearth of information about the experiences of caregivers of people with advanced dementia. However, the literature establishes that family members carry the burden of care for people with dementia in India. As such, family carers are more likely to experience high levels of stress and illness and are likely to engage in coercive behaviours that could result in physical or psychological harm to the person with dementia. Additionally, the literature highlights the lack of understanding of dementia among caregivers for people with dementia and the absence of training or support for family carers.

2. Review of available public health data and epidemiological studies indicate that there is sufficient evidence to confirm that dementia is a major public health concern in India. Scoping of current services demonstrates that the development of the care and service infrastructure is in its infancy and that consideration is needed of dementia education, access to expert nursing and workforce planning to achieve good quality services.
3. Our preliminary investigation with family carers to explore their experiences of advanced dementia has revealed intersecting vulnerabilities for both the person with dementia and the family carer, putting them both at risk of harm, abuse or poor wellbeing. The interplay of a range of social, economic factors coupled with stigma and lack of dementia understanding or support often result in shame with the burden of care falling on one family member – often this is a daughter in law who has a cultural duty to care for her parents-in-law. Negative psychological impacts on both the person with dementia and the family carer include depression, suicidal thoughts, stress and loneliness. The combination of these experiences gives rise to what we have called acts of ‘desperate care’. This includes using restraint, close monitoring and isolation with the intention of protecting both the family and the relative with dementia.
4. Using the Indian Nursing Council curriculum guidelines and Manipal College of Nursing course content as examples, we have found that education on advanced dementia was absent in both undergraduate and postgraduate nursing curriculum. Reference to an existing interprofessional advanced dementia-learning framework, developed by European educators, reveals a major education gap in both practitioner education and provision of training for family carers. Furthermore, there is little focus on dementia at all stages of the condition, across health and social care education related to the care of older people or indeed people of any age.
5. The concept of a portable dementia awareness resource to support community and family carer understanding of dementia was well received. Furthermore, there was recognition that the existing UWS Class in a Bag (Copy Righted) could be adapted to provide scalable education across a range of practitioner groups including unqualified home nurses who provide care in the family home, staff who work with people with dementia in care facilities and family carers/community members.

Clearly, there is much to be done to support the many people living in India whose lives are affected by dementia. Our next steps will include development of caregiver education supported by a programme of research within a Dementia Centre of Excellence. An ambition that will build on the existing connections with the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland UK and the Manipal College of Nursing at MAHE.

Our ambitions focus on the development of dementia care capacity and capability. This can only be achieved through multi agency and multi stakeholder commitment and requires establishment of wider collaborative relationships many of which are still to be forged. Our intention is to disseminate findings strategically and build a coalition of local support with key influencers. We recognise that our work is just at the beginning but our efforts will be propelled by the project legacy. We are most grateful to the project funders and to the many individuals who have worked with us and generously given of their time and insights.

We have established a partnership agreement between UWS and MAHE, which sets, out our collective commitment to use our scholarship and nursing wisdom to propel changes that will support people with advanced dementia in India and their family caregivers to live the best life possible, and to equip practitioners to lead and drive transformative change.



## References

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International journal of social research methodology*, 8(1), 19-32.

Homerova, I., Waugh, A., MacRae, R., Sandvide, A., Hanson, E., Jackson, G., Watchman, K. and Tolson, D. (2016) Dementia Palliare Best Practice Statement. University of the West of Scotland. [cited 2016 March 21] Available from: <http://dementia.uws.ac.uk/documents/2015/12/dementia-palliare-best-practice-statement-web.pdf>

Ritchie, J., & Spencer, L. (2002). Qualitative data analysis for applied policy research. In *Analyzing qualitative data* (pp. 187-208). Routledge.

Tolson D, Holmerova I, Macrae R, Waugh A, Hvalic-Touzery S, de Abreu W, Lillo Crespo M, Merta A, Hanson E. (2017) Improving Advanced Dementia Care an Interprofessional Learning Framework *JAMDA* <http://dx.doi.org/10.1016/j.jamda.2017.03.014>

WHO (2017) Global action plan on the public health response to dementia 2017-2025. WHO Geneva ISBN 978-92-4-151

