

Alzheimer Scotland Centre for Policy and Practice



Mapping advanced dementia education provision in India against a bestpractice interprofessional learning framework

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

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Mapping advanced dementia education provision in India against a best practice interprofessional learning framework

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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 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 mapping of current practitioner education using a skills framework to guide the development of sustainable advanced dementia community and practitioner education.

Introduction and Background

In 2010 the Dementia India Report was published which outlined the current and future impact of dementia and outlined priorities and actions (Alzheimer's and Related Disorders Society of India et al., 2010). Despite this being over eight years ago, there is currently no national plan in India, and supportive strategies and legislation are scarce. The Chair of ARSD recently reported the development of a national dementia plan for India, supported by Alzheimer Disease International and WHO.

As a member state of the World Health Organisation, India is signed up to the Global action plan on the public health response to dementia 2017-2025 (World Health Organisation, 2017). Part of the Global action plan is for 75% of member states to have a national action plan on dementia by 2025. The global plan asserts that the approach to human rights in all policies, plans and legislation should be consistent with the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

"The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity".

(UN General Assembly, 2006)

Additionally, action area 4 Dementia diagnosis, treatment, care and support outlines how adequately trained, and qualified workforces are required to ensure that the aspirations of both global and national action plans can be enacted (World Health Organisation, 2017). Workforce education should support staff to develop skills and knowledge to be able to work across services, foster collaboration with family carers and provide integrated, evidence-based care throughout the trajectory of the illness. Staff need to be able to apply this knowledge and their skills in all settings where there are people living with dementia. The World Health Organisation (2017) acknowledges that the complexity of the experience of dementia can challenge the current knowledge, capacity and skills of the workforce.

The need for education of the dementia workforce was established in the paper by the ARDSI (Alzheimer's and Related Disorders Society of India et al., 2010). In their model for delivering dementia care services, seven core strategies outlined the development and education required for service development. Education is seen as essential for creating awareness of dementia in communities, building capacity in all health care teams, to develop long-term care services both residential and in the community, develop specialised services for people with severe dementia, and improve legal and education services. ARDSI proposed a 'National Dementia Training of Personnel Program' to create and implement a multi-professional education strategy across India to increase the capacity of the existing workforce and to address the critical shortage of specialist health care professionals.

In 2017 the Mental Health Care Act was passed, and the definition of 'mental illness' is considered to include dementia. In chapter V of the act, the rights of people with mental illness are outlined and include their right to:

- access mental health care
- community living
- protection from cruel, inhuman and degrading treatment
- confidentiality
- restriction on the release of information in respect of mental illness
- access medical records

Additionally, the act outlines the responsibility of the government to; create awareness about mental health and illness and reducing the stigma associated with mental illness, take measures to ensure the human resources are in place including implementing educational and training programmes in collaboration with higher education institutions (Ministry of Law and Justice, 2017). Current use of the Act with people living with dementia in India is untested. A critical appraisal of the Act in relation to geriatric healthcare asserts that the Act has the potential to help developments and improvements of mental health care services underpinned by the rights-based approach; but urges caution about undermining the role of family caregivers and increasing caregiver burden (Antony et al., 2019).

This legislative and policy backdrop demonstrates that India is on the cusp of critical developments in right-based care for people living with dementia and their families. Next is a brief analysis of the family caring and health care education situation, which illuminates the starting point from which to make the aspiration of the legislative and policy background a reality.

Communities and families

The care of people living with dementia is predominantly in the home environment with daughter-in-laws providing the majority of care for children, people living with dementia and

the home (Das et al., 2014). Male members of the household are responsible for financial support. More recently, in urban areas, housewives are increasingly taking up employment, and the *'reliability and universality of the family care system has been eroded'* (Das et al., 2014). Carer stress and burden is outlined as a key feature of the family experience when they have a person with dementia in the family. It is recognised that available services for people living with dementia across India are inadequate with approximately 100 memory clinics, tenday care centres and eight residential care facilities serving the 3.7 million people with dementia in India.

Outlined within WHO (2017) action plan guidance is community education needs; these include:

- the need for increased community awareness of an understanding of dementia,
- education to reduce stigma and discrimination
- education about the human rights of people with disabilities
- enhancement of the population to recognise early symptoms of dementia
- public education on risk factors associated with dementia

Community and caregiver education projects include a Dementia Friendly Community initiative, in Cochin developed by the ARDSI in 2011-2012 in which awareness programmes were delivered across Cochin communities. Little information is available on the recent successes of this initial project.

Findings from studies in India on homecare and education programmes for family caregivers are scarce, with one study demonstrating positive outcomes for a homecare programme which included caregiver education (Dias, 2008). There are several internet-based information resources for family caregivers, including resources from ARSDI, Nightingale Medical Trust and Dementia Care Notes site.

The dementia workforce

In 2010, the Alzheimer's and Related Disorders Society of India asserted that there was '*no structured training on the recognition and management of dementia at any level of the health service*'. Services were described as insensitive, including not providing adequate information and support for family caregivers (Alzheimer's and Related Disorders Society of India et al., 2010). Das in (2014) reported that nurses, health care attendants and physicians within general hospital and primary health care settings in India were not educated to work effectively with people living with dementia; recommending that undergraduate geriatric, general medicine and primary care workers require additional aspects on dementia care education. Searching and sourcing of literature illuminated a significant gap in current knowledge about dementia education in health and social care professions in India. One available study of third and fourth year nursing students in Bangalore found that while their knowledge was inadequate, they generally had positive attitudes towards people with dementia, although only 49% felt comfortable working with people living with dementia when they were agitated or upset (Poreddi et al., 2015).

In 2010-2011 the National Programme for Health Care of the Elderly (NPHCE) directed the development of free, specialised health care facilities for people over 60 throughout the state health delivery system. While Das (2014) describes some of the positive outcomes of this programme he does highlight the requirement of staff participating in this programme to have integrated knowledge and skills to work with people living with dementia, particularly those providing home-based support.

The use of paid and unpaid social carers in the community varies between urban and rural areas. Demand for paid carers is increasing, yet there is no structured education available for this part of the dementia workforce. It is argued that this workforce requires short education programmes and regulation of the agencies who coordinate them (Alzheimer's and Related Disorders Society of India et al., 2010).

Research on advanced dementia and staff knowledge and skills within care homes is scare and' *lack of adequate of elder-friendly long-term care facilities in India is a huge concern*' (Das et al., 2014).

Advanced dementia

Advanced dementia does not feature in the literature from India reviewed for this report. The classifications of the stages of dementia are three stages, early/mild, middle/moderate and late/severe with severe encompassing advanced and palliative stages (Alzheimer's and Related Disorders Society of India et al., 2010). Concepts such as advanced dementia and the later palliative/end of life stage are not present.

Advanced Dementia Education Mapping Objectives

To collect baseline information on accredited nursing and community education on advanced dementia in India.

To collect information on social policy, curricular guidelines, rights and values-based practice and best practice guidelines which focus on nurse and community education on advanced dementia nationally and internationally.

To carry out a gap analysis and identify the gap between 'what is happening' and 'what should be happening' using the best evidence data gathered.

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.

Methods

Use of the "examine, empower, enact" framework as the approach for the work (UNDP and United Nations Development Programme (UNDP) Bureau for Policy and Programme Support, 2018). Presented here are the findings of the 'examine' part of the processes.

Data gathering

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. Two team members gathered information about 'what is happening', and one team member collected data about 'what should be happening'. An overview is provided in Appendix 1.

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 and 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.

Data analysis

Current curricular content was mapped against the Dementia Palliare Best Practice statement. The Dementia Palliare Best Practice Statement was developed as part of the European Union Erasmus+ programme Dementia Palliare: Interprofessional experiential learning solutions: equipping the qualified dementia workforce to champion evidence-informed improvement to advanced dementia care and family caring project 2014-2016 (Holmerova et al 2016; Tolson et al 2017). The statement is divided into six sections covering:

Section 1: Protecting rights, promoting dignity and inclusion

Section 2: Future planning for advanced dementia

Section 3: Managing symptoms and keeping well

Section 4: Living the best life possible

Section 5: Support for family and friends

Section 6: Advancing Dementia Palliare Practice

At an online meeting, all the benchmarking data were compared; the gaps emerged from these discussions. Cultural and societal differences were discussed and integrated into the findings.

Findings

Undergraduate and postgraduate nursing programmes

All undergraduate and postgraduate nursing programmes are delivered under the auspices of the Indian Nursing Council syllabus. Dementia is highlighted as indicative content in promotion of wellness for the elderly and skill in providing nursing care learning outcomes for medicalsurgical nursing in the second year. The clinical speciality Mental Health Nursing includes the human rights of people with mental illness and dementia in their learning outcomes. MSc programmes have similar learning outcomes and content.

The findings of the gap analysis based on undergraduate and postgraduate nursing programmes in Manipal College of Nursing indicated an absence of education in the following areas:

- Protecting rights, promoting dignity and inclusion.
- Future planning for advanced dementia

- Managing symptoms and keeping well
- Support for family and friends
- Advancing dementia practice

Content relevant to 'Living the best life possible' is present in fundamental skill development in BSc and Diploma Nursing programmes. This content, however, is not dementia specific. Dementia is covered as part of the mental health nursing unit, organic brain disorder, which is four hours. Specific dementia content, including pharmacological and non-pharmacological management of dementia, is covered in a 2-hour session in the undergraduate nursing programme. Geriatric nursing, (only available in Manipal) is present in undergraduate and post-graduate programmes and consists of 40 hours of theory, one hour of which is dementia specific and one-week clinical experience. MSc programmes, including mental health nursing and community health nursing, have one session of 2 hours on dementia. There are no specialist dementia programmes available for postgraduates.

The lack of dementia-specific services relates to the lack of opportunity for the health workforce to develop appropriate knowledge, skills and experience. Where education on dementia is present in medical and nursing curricula, they are medically focussed. This medical dominance is aligned to how services are currently structured in that specialist services are limited in number, and where they exist, they provide medical interventions.

Family caregivers/focus group findings

Findings from analysis of the focus groups with family carers replicated what is known in the international literature. Within the sample of family caregivers, there is:

- Fatalistic attitudes to dementia
- Minimal knowledge regarding the potential for environmental modifications, including technology, to support caregiving in the home.
- Reduced understanding of the individual experience of dementia.
- Lack of understanding of the biopsychosocial impact of dementia on the people living with dementia, including impact on the senses and perception.
- Lack of awareness of strategies to manage everyday day care needs of people living with dementia, including strategies to reduce the risk of 'desperate care'.

Family carers felt that the paid carers they used required education and skills development on how to work effectively with people living with dementia.

Clinical and best practice guidelines

There is one clinical medical guideline available for people living with dementia in India (Shaji et al., 2018). No nursing or social care guidelines were available from a desk-based internet search.

Discussion and recommendations

This summary report highlights progression towards a Dementia Plan for India coupled with the realisation that support and preparations essential for dementia education and practice development necessary for implementation is slow. Using the Dementia Palliare Best Practice (Holmerova et al 2016, Tolson et al 2017) 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 were scarce 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. A fuller report on experiences of care giving is found in Sub Report Series Number 4.

The Executive Summary (Report Number 1) from this project sets out a number of recommendations arising from the dementia education mapping and other project activities. The key project findings and recommendations reflect the desirability of establishing centres of dementia education excellence that include programmes of applied research to propel progress.

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Appendix 1

Mapping Current Dementia Education against the Palliare (Advanced Dementia) Best Practice Statement: An Interdisciplinary Learning Framework

Area examined Section 1: Protecting rights, promoting dignity and inclusion		
What is happening	What should be happening (professional skills and knowledge)	
	Professionals have reflected upon their value base and its influence on their contribution to supporting people with dementia, their families and friends.	
	Professionals understand that citizens may not fully understand dementia and this may affect people with dementia, their families and friends seeking support, accessing care services or being involved in the care and support of people with dementia.	
Currently not in place	Professionals are fully aware of human rights legislation; values based practice, The Glasgow Declaration of Rights and the impact of stigma and discrimination on people with dementia, their family carers and professionals working with people with dementia.	
	Professionals ensure that their daily practice and the practice of others, is underpinned by adhering to, applying and advocating the principles of value based practice, ethical practice and human rights legislation. This includes; candour, legality, partnership and compassionate approaches to working with people with dementia, their family and friends.	
	Dignity is supported at each interaction with the person with dementia and their families whilst meeting biological, psychological, spiritual, existential and social needs.	

What is happening	What should be happening (professional skills and knowledge)
Currently not in place	Professionals provide the person with dementia a full biopsychosocial assessment of assets, strengths, needs and preferences. This assessment needs to take account of past life experiences that may surface as the dementia progresses (first language, migration, conflict).
	Whilst in the post diagnostic support phase, professionals engage with the person with dementia and their family to discuss and agree a shared perspective and approach to planning for advanced dementia care. Planning should be considered as a process and not as a one off event, this acknowledges change over time.
	Professionals develop their skills and knowledge with regards to Advanced planning, legal protections concerned with capacity and Advanced Directives. This should be shared in an appropriate format to support people with dementia and their family to develop and communicate these formal agreements with the family and health and social care team.
	Professionals explore and support opportunities for independence and social connectedness for the person with dementia and their families. Existing social networks are strengthened where possible.
	Professionals provide opportunities for peer support and practical education for families and friends. This education focuses upon skills and opportunities for communication, practicalities and person centred strategies to support.

What should be happening (professional skills and knowledge)
Professionals will support implementation of the wishes, needs and aspirations outlined in the persons care plan.
Professionals will continue to have direct and open conversations about the potential trajector of the illness during advanced dementia. Professionals develop skills and networks to enable regular engagement with health, social and non-statutory services and harness the range of expertise that different disciplines can bring to maintain wellbeing for the person with dementia and their families.
Professionals need to develop the knowledge and skills so optimal comfort, safety and well- being is achieved when a person may have complex physical symptoms and comorbidities.
Professionals provide education and engage in discussions regarding maintaining and, where possible, improving wellbeing and a healthy lifestyle.
Professionals are able to discriminate in an evidence informed way between necessary and unnecessary or ineffective aggressive interventions or treatments.

Section 4 Living the best life possible			
What is happening	What should be happening (professional skills and knowledge)		
Covered in UG and PG module (Fundamental care needs	Professionals have the skills and knowledge to provide and support others to provide		
we teach in First year BSc Nursing and Diploma nursing.	fundamental care needs. These include:		
All these topics are covered in general; but not specific	identification and management of painmanagement of sensory needs		
to dementia).	 management of movement, walking and attaining physical comfort skin condition management 		
	 continence care sleep management nutrition and eating bathing and washing 		
	 oral care Professionals understand that the experience of stress and distress by people with dementia is complex and multi-faceted. Professionals understand how distress is expressed by the individual. Professionals understand and educate other professionals and carers about the need to 		
	investigate all changes in behaviour, for example to identify and treat delirium or depression. Professionals provide a comprehensive assessment and care plan when the person with advanced dementia is experiencing stress and distress.		
Partly covered in UG and PG module (We teach	Professionals have the knowledge, skills and behaviour to apply approaches that enable people with advanced dementia express themselves and their views.		
pharmacological and non pharmacological management	Professionals provide a safe, enabling and secure and dementia friendly environment. Professionals understand that there are a range of nonpharmacological interventions that		
for both UG and PG students. During community posting,	promote quality of life. Professionals understand how to use these with people who have advanced dementia.		
students understand the support needs and take	Professionals understand the importance of meaningful activities and their role in ensuring the person with advanced dementia is able to participate in activities that are meaningful and		
appropriate action.	enjoyable for them. Professionals understand the importance of 'whole person care', the importance of relationships and having someone understanding to talk to. Professionals work with people with dementia and their families with an approach which maintains and supports personal identity or selfhood and recognises how a person with advanced dementia experiences the world.		
	Professionals understand the support needs of family and friends, and how to give or signpost appropriate interventions.		

Section 5 Support for family and friends			
What is happening	What should be happening (professional skills and knowledge)		
Currently not in place.	Professionals have the knowledge, skills and networks to enable family and friends to engage with care settings / services to maintain their own biopsychosocial wellbeing.		
There are very few dementia care centres in India where	Professionals provide opportunities for peer support; skills based education and other joint learning opportunities.		
the professionals can improve their competency.	Professionals encourage a whole family system approach to support and care. This means including both young and old, male and female members of the family in support processes.		
Section 6 Advancing Dementia Palliare Practice What is happening	What should be happening (professional skills and knowledge)		
	Professionals to lead practice reforms and model evidence informed Dementia Palliare practice.		
Currently not in place	Professionals demonstrate a critical awareness of policy, legislation and rights relating to people with dementia and their family and friends and have the ability to apply this knowledge to advance practice, develop involvement strategies and champion change.		
Few professionals have the knowledge to critically appraise research	Professionals to proactively lead interprofessional and collaborative working to support transitions, continuity and co-ordination of care.		
	Professionals to proactively lead on effective partnership working and positive relationships with family and friends.		
Majority of the professionals are not involving in	Professionals are able to critically appraise research, undertake small scale research or tests		
professional development activities related to dementia	of change and understand how this can be meaningful applied in a practice setting.		
because there are very few opportunities in India related to dementia care.	Professionals participate in continuous professional development activities (self directed learning, training, membership of or affiliations with dementia learning communities, universities, health institutions or carer groups) so their knowledge and understanding of advanced dementia is refreshed.		