

Letter to the Editor

Specialized Education Programme on Neurodegenerative Diseases Care of Older Adults in Sri Lanka: The Necessity and Possibility**Rathnayake, N.¹, Sundarapperuma, S.M.T.D.¹, Nirmani, K.G.P.¹, Wickramarachchi, B.I.¹, De Silva, K.K.P.M.K.¹, Herath, H.M.P.², Dasanayake, H.D.W.T.³, Warnakulasuriya, S.S.P.⁴ & Persson, M.⁵**¹Department of Nursing, Faculty of Allied Health Sciences, University of Ruhuna, Sri Lanka²Department of Nursing and Midwifery, Faculty of Allied Health Sciences, Kotelawala Defense University, Sri Lanka³Department of Nursing, Faculty of Allied Health Sciences, University of Peradeniya, Sri Lanka⁴Department of Clinical Sciences, Faculty of Nursing, University of Colombo⁵Faculty of Health Sciences, Kristianstad University, Sweden

As Sri Lanka undergoes a demographic shift with an increasing aging population, the prevalence of neurodegenerative diseases (NDD) among older adults is on the rise. Addressing the unique challenges posed by such conditions including Alzheimer Disease (AD), Dementia and Parkinson Disease (PD) requires a collaborative effort to enhance the knowledge and skills of caregivers and healthcare professionals. In this letter to the editor, we justify the necessity and explain the possibility of establishing and implementing a specialized advanced education programme to create trained cadre for NDD care for older adults in Sri Lanka. We believe that establishing such a programme is a promising initiative that could help to address the burden of NDD among older adults in Sri Lanka while it enhances the quality of healthcare provisions in Sri Lanka.

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Neurodegenerative diseases

Neurodegenerative diseases are a wide range of pathological conditions characterized by the progressive degeneration of the structure and the function of the nervous system that are essential for mobility, coordination, strength, sensation, and cognition (Liu et al., 2012). Ageing is a major risk factor for NDD (Tay et al., 2018). Although the rate of progression of these diseases differs substantially, they are all unavoidably progressive and require symptomatic treatment since they are currently inmedicable (Peplow et al., 2022).

Prevalence of NDD and its burden

It has been estimated that, globally, about 10 million people develop NDD each year, and nearly 60% of these estimates reside in low- and middle-income countries. According to the published findings in Sri Lanka, the overall prevalence rate of dementia was estimated at 3.98% (Silva et al., 2003) among older adults. NDD has become one of the main causes of disability adjusted life years of the older population worldwide (Deuschl et al., 2020), which demands long-term care and facilities. Patients with NDDs have severe or profound core activity limitations. Therefore, their hospice facilities rely on carers to provide care for their personal needs. This would create a massive socio-economic impact, especially in low-income countries like Sri Lanka. Due to the absence of having a well-established aged care delivery system in the country, all

the caring burden accumulates within the family in such patients. Further, NDDs can be overwhelming, not only for the patients, but also for their caregivers and immediate families due to a lack of awareness and limited understanding of NDD. This results in stigmatization, discrimination and social exclusion of patients and families.

Necessity of education and training for care of older people with NDD

With increasing of life expectancy, the demand for specialized care particularly in NDDs is higher than ever. Caring for older individuals with NDD involves navigating complex challenges, including cognitive decline, motor impairment, and emotional distress. Therefore, holistic care approach with a multidisciplinary team care is essential for these patients to address the complex needs emerged from physical and psychological impairments embedded in the inclusive sociocultural contexts (Mc Veigh et al., 2019). However, delivering high-quality and comprehensive care for NDD is a challenge for health systems around the world due to the scarcity of focused education programmes.

Lack of NDD education in undergraduate curricula of medical and nursing programmes is an international issue. In recent years, some efforts have been made to improve NDD education for undergraduate medical and nursing students in a global context. Although the curricula of medicine and nursing undergraduate programmes in Sri Lanka undergo rigorous revision and re-

design, there is also no stand-alone courses specifically focusing on NDD in elderly has been included. Hence, a comprehensive and systematized healthcare model in planning and delivering care for NDD patients is a pivotal requirement in the current context.

Therefore, a well-structured education program is mandatory to empower healthcare professionals and caregivers for implementing personalized care plans, fostering a supportive environment that promote the overall wellbeing of patients with NDD. The skills in delivering optimal holistic care, various soft skills i.e. communication skills, self-awareness, empathy, leadership and managerial skills are mandatory components in such a programme.

Necessity of establishing specialized education programme for caring patients with NDD in Sri Lanka

Neurodegenerative disease in older adults is becoming a huge burden to the economic and healthcare system in Sri Lanka. Since the 3rd highest proportion of the older population in Asia has been recorded from Sri Lanka (Samaraweera & Maduwage, 2016), it is estimated that NDDs are a public health concern and a leading cause of disability and dependency among Sri Lankan older population. Consequently, there is an urgent need to improve healthcare for people living with NDD in the country now and in the future. In line with the argument that the increasing older population coupled with the high prevalence

of NDDs justifies the necessity of special attention towards them, including specialty care modalities, education and research.

Further, there is a supportive social system for the older aged people in Sri Lanka. However, the recent socio-economic crisis has precipitated a shift in the traditional extended family structure, compelling individuals to seek employment opportunities beyond their localities. This would affect for the family care support for the older adults with NDD. Therefore, a care training cadre is required apart from the informal caregivers.

Health professionals, such as registered nurses, physicians, general practitioners, neuropsychologists and geriatricians, need to work collaboratively to contribute their specialist knowledge to the diagnosis, treatment, care and palliation of people living with NDD. These health professionals also need to engage in shared decision-making to complement their roles and foster client-centered treatment and care to provide the best-possible NDD care.

Given the importance of having interdisciplinary care for NDD care, it is important to understand how worthy and economical it is to create a comprehensive care model which incorporates knowledge, understanding and adequate skills with training in all these interdisciplinary aspects in a country such as Sri Lanka. Thus, a trained cadre to meet the caring and rehabilitation needs of NDD patients should be created in the Sri Lankan context providing a comprehensive understanding

specific to the local context. Collaborations with international organizations developing a successful education program with the support from other countries could be a remedial action to address this issue. Hence, establishing an advanced education programme that is specifically leading to a Master's level education programme to create this cadre is much needed at the moment. This in turn, leads to resolving the issues such as lack of adequately trained staff, financial concerns and will enhance the health indicators of Sri Lanka.

Further, this kind of programme for health professionals who already have an understanding about the health concepts would facilitate specialization in this area for them to have competency not only in caring for people with NDD but training and advocating all stakeholders in the context of NDD care. This creates more opportunities of employment and research as well.

It will provide a multitude of advantages to the education sector in Sri Lanka, apart from the health sector. Establishing a Master degree for this purpose would facilitate the universities in Sri Lanka in strengthening the capacity of teachers by exposing them to the global experts in the field. It would be long-lasting and further, it will enhance the quality of education provided by the individual universities in a wider aspect. Internationalization of the curricula will facilitate pedagogical approaches and professional qualification of teachers. Furthermore, such programmes explore avenues for research and create sustainable

and economically stable environment within the university system.

Possibility of establishing specialized education programme in caring for patients with NDD in Sri Lanka

“nEUROcare - an European initiative for capacity building to meet the challenges in caring for people with neurodegenerative disorders in Sri Lanka” (618596-EPP-1-2020-1-SE-EPPKA2-CBHE-JP) is a project aimed at Capacity Building in the field of Higher Education (CBHE) (<https://neuro-care.lk/>). This is a joint project through the main coordination with Kristianstad University (Sweden) and partner Higher Education Institutes/Universities in Europe and Sri Lanka: namely Triskelion (Norway), University of Ljubljana (Slovenia), University of Tartu (Estonia), Neapolis University Pafos (Cyprus), University of Colombo (Sri Lanka), University of Ruhuna (Sri Lanka), University of Peradeniya and Kotelawala Defense University (Sri Lanka). The ultimate target of the programme is to establish a postgraduate education programme (Masters of NDD by coursework) in each Sri Lankan partner University with the accreditation and approval from the University Grants Commission, Sri Lanka and be implemented continuously (<https://neuro-care.lk/>).

With this initiative, Sri Lankan academic staff is being trained by an internationally qualified team of clinical and academic staff from the European region while further strengthening the infrastructure in each university. Further, facilities for such training would be provided by the nearby health care institutions. The curriculum of the programme as well as the materials for

study are being developed considering cultural, religious, political and social context of Sri Lanka.

Summary

The establishment of a Master's degree programme on NDD care is a promising initiative that could help address the burden of NDD among older adults in Sri Lanka. It will provide specialized training and education for healthcare professionals. This programme would help to improve the quality of care and reduce stigma associated with NDD which could lead to better access to care and support for such individuals and their families. This programme could help to achieve the sustainable development goals of good health and wellbeing and quality education in Sri Lanka. It could also have broader economic, social, and political benefits, such as improving the country's healthcare system and creating new job opportunities for healthcare professionals. Overall, the initiative for the establishment of a Master's degree programme on NDD care under the nEUROcare project is a helpful step towards improving the lives of individuals with NDD in Sri Lanka and promoting sustainable development in the country.

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