

**Care, communication
and biomedical
challenges**



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Challenges in caring for people with neurodegenerative disorders (NDDs); A narrative on Asian perspectives

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Background

Neurodegenerative (NDDs) are a public health concern and a leading cause of disability and dependency among the elderly. Regions like Asia, Latin America and Africa are currently witnessing rapid demographic aging. 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. In most developing countries, older people, whether or not widowed, typically live with their families in multigenerational households. The care network has often been developed with a family centered approach in people with NDD where multiple socio-economic challenges play into account. The priorities should be made clear to identify the barriers available in Asian countries in providing quality care for people with NDDs. Thus, this review sort to gather information published in the Asian countries with regards to the challenges in caring for people with NDDs.

Methods

Original research articles, abstracts, reviews, and letters to the editor, published in the English language, during the last five years (2019 to 2023) were searched on databases (Google Scholar, PubMed, ResearchGate, Hinari, etc). The studies conducted in Asian countries were considered. Search terms such as “neurodegenerative disorders, challenges in NDD care, dementia care, NDD in Asia, and Alzheimer’s disease” were used during the thorough literature search. Reference lists of included full papers were also searched online, if relevant. Articles published in languages other than English, studies conducted in non-Asian countries, and literature older than five years from the date of publication were excluded from the review. The included literature was thoroughly considered for the aim of the study, study setting, study design, main findings and conclusion.

Results

Twenty-four publications were considered relevant according to the inclusion criteria. Most of the publications were found related to dementia care (ten papers). Few others (four papers) have considered caring for people with Alzheimer’s disease and Parkinson’s disease (two papers). This review found studies published in India, Sri Lanka, Nepal, Bangladesh, Indonesia, and Pakistan with regards to NDD care. Three main themes were identified as the ‘challenges’ in caring for people with NDDs, according to the main findings of the published literature. The themes included “Informal caregivers involve in NDD care”, “Lack of specialized training for healthcare professionals in care of NDDs” and “inadequate social/health services available for NDD care”.

Under the informal caregivers involved in NDD care, it has been noted that less empowerment of caregivers, limited knowledge/resources/skills in caring for people with NDDs, no formal preparation of caregivers, late presentation of people with NDDs to healthcare services, caring responsibilities at home is shared by all members, etc. as challenges.

With regards to the second theme, this review notified the inadequacy of specialized training of healthcare professionals in NDD care. The challenges included the wide range of differences in attitudes towards NDDs and

inadequate knowledge of dementia among nursing staff, unavailability of national policy on healthcare professional education and training to improve dementia care practice, lack of integrating education and training of dementia care in the undergraduate programs of medicine and nursing, deficits in the knowledge of dementia and a low level of positive attitude among the healthcare professionals who work in hospital settings where people with dementia are cared for, etc.

This review further captured that Asian populations have fewer available facilities in the health sector for the care of people with NDDs. There are few assisted living facilities or institutions that provide long-term care in low-income countries. Some countries even do not find cost-effective services available for people with NDDs. In most settings, families do play a vital caring role in looking after older adults with NDDs. In addition, inadequate resources and funding provided by the government organizations, insufficient workforce, unavailability of special palliative care services, etc. were identified.

Discussion

The inadequate training of healthcare professionals in NDD care reflects a systemic issue in Asian countries compared to the developed nations in the world. This needs to be addressed through comprehensive education and training programs. Bridging the gap in knowledge and fostering positive attitudes among healthcare professionals can significantly improve the quality of care provided to individuals with NDDs.

Additionally, the scarcity of specialized facilities and services for NDD care in low-income countries poses a significant challenge compared to high-income countries. Lack of access to assisted living facilities and palliative care services further compounds the difficulties faced by patients and their families.

Overall, addressing these challenges requires a multi-faceted approach involving policy changes, education initiatives, and increased funding to improve the quality of care for individuals with NDDs in Asian countries.

Conclusion

Low and middle-income countries encounter significant gaps in providing quality care for people with NDDs. The main challenges include informal caregiving, inadequate specialized training of NDD among healthcare workers, and the gaps in social/health services available for the care of people with NDDs. Establishing promising initiatives such as specialized training for healthcare workers, setting up cost-effective or free-of-charge training services for family caregivers, running special care units for people with NDD at every main hospital in the country, and establishing social services with a trained workforce, conducting more research to improve evidence-based practice could be suggested to fill up the gaps.