Correspondence

Exploring the barriers for guideline-based management of dementia amongst consultants in Kerala, South India: A qualitative study

Sir,

The diagnosis and management of dementia can be challenging. The variance in the symptoms of dementia and the natural acceptance of these symptoms as a part of ageing delays its recognition as a pathological process. The National Institute of Health and Clinical Excellence (NICE) in collaboration with the Social Care Institute for Excellence (SCIE) provides guidance for diagnosing and managing dementia. It describes with high methodological rigour the pharmacological, psychological and social interventions for people diagnosed with dementia. The guideline applies to both medical and non-medical service providers, as well as carers of people with dementia. The NICE-SCIE guideline also gives direction for adaptation to various settings.

The burden of cognitive impairment in India varies widely. The State of Kerala reports the highest prevalence of dementia in the country. In this direction, the use of standard guidelines amongst neurologists would make the management of dementia more evidence-based. Adoption of existing national or international guidelines is known to improve evidence-based clinical practice and quality of care. This study, therefore, explored the barriers in using the NICE guidelines for dementia amongst the neurologists in their regular clinical practice in Kerala.

The present study was undertaken by Health Action by People, a not-for profit non-Government Organization in Thiruvananthapuram district, Kerala between March and August 2018, after procuring ethical clearance from the Institutional Ethics Committee.

Exploratory interviews of neurologists were undertaken to understand the barriers in using guidelines, particularly the NICE-SCIE guideline for managing dementia. Fourteen in-depth interviews were conducted in two phases. The interview guide was developed exclusively for this study and was pre-tested. It included questions on the awareness and use of guidelines for dementia management, in general, the use of NICE guidelines, and the factors influencing the guidelines’ use. For this after interviewing the initial six consultant neurologists the schedule was modified appropriately. A total of 12 consultants were interviewed in the first phase. In the second phase, two consultants were interviewed who had a particular interest in dementia care. Written informed consent was obtained from all the participants. All interviews were audio-recorded and transcribed verbatim to allow detailed analysis. Researchers reviewed the transcripts and independently developed codes. The emerging themes were discussed with fellow researchers and specialists in dementia care. After refinements, the final overarching themes were identified.

All respondents encountered dementia patients in their clinics at least on a weekly basis, while a few of them saw such patients daily. Three overarching themes emerged from the analysis of these interviews as listed in Table I. Quotes (Q) listed in the text are detailed in Table II.

Theme 1- Lack of standardized approach to dementia care: It emerged from the in-depth interviews that neurologists broadly did not adopt any guidelines for managing dementia in their clinical practice. Some of them were ignorant of any guidelines for dementia care, particularly the NICE guidelines (Q1, Q2). Few of the respondents (neurologists) were aware of other guidelines in dementia such as the American Academy of Neurologist guidelines. They expressed practical difficulty in following voluminous guidelines and the need for training in guideline-based management of dementia. A readable, user-friendly edition of guidelines which will increase the
utilization was their expressed preference. Overcrowded outpatient departments and working under time pressure emerged as the primary deterrent for following guidelines (Q3). It was opined that a formal discussion about care plan, exercise and cognitive stimulation programme did not happen in practice. There was also a perception that the NICE guidelines were not suited to the Indian socio-cultural setting. The essential criteria for a guideline to be applied clinically include its adaptability, readability and feasibility in a given context. Many respondents felt that the lack of essential infrastructure, both physical and human resources, hindered the operationalization of any guidelines (Q4). Moreover, the recommendations necessitate the services of trained para-medical and other supporting staff members as well which is lacking in the current setting as perceived by most of the interviewees (Q5).

Table I. Themes and corresponding sub-themes which emerged as barriers for using dementia management guidelines amongst consultant neurologists

| Theme 1: Lack of standardized approach for dementia care |
|--------------------------------------------------------|
| • Neurologists were unaware of clinical guidelines to manage dementia. |
| • The guideline was voluminous and not adapted to the current setting. |
| • Lack of trained staff members for dementia care. |

| Theme 2: Viewpoints of the care-givers and family members |
|----------------------------------------------------------|
| • Early initiation of pharmacological therapy. |
| • Cognitive impairment seen as a natural consequence of ageing. |
| • Poor health-seeking and a nihilistic approach to dementia care. |

| Theme 3: Need for health system preparedness |
|---------------------------------------------|
| • Need for a political commitment and policy-level interventions in dementia care. |
| • Absence of inter departmental collaboration. |

Table II. Quotes for various themes depicting the barriers for using dementia management guidelines among consultant neurologists

| Theme 1: Lack of standardized approach to dementia care |
|--------------------------------------------------------|
| Q1 ‘To be frank…I am aware of NICE guidelines on epilepsy but less aware of dementia guidelines…but you see I don’t think there will much difference in these guidelines. FDA is the basis of all the guidelines…that is why I follow these guidelines...’ (RSID005) |
| Q2 ‘There are no guidelines for dementia. There are only criteria for the diagnosis… we don’t strictly follow them...’ (RSID004) |
| Q3 ‘We cannot follow these because we are all busy in the OPD schedule…Usually, neuropsychologists are doing such testing of the dementia patients...we usually refer the dementia patients to neuropsychologists to get the tests done...’ (RSID004) |
| Q4 ‘These guidelines first of all...almost all are developed in developed countries, so generalization to our setting is not possible. We have first to consider the incidence and prevalence of dementia, what are the commonest cause in Indian population...we have to specifically look for the risk factors of dementia...because the risk factors for the western population is not the same for our population...and the inherited group of dementia is more popular in western population ....’ (RSID008) |
| Q5 ‘I think the training of the support staffs, especially dedicated persons to counsel these patients. Especially as far as the initial assessment is concerned we find it difficult to do the assessment. Yes the nurses should be empowered more...that is the easiest way to approach the situation.’ (RSID003) |

| Theme 2: Viewpoints of the caregivers and family members |
|----------------------------------------------------------|
| Q6 ‘One of the reason is that the patient will not stick to our words...Once the patient seeks treatment for dementia for the first time, most of the time they won’t come back to me they go back to some other doctors for next visit. Many a time we are forced to start the medicines in the initial phases also...so basically it is difficult to adhere to the guidelines....’ (RSID001) |
| Q7 ‘Non-pharmacological, we can’t do much in OP wise...we have some leaflets and pamphlets ...we give them...how to take care of the dementia patients ...’ (RSID012) |

Contd...
could add to non-pharmacological management was also not acceptable to some of the consultants (Q7). The clinical practice guidelines for managing dementia developed by the Indian Psychiatric Society also document the importance of non-pharmacological therapy for the management of cognitive symptoms and associated non-cognitive behavioural problems. Often, the caregivers did not perceive dementia as a disease, but a part of the natural ageing process. Hence, the compliance to treatment was inadequate. One of the respondent (a dementia care expert) even opined that the therapeutic nihilism for dementia and related disorders inhibited people from seeking treatment (Q8).

**Theme 3: Need for health system preparedness:** The specialists felt that the critical factor for guideline implementation should stem from the political and administrative initiative: the government’s policy decision will bring in significant differences in the management of dementia. Many consultants opined that families found it challenging to cope with the expenses, consequently opting inadequate care.

It was suggested that the current social security measures at the governmental level are inadequate to meet the demands of dementia care (Q9). The ideal management which was envisaged as a team work collaborating with nurses, psychologists, psychiatrists, physiotherapists, geriatricians and neurologists was not felt as feasible in the current scenario. Untrained supporting staff (for cognitive evaluation) and absence of teamwork (nursing, psychologists, psychiatrist and physiotherapists) were identified as significant barriers to the implementation of any guideline (Q10). In this context the need for adequate training of the support staff on cognitive assessment and its management was deeply felt. In this context various replicable models of training programmes for rural healthcare providers have been documented with proven utility and effectiveness.

The consultants expressed a need for adaptation of NICE guidelines to better suit the Indian sociocultural setting. Compatibility of the guideline with the existing health system is an essential determinant for its acceptance and implementation. A user-friendly version of the guideline would also improve its use amongst the healthcare professionals. As the implementation of guidelines in a clinical setting also depends on various other factors, complained and streamlining of para-medical staff and hospital management should also be explored.

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