

The impact of dementia on migrant communities: A complex challenge in a globalised world

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Abstract

While there is now worldwide recognition of the challenges that dementia brings to national health economies, less well understood is the impact of dementia as a health issue in migration. As migrant communities settle both lifetime health risks and the age structure of the population may place some migrant communities at greater risk of developing dementias such as Alzheimer's disease and vascular dementia than the mainstream population. Delayed presentation for diagnosis, fear of discrimination and cultural stigma all increases the likelihood that individual cases will be complex in nature and that overall numbers will increase in those metropolitan areas across the globe that are often called 'gateway cities' for international migration.

Introduction

Dementia as a health issue for migrant communities

The 2015 UN International Migration Report [1] estimates there are 244 million migrants worldwide, with Europe hosting 76 million and North America 54 million. The same study points out that most migrants are of working age. Worldwide one in five of the members of foreign born populations lives in the global gateway cities [2], for example London in the UK has an approximately 37% foreign born population [3].

Both nationally and internationally the study of health issues for migrant populations has yet to single out dementia as a focus for policy development and research. There are two reasons for this

1- The assumption that the issue is relatively marginal for migrant populations due to the mean age of migrant populations being well below 65

2- The assumption that the international focus on the impact of dementia on national populations across the world sufficiently addresses the challenges for those who migrate

These assumptions need to be challenged when considering the impact of living with dementia for those who have migrated and on their adult children who are often the carers of those migrant parents who are now living with dementia.

The degree of complexity involved in supporting people living with dementia in such populations is under-researched and the volume of individuals and families affected is not fully appreciated. The number of people involved and complexity of the impact becomes apparent when considering the situation in metropolitan areas with long settled and diverse migrant communities where a significant proportion of people in the migrant communities concerned are over 65 and there are identified population specific health issues likely to increase the likelihood of vascular dementia and Alzheimer's disease and also where lifelong experience of health service access is associated with the experience of discrimination.

The UN International Migration Report for 2015 points out that globally 13% of the migrant population is over 65. This is twice the proportion of over 65s in the global general population. The International Organization for Migration's (OMD) World Migration Report for 2015 points out that migrant populations are more susceptible than the local host population to the health risks associated with poor diet, lack of exercise and smoking. These are all increasingly seen either as direct risk factors for developing Alzheimer's disease or associated with the risk of vascular dementia through conditions such as heart disease and diabetes.

When migrant populations are stratified from local census data there are identifiable migrant populations that are at increased risk of developing dementia [4]. These risks arise out of the differing migration history of migrant communities. The significant age demographic variations across the migrant communities are often not considered when dementia services are commissioned based on aggregated age data about the local migrant communities as in aggregate the migrant population is not considered to be at high risk of developing dementia.

Complex features of the experience of dementia for migrant communities

The migration history of individual families in migrant communities may mean that family-based support is globally dispersed. The cultural stigma surrounding dementia may mean the person living with dementia and their immediate family carers are socially isolated within their own communities. The costs of caring both psychologically and economically fall both on the individual living with dementia and their family in these cases, often exacerbated by late presentation to diagnostic and support services and the lack of access to culturally appropriate services or a culturally mindful approach in dementia

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care practice. This pattern is characteristic through the entire period of living with dementia from the initial approach to diagnosis to end-of-life care. Gaskin et al. [5] have done some work on illustrating the additional costs for African-Americans as a minority community in the USA. They estimate that family carers and people living with dementia bore about 60% of the \$71.6 billion cost of care for that population in 2012. African-Americans are two to three times more likely to develop Alzheimer's disease than the non-Hispanic white US community. In the USA this minority population accounts for 20% of all the people living with Alzheimer's disease

Neither the complexity of the issues nor the scope of the impact on migrant communities is considered by healthcare decision makers in the strategic planning and investment decisions for local dementia services. This complexity has not yet been explored in research. Healthcare decision makers often assume that the overall demographically younger migrant populations are not experiencing the impact of dementia at significant scale and fail to consider the age structure distinctions between the settled and newer migrant communities thus underestimating the total numbers of people involved. For metropolitan areas worldwide this will become a rising demand characterised by late presentation of complex cases of elders from minority communities in crisis as their physical health or family support networks collapse.

Some of the more recent projections of the increase in incidence of dementia seem to indicate that the rate of increase in the developed world may be slowing [6], although some have argued that this is not sufficiently demonstrated yet in current evidence [7]. It is also argued that the highest rate of increase in dementia in the next 35 years will occur in primarily in developing countries [8]. There are calls for an increase in the funding available for research into dementia, international improvements in health policy regarding the support for people living with dementia and their family and carers and an increasing focus on human rights for and by those living with dementia. However these developments largely bypass those from migrant communities living with dementia as their dementia health issues are left at the margins of health policy, although there have been some signs in the UK of increasing awareness of the lack of dementia research focus on migrant communities [9].

A conceptual framework for understanding the experience of dementia within a dynamic and interconnected world of population migration, cultural shifts and personal histories that recognises the additional challenges for those from migrant communities living with dementia needs to be developed. This would acknowledge the additional complexities faced by migrant communities in living with dementia apart from the complexity of other physical co-morbidities and the cultural stigma holds dementia for many communities. The framework needs to be international in scope recognising the thematic commonalities globally that recur across migrating communities and that will emerge as communities move from being new arrivals to be being part of a settled diverse local population. These thematic commonalities include the fear of the experience of being discriminated against in health services as a migrant as well as anticipating receiving a lack of understanding of cultural values and expectations by the host country's service personnel. Another thematic commonality would be the fear of the loss of key existential personal qualities central to individual migrant's personal history and social struggle e.g. independence, willpower and resilience.

These elements of the migrant experience of dementia have a commonality across all migrant communities in relation to the

host country's health and social care system. The complexity of this experience is not addressed by simply focusing on information and support needs in the context of cultural stigma regarding dementia. For example in the UK the African-Caribbean population is at a higher risk of vascular dementia than the indigenous White UK population. While there is cultural stigma regarding dementia with the African-Caribbean community the longstanding concerns in this community about discrimination in mental health services [10] must play a role in delaying access to diagnosis. Individual life histories of African-Caribbean people living with dementia that underpin personal narratives of independence and persistence against adversity in the experience of migration can also create barriers to asking for help with managing dementia from UK health services [11].

Beyond cultural competence in dementia

Jutlla [12] illustrates the complexity of the migrant experience for a UK Sikh community in setting out the argument for a more sophisticated understanding of cultural competency training in dementia and the application of person centred care in working with migrant communities. Further work must be done to determine how this complexity can be addressed at scale across the dementia pathway with strategic healthcare investment involving multiple migrant communities and including providing support to developing the resources of the migrant community itself to understand dementia and support carers.

For example recent work using a model called 'Reminiscence Tea House' by the Chinese National Healthy Living Centre in London in the UK seeks to change traditional views in Chinese communities across London about those living with dementia and has even involved inventing a new Chinese language word for dementia. The Chinese migrant community is internationally a very old settled migrant community in many countries but the settled older population is often invisible to institutional health policy makers. This initiative has focused on Chinese people raising awareness about dementia in their own communities, training for Chinese family carers and Chinese language based advocacy for people living with dementia [13].

Consideration also must be given to the generationally evolving experience as the first generation migrants' children may have limited working knowledge of their parents' generations lived experience, or even their language. Training professionals in cultural competent care must go hand in hand with engaging with communities and building resilience in family carers and communities

Contemporary large scale movements of population in a world in which people characteristically have longer life spans and the concentration of this global population migration through gateway cities, indicates there is significant risk of these very complex cases of dementia emerging at scale at least in these gateway cities over the next 30 years. The current status of pharmacological research offers little assurance of a large scale pharmacological intervention creating a reduction of the impact of the major dementia, Alzheimer's disease.

Conclusions

While there is increasing international recognition of the healthcare provisions and economic challenges faced by the major dementias, Alzheimer's disease and vascular dementia this is largely thought of as a problem of national population's rather than migrant communities. The scale of international migration and historical pattern of migration will lead to an increase in demand for dementia services from migrant

communities not only as a result of generally increases in longevity but also due to differential health risk and age profile structure within migrant communities.

For members of migrant communities developing dementia their individual clinical cases will be complex involving not only physical co-morbidities but also social, cultural and psychological barriers to accessing services. This complexity needs to be taken account of in planning appropriate services and to do this effectively there should be more research on the impact of dementia in these communities. The numbers of people from some migrant communities developing dementia will rise over the next 30 years, and this rise will be focused in those more long settled communities with underlying high health risk factors for developing dementia. Metropolitan areas worldwide that have long been recognised as gateway cities for migrant will have the highest number of people from migrant communities living with dementia.

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