

Dementia: time trends and policy responses

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Abstract

In recent years, dementia has been considered a public health priority and become a topic of major political interest. Recent reviews and studies have reported with varying degrees of alarm an impending and existing “dementia epidemic” with increasing predicted trends in prevalence and enormous numbers of people with dementia particularly in low- and middle-income countries (LMICs). However, robust evidence from dementia research in high-income countries suggests stable or decreased prevalence over the last decades. Current evidence is not sufficient to suggest increasing trends of prevalence in LMICs once variation in methodological factors and study populations are taken into account. Changes in diagnostic methods over the last decades substantially influence the identification of dementia cases with systematic difference between the resulting individual prevalence studies. Potential geographical variations at the country level might indicate potential risk factors at population levels or systematic difference in clinical application of dementia diagnosis. Although it is important and necessary to use information from dementia research for evidence-based policymaking, over-interpretation of results without carefully considering underlying factors could exaggerate the findings and influence policy planning in ways which do not serve current and future population best. Planning of dementia policy needs to take full cognisance of the provenance of the data being used and be integrated with policies which optimise health across the lifecourse.

Keywords

Dementia; Policy planning; Review

Abbreviations

CCMD: Chinese Classification of Mental Disease

DSM-III/ -IV/ -V: Diagnostic and Statistical Manual of Mental Disorder Third/ Fourth/ Fifth Edition

GMS-AGECAT: Geriatric Mental State Examination- Automated Geriatric Examination for Computer Assisted Taxonomy

ICD-9/ 10: the International Statistical Classification of Diseases 9th / 10th

LMICs: Low- and middle-income countries

1. Introduction

In recent years, dementia has become a public health priority with substantial impact on not only individuals and their families but also health care, economic and welfare systems of whole societies [1]. In 1980s, the governments of developed countries started to express concern about rapid population ageing with dementia and cognitive decline being important causes of disability in later life [2]. To investigate dementia in general populations, several epidemiological studies were conducted in North America and Western Europe between 1980s and 1990s. The findings provided important evidence for health policy planning [3, 4]. Awareness of dementia has increased the need for good data extending from high-income to low- and middle-income countries (LMICs) which now contain large number of ageing population with emerging epidemics of non-communicable diseases. It has also moved from professional to public arenas involving the active campaigns, lobbying of charities and awareness of business opportunities. Dementia has become a topic of major political interest. In the UK, the Prime Minister's Challenge on Dementia commits to delivery of major improvements in dementia care and research by 2015 [5]. The G8 summit held in December 2013 called for international action to address the problem of dementia and brought together policy makers, researchers, pharmaceutical companies and charities from around the world [6]. The summit agreed on an increased spends on dementia research and the development of international collaborations, information and data sharing.

This surge in interest in ageing populations and health care provisions can and will affect resource availability for dementia research, which should provide better evidence-based strategies for policy planning. Recent reviews and studies have reported with varying degrees of alarm an impending and existing “dementia epidemic” with increasing predicted trends in prevalence and enormous numbers of people with dementia particularly in developing countries [7]. However, these somewhat hyperbolic statements of a worsening situation need to be constantly examined and updated.

2. Time trends and geographical variations in dementia

Over the last decades, several reviews or studies have attempted to investigate the epidemiology of dementia in national and international populations with the exploration of temporal and geographical variations of prevalence. Here we summarise existing evidence of epidemiology of dementia worldwide drawing on relevant systematic reviews (or meta-analysis) and recent epidemiological studies designed to compare the changing epidemiology of dementia in the well-defined populations. Consideration of very different economic and social situations across countries exists, thus synthesis of current evidence from dementia research is reported according to country income levels (high vs low- and middle-income countries).

High-income countries: Western Europe, North America and Japan

Governments of high-income countries have been aware of demographic ageing and potential increase in dementia since 1980s. The EURODEM collaborative study synthesised the results of community-based studies in European countries between 1980s and 1990s [3]. The prevalence of dementia steadily increased with age and showed similar estimates and patterns across different countries. These results were used to predict the number of people with dementia over years and assist in policy making and service provision while few epidemiological surveys were conducted in the post-EURODEM period [8, 9]. In the last five years, a small number of new studies which aimed to provide updated estimates and investigate changes in prevalence have repeated earlier methods in the same areas. The findings of these studies suggest stable or reduced prevalence of dementia over the last 20 years [10-12]. The number of people with dementia in European countries is considered to be lower than the estimates in 1990s had predicted given the changes in age structures of these populations.

Similar to Western Europe, the results of early prevalence studies in the US have been used to estimate nationwide prevalence using the projection methodology with different assumptions of demographic ageing [13-16]. In contrast, the two studies comparing repetitive surveys

across different time periods also reported a stability or decline of the prevalence of dementia and cognitive impairment over time [17-20].

In East Asia, Japan also experienced the pressure of population ageing and conducted early dementia research in 1980s. In contrast to the US and Europe, recent reviews have reported an increasing trend of dementia prevalence in Japan over last decades [21, 22]. However, this finding might be driven by variation of study methods and characteristics of study populations over time [21, 23]. Despite potential bias in study designs and analysis methods, some studies applying the similar study methods in the small areas reported stability of dementia prevalence from 1980s to 1990s but with high prevalence in surveys after 2000 [22, 24, 25]. The prevalence of dementia in Japan could have potentially increased in recent eight to ten years but have been relatively stable before 2000. In South Korea, the estimated prevalence was generally higher than other developed countries since mid-1990s without obvious difference between various diagnostic criteria [26].

Lower- and middle- income countries: global prevalence of dementia and China

The 10/66 Dementia Research Group has conducted investigation of dementia prevalence in numerous urban and rural sites in Latin American, India and China using consistent measurement methods [27]. Estimated prevalence of dementia has varied across countries and

within countries between urban and rural areas. The influence of diagnostic criteria (DSM-IV and 10/66 algorithm) on prevalence estimates has been reported to be substantial in the populations of developing countries [28].

To investigate global burden of dementia and the prevalence in LMICs, the 10/66 Dementia Research Group conducted a systematic review of the worldwide literature from 1980 to 2009 [29]. The results were included in the WHO report of dementia in 2012 [1]. A four-fold variation was found in age-adjusted prevalence of dementia in populations aged 60 and over across regions. Although substantial variation of methodological factors was inevitable, lower estimated prevalence was generally found in African regions while Latin America had particularly high prevalence [1, 30]. The regions without sufficient prevalence data including Middle East, Eastern and Central Europe, Central Asia and Oceania were based on relevant estimates from the 2005 Delphi Consensus study [29, 31]. The data have been updated in 2013 including newer studies in East Asia and Africa with an estimated prevalence which is higher than the original report [7]. The number of people living with dementia worldwide is estimated to have been nearly 45 million in 2013 and expected to increase to 75 million in 2030 and 135 million in 2050. However, these higher estimates could be substantially driven by recent prevalence studies using newer diagnostic standards based on recent reviews of Chinese studies applied to the massive Chinese population.

With the largest populations in the world, China started to be concerned about the impact of demographic ageing and dementia more recently. Several reviews have summarised a number of studies since late 1980s [32-35]. The authors report a substantial increase of dementia prevalence in mainland China with a doubling of age-specific prevalence from 1990 to 2010 [32, 34]. However, this pattern could be largely attributed to variation of study designs and methodological factors as these are significantly related to heterogeneity of prevalence studies in China [35, 36]. Higher prevalence was found in the recent studies using newer diagnostic criteria (DSM-IV and 10/66 algorithm) than those using older diagnostic criteria (DSM-III, DSM-III-R and CCMD). The increase of dementia prevalence in China is considered therefore to have been amplified by these changes in methodology over time.

In a review of prevalence studies in Brazil from 1990 to 2010, over-estimated prevalence was found in the research with poor quality of study designs such as biased sampling methods, unstandardised measurements and assessors [37]. Methodological variations and quality of study can considerably modify prevalence estimates.

3. Evidence for time trends and geographical variations

Instead of expected increasing trends, robust evidence from dementia research in high-income

countries suggests stable or decreased prevalence over the last decades. The results of recent studies actually suggest that the number of people with dementia in current European populations is stable or lower than the estimates in earlier years. Increasing trends of prevalence have been reported in the low- and middle-income countries mainly based on pooled estimates of the individual studies without taking methodological variations and characteristics of study populations into account. Changes in diagnostic criteria over the last 30 years substantially affect the identification of dementia cases with systematic difference between the prevalence studies using newer and older criteria. Broader definitions of dementia and cognitive decline in recent years could include more suspected and borderline cases with increasing prevalence. Broader definitions of dementia and cognitive decline in recent years seem likely to include more suspected and borderline cases with increasing prevalence particularly in the changes the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-V). The definition of “neurocognitive disorder”, which replaces the term “dementia”, could substantially increase the proportion of people diagnosed with mild cognitive decline. New studies using the DSM-V criteria are expected to measure a higher prevalence of dementia and cannot be directly compared with the previous estimates. In developing countries, where dementia research is associated with the development of diagnostic methods and medical services, increasing trends and estimated numbers of people with dementia might be substantially attributed to changes in diagnostic methods rather than

true increases over time.

Furthermore, societal changes and variations in methodological factors can also importantly moderate the time trends of dementia prevalence. Even though some studies have had to control the influence of various methodological factors, there could be the remaining variation “within diagnostic criteria”. Trainings of clinicians and application of diagnostic methods have also changed with time even if subtly. In recent years, the rise of awareness campaigns, changing knowledge and attitude to dementia in professionals and public have made whole societies better prepared to discuss this later life condition. Changes in the social environment might potentially increase the identified number of people with dementia who have previously been considered as a natural stage of ageing and rarely recorded in medical histories. Such variations in diagnostic practice are difficult to measure and the findings of epidemiological studies need to be interpreted very carefully with the consideration of not only design and methods but also social contexts of investigations and health care.

The findings of the 10/66 study indicate geographical variation of dementia prevalence across developing countries and areas. Although the four-fold difference of prevalence at country level was found in the global review, the influence of methodological factors and the development of social environment could potentially moderate the estimates [1, 30]. Recent

meta-analysis reviews with taking methodological difference into account suggest an impact on prevalence in different levels of geographical units [34, 38]. Similar to time trends, evidence for geographical variation based on literature reviews has the limitation of not being able to completely adjust for the heterogeneity between individual studies [39]. Definitions of urban/ rural areas and the sizes of city, county and other geographical units can vary considerably across countries and cause difficulty in comparisons.

4. Challenges and responses

Since dementia has become a topic of political interest, evidence for time trends and spatial variation has been reported from many epidemiological studies. With this increasing interest and popularity, the conclusions of “enormous numbers”, “increasing patterns” and “substantial burden of disease” could be more appealing than any measured reflection on impact of methodologies and conflicting evidence as they can be used by charities, politicians and interested parties (clinicians and specialists) to attract more attention from both public and private sectors including potential investment from pharmaceutical companies and healthcare businesses. Although it is important and necessary to use the information from dementia research for evidence-based policymaking, over-interpretation of results without carefully considering underlying factors could exaggerate the findings and influence policy planning in ways which do not serve current and future populations best.

Current evidence is not sufficient to suggest increasing trends of prevalence in LMICs taking variations of methodological factors and study populations into account. As health systems in LMICs are still vulnerable with limited resources, over-emphasis on “dementia epidemic” and misleading policy planning might have unintended negative influences on health systems. In the G8 summit, international strategies for dementia were linked to previous experiences of “HIV/ AIDS” and “climate change” [6]. Although the epidemic of HIV/ AIDS in Africa has been addressed successfully, specific funding for HIV/ AIDS projects has driven the priority of health policy and has been reported to seriously interfere with the development of whole societal health systems in these lower income countries [40]. Even though the increasing number of older people is a substantial concern in LMICs, the priority policy should focus on addressing major determinants of health and establishing complete health care systems for basic needs of whole population as they can be beneficial to health of whole societies thus reducing the impact and burden of non-communicable diseases and dementia now and into the future.

Current evidence from high-income countries is actually more optimistic than previous prediction. The reduction of dementia risk in European and the US populations over the last decades is considered to be likely to be associated with earlier life better education, healthy

lifestyle factors, decreased vascular diseases and other chronic illnesses [20]. Public health policies aimed at whole populations and health care provisions could modify dementia risk in later life over years. This implies that a pure “dementia-orientated policy” could be problematic for effective prevention. Based on the evidence from observational studies, over attention and specific focus on dementia policy and research in secondary (screening) and tertiary (cure and therapy) care might improve individual care provision but have limited influence on population health as key confirmed risk factors and protective features for dementia are related to health conditions in early and middle ages. Policy responses to dementia need not only to consider improvement of care delivery but also integrate with general public health issues (such as smoking, alcohol consumption, physical activity and associations of head injuries) and interventions to reduce impact of other non-communicable diseases.

Although the prevalence of dementia has been investigated in several low- and middle-income countries, there is no available information in the certain regions such as Middle East, Eastern and Central Europe. High prevalence of cardiovascular diseases in these areas could play an important role on modifying the risk of dementia over time with potential geographical variation across countries [41]. To provide robust evidence for time trends in LIMCs, it is important to conduct longitudinal studies with rigorous study designs and quality

control over time and to investigate the trends in prevalence, trajectories of cognitive function sensitive to the sociocultural environment and changes in risk factors across birth cohorts.

Identifying important and specific risk factors in the populations of LIMCs could be an evidence-based and efficient approach for policy planning.

5. Conclusions

Interpretation of new results and comparison with earlier studies in the field of dementia need additional consideration of societal changes and research contexts. Stable or reduced

prevalence of dementia has been suggested from studies in high-income countries while lack of comparable information over time is a major issue in low- and middle-income countries.

Geographical variations at country level might indicate potential risk factors at population

levels or systematic difference in clinical application of dementia diagnosis. Changing profiles of potential risk factors in early and middle life could importantly moderate the

occurrence of dementia in later life. Planning of dementia policy needs to be integrated with attention to policies which optimise health across the lifecourse.

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