

Behavioural and psychological symptoms and signs of dementia in low and middle income countries

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The growing number of people suffering from dementia is a major public health issue. Dementia is accompanied more often than not by behavioural and psychological symptoms and signs (BPSS). This editorial aims at providing a short discussion of the outstanding importance of BPSS in low and middle income countries (LaMIC).

CLINICAL FEATURES

Dementia is a clinical syndrome caused by a number of brain diseases (Alzheimer's disease, vascular dementia, Lewy body, frontotemporal dementia, or mixed disorders being the most common underlying pathologies) and characterized often by an inexorably progressive deterioration in cognitive and functional abilities.¹ Dementia is defined as a decline, usually over several years, of some or all cognitive or intellectual functions including memory, language, judgment and others leading to a person's growing loss of autonomy. The dementias are most often accompanied by variable degrees of BPSS (also called behavioural and psychological symptoms of dementia or neuropsychiatric features of dementia) including, social withdrawal, lack of motivation, aggressiveness and agitation, delusions, and depressive and anxious states as well as others.² Along with the decline of functional competence³ BPSS cause most of the patients and their caregivers suffering and burden. BPSS may be an even more important contributor to the overall burden than functional impairment.^{2,4} However, a given BPSS may not reliably appear in any one dementia diagnosis. Unlike the quite predictable decline seen in cognitive and functional abilities of those suffering from Alzheimer's disease, BPSS usually fluctuate in regard to both their presence and intensity. The first presentation of BPSS, often in the form of affective changes, may even precede the onset of a full dementia syndrome. Thus, BPSS may be a very early feature of dementia and help its early detection.



PREVALENCE

The growth of the older population, both absolute and relative to the younger segments of the population is responsible for the increasing prevalence of cognitive disorders in the elderly. The annual incidence rate of dementia for people over 65 years of age is about 1%.⁵ The number of people with dementia in Europe in 2000 was approximately 7.1 million, and by 2050 this figure may rise to 16.5 million people.⁶ However, even more important, a historically new situation is the 'greying' of the developing countries. Indeed, particularly rapid increases in the numbers and of the proportion of older people are expected in China, India, and Latin America. By 2050, the number of people aged over 60 years will have increased to 1.25 billion, accounting for 22% of the world's population (twice as many as in 2000) with the great majority of them living in LaMIC.⁷ Indeed, about three in four elderly with dementia will live in LaMIC by 2050. These figures may be roughly equated with those for BPSS. They may not be that different in LaMIC from those found in high income countries (HIC), but reliable studies are lacking. Certainly, BPSS are extremely common although there is major controversy surrounding their real occurrence. However, putting all the types of BPSS together, their global point prevalence in the demented living in the community was over 50% and their 5-year prevalence was found to reach almost 100%.⁸ This tremendously high prevalence of BPSS and the deleterious effects on both patients and caregivers bear witness to the overall importance of BPSS.² There are only a few population-based studies of BPSS in dementia or other cognitive disorders, and even fewer in LaMIC. However, better characterizing the clinical spectrum of BPSS and determining the risk and causal factors for the development of BPSS in order to eventually devise more effective and efficient strategies for the management of BPSS in LaMIC would be of great importance.

ORIGINS OF BPSS

Although dementia is a *condition sine qua non* for BPSS, they usually cannot be explained by dementia alone. In spite of their dependence on either the type of dementia or the severity of dementia,^{2,9} many more aspects must be considered as predisposing or precipitating factors. These include cultural and societal factors, familial and environmental ones, as well as individual genetic, somatic and psychological variables.² For instance, some studies in AD patients found that premorbid psychiatric syndromes are possible risk factors for BPSS in the elderly.¹⁰ They

may even be risk factors for cognitive decline along with a number of other factors such as fewer years of education,¹¹ racial and constitutional factors¹² or personality traits^{13,14} to name but a few. What precedes suggests, among other tracks of thought, that factors related to cognitive decline, and possibly BPSS, may be associated with features such as the level of school education and cluster in LaMIC. However, the dearth of studies on mental disorders or on BPSS in LaMIC explains the absence of solid knowledge in the field.

PUBLIC HEALTH ISSUES

The economic costs of dementia are enormous and both the financial and emotional pressure placed on the working population will rise markedly. Costs include a) formal health care, social/community care, respite and long-term residential care or nursing home care and b) informal care – unpaid care by family members including their lost opportunity to earn income. Informal care is more used in LaMIC, where few formal health or social services are available. Caregiving in LaMIC relative to HIC is associated with further substantial economic disadvantage.¹⁵ In Switzerland, costs for formal dementia care have been estimated to be over half of the total costs¹⁶ and the shift from informal to formal care may also occur in LaMIC in the future and put considerably strain on the governments of LaMIC. While health care services are cheaper in LaMIC as compared to HIC, families from poorer countries spend a greater proportion of their income on health care for the person with dementia. How much of this burden is due to BPSS is unclear although it has been estimated to be around 30% of the global cost in community dementia care of HIC.¹⁷ Whatever the real figure may be, it is likely to be exorbitant.

In Europe, only about one third of all patients are diagnosed at the earlier stages of the disease and, overall, only one in two patients receives a diagnosis. Many of those who are diagnosed receive no or inappropriate treatment and this is therefore likely to hold true for BPSS as well. It goes without saying that this situation is even less enviable for the demented elderly in LaMIC although hardly any reliable figure is available. The reasons of under-diagnosis and under-treatment are manifold and constitute likely targets of the public health effort to be made. Among these reasons figure:

- a negative view on ageing generating confusion between normal aging and beginning dementia;
- a fatalistic view on the disorders considered irreversible including BPSS, thus discouraging medical help;

- the confusion between non-existing curative treatments of the underlying disease and symptomatic and efficient treatments of BPSS in particular;
- a lack of education of many general practitioners or other health professionals as to BPSS;
- a lack of time health professionals have to proceed to adequate care of the demented and their caregivers;
- low help-seeking behaviour of both the patient and their family which is worst for the oldest-old;
- frequent denial not only by the patient but also their families that cannot accept the change in their proxy's image and their relationship with them;
- low credit given to drug treatment;
- even lower credit given to non pharmaceutical treatments;
- lack of financial resources.

ACTIONS THAT SHOULD BE TAKEN

From the public health care perspective it may not be justified to diagnose dementia disorders as long as little or nothing can be done to help. And indeed, for the most frequent dementias there are to date no disease-modifying treatments. While awaiting them, it is pivotal to consider that BPSS respond to symptomatic treatments. Thus, although screening for dementia in the general elderly population may not be opportune,¹⁸ in particular in LaMIC, it is crucial that those with BPSS come to medical attention. Indeed, the availability of treatment options of BPSS is at least some consolation in the absence of disease-modifying interventions for dementia. A major focus of public health policy should therefore be on improving psychosocial interventions and care systems for elderly patients with BPSS at both early and more advanced disease stages in LaMIC.

The scientific community makes huge efforts to elaborate sophisticated diagnostic procedures to detect neurodegenerative diseases at the earliest possible stages. This attitude is crucial in university settings, but it may further increase the mental health gap¹⁹ between those who need services and those who receive them in LaMIC and even in HIC. Up to 50% of people with serious mental disorders receive no treatment at all in HIC, while in LaMIC this proportion goes up to 85% (WHO Executive Board on the 'Global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level). Diagnostic categories difficult to

implement in current practice due to the requirement of sophisticated technical equipments may increase the mental health gap, particularly in the elderly who face double stigmatization both due to ageism and mental disease.

On the professional policy level in LaMIC, the needs are manifold²⁰ and recognizing those of the elderly with BPSS and their proxies will allow providing diagnosis and treatment to be delivered by multidisciplinary health teams according to national standards. Support based on internationally accepted human rights standards is required from the health, social, financial, and legal systems for both people with dementia and their caregivers.²¹ In the absence of disease-modifying treatments, the quality of life of people with dementia and their proxies may still be improved through an early diagnosis to optimize physical health, cognition, activity and, most importantly, detecting and managing BPSS.²² Effective, community-level primary mental health care including GPs, nurses, social workers, or occupational therapists for older people is crucial. They will be backed up by a more limited number of multidisciplinary specialist teams. Enhancing the coordination between first-line care and specialist clinics is central. The question of the geographical implantation and density of outpatient, intermediary, hospital, and residential settings is a difficult equation to solve as it must take into account both the proximity of care needs of the patients and their proxies and the competence level of professional carers that depends on the existence of a limited number of specialist clinics. The development of telemedicine may be of help here, paradoxically perhaps even more so in LaMIC than in HIC. Thus, care structures may take up a number of forms and be affiliated to a variety of care delivery services depending on the national or more local service organisation. They should include outpatient and inpatient care backed up by medically oriented geriatric and gerontopsychiatric teams as well as psychosocial support services. Hospital care is almost entirely carved according to the needs of patients with acute mono-pathologies unlike the health problems that usually prompt the elderly to attend or be admitted to an acute care hospital. Hospitals must become senior-friendly and consider underlying pathologies. Structures intermediary to outpatient and hospital settings, such as day hospitals and day centres, may be helpful. One of the main objectives of these structures is to guarantee respite for the family and other informal home carers of demented patients, this need being often prompted by BPSS. Culturally adapted residential care and alternative models that avoid ghettoizing the elderly are paramount.

EDUCATION ON BPSS

Training is a prerequisite for good care. Most training for health professionals does not include instruction about specific care for older people.²² All health providers should be trained in mental health, including BPSS care, and receive themselves support both in short and long-term care settings. De-stigmatisation is a major topic here that aims at reducing the negative views professionals as well as the general public have as to BPSS (and dementia in general and other mental health disorders) and the possibilities of care. Support is required from national bodies, promoted by supranational organizations, and, most importantly, from governmental agencies that are responsible for social and medical care planning and financing within the realm of their cultural and societal characteristics.

RESEARCH ON BPSS

Implementation of good clinical practice must be accompanied, if not preceded, by research. However, 13% of the global burden of disease is due to mental disorders, but only about 2.5% of all relevant research on global burden of disease is spent on mental health,²³ mainly in HIC. Despite the evidence and imminence of the crushing weight on the public health system in LaMIC, less than 6% of research on mental health stems from LaMIC, an amount that hardly increased over a 10-year period between 1992 and 2001.²³ National research agencies of LaMIC must prioritise research on BPSS (and, more generally, on aging and mental disorders in the elderly) which is still not given adequate attention in many countries. In the absence of disease-modifying treatments in early dementia, a research focus on BPSS should be developed in LaMIC despite methodological challenges. Studying and implementing care for proxies is crucial as accompanying a close parent having BPSS represents a considerable human challenge.² Improving psychosocial and pharmacological treatments for BPSS should be a central line of research, not only in beginning dementia but also at the moderate and more advanced stages for people living in both community and institutional settings. Studies in LaMIC are increasing in frequency, but direct cross-country comparisons remain rare.² Taking into account cultural influences in our fast-racing multicultural societies with major migratory phenomena worldwide occurring right now is mandatory.^{2,24} What occurs in LaMIC is also an issue for HIC.

REFERENCES

1. World Health Organization (WHO). The ICD-10 classification of mental and behavioural disorders: diagnostic criteria for research. Geneva: World Health Organization; 1993.
2. International Psychogeriatric Association (IPA). IPA Complete Guide to Behavioral and Psychological Symptoms of Dementia (BPSD). International Psychogeriatric Association, 2010.
3. Mathers CD, Loncar D. Projections of global mortality and burden of disease from 2002-2030. *PLoS Med.* 2006;3: 2011-2030.
4. Burgio L. Interventions for the behavioral complications of Alzheimer's disease: Behavioral approaches. *Int Psychogeriatr.* 1996;8(suppl 1):45-52.
5. Rocca WA, Cha RH, Waring SC, et al. Incidence of dementia and Alzheimer's disease: a reanalysis of data from Rochester, Minnesota, 1975-1984. *Am J Epidemiol.* 1998;148(1): 51-62.
6. Wancata J, Musalek M, Alexandrowicz R, et al. Number of dementia sufferers in Europe between the years 2000 and 2050. *European Psychiatry.* 2003;18:306-313.
7. World Health Organization (WHO). Interesting facts about aging. Geneva: World Health Organization; 2012.
8. Steinberg M, Shao H, Zandi P, et al. Point and 5-year prevalence of neuropsychiatric symptoms in dementia: the Cache County Study. *International Journal of Geriatric Psychiatry.* 2008;23:170-177.
9. Aalten P, Verhey F, Boziki M, et al. Consistency of Neuropsychiatric Syndromes across Dementias: Results from the European Alzheimer Disease Consortium. Part II. *Dement Geriatr Cogn Disord.* 2008;25:1-8.
10. von Gunten A, Pocnet C, Rossier J. The impact of personality characteristics on the clinical expression in neurodegenerative disorders – a review. *Brain Res Bull.* 2009;80:179-191.
11. Kumar P, Parslow RA, Jorm AF, et al. Clinical and neuroimaging correlates of mild cognitive impairment in a middle-aged community sample: the personality and total health through life 60+ study. *Dement Geriatr Cogn Disord.* 2006; 21(1):44-50.
12. Lopez OL, Jagust WJ, Dulberg C, et al. Risk factor for mild cognitive impairment in the cardiovascular health study cognition study: part 2. *Arch Neurol.* 2003;60: 1394-1399.
13. Mendez M, Antonietti JP, Donati A, et al. Personality Traits and Behavioural and Psychological Symptoms in patients with Mild Cognitive Impairment. *Dement Geriatr Cogn Disord.* 2013;35:87-97.
14. Pocnet C, Rossier J, Antonietti JP, et al. Personality traits and behavioral and psychological symptoms in patients at an early stage of Alzheimer's disease. *Int J Geriatr Psychiatry.* 2013;28:276-283.
15. Prince M. 10/66 Dementia Research Group. Care arrangements for people with dementia in developing countries. *Int J Geriatr Psychiatry.* 2004;19:170-177.
16. Kraft E, Marti M, Werner S, et al. Cost of dementia in Switzerland. *Swiss Med Wkly.* 2010;140:w13093.
17. Beeri MS, Werner P, Davidson M, et al. The cost of behavioral and psychological symptoms of dementia (BPSD) in community dwelling Alzheimer's disease patients. *Int J Geriatr Psychiatry.* 2002;17(5):403-408.

18. Rapport Alzheimer France. Available at: <http://www.assemblee-nationale.fr/12/rap-off/i2454.asp> [Accessed 2013 Dez 12].
19. World Health Organization (WHO). mhGAP Intervention Guide for Mental, Neurological and Substance Use Disorders in Non-Specialized Health Settings: Mental Health Gap Action Programme (mhGAP). Geneva: World Health Organization; 2010.
20. Prince M, Acosta D, Albanese E, et al. Ageing and dementia in low and middle income countries – Using research to engage with public and policy makers. *Int Rev Psychiatry*. 2008;20:332-343.
21. Yasamy MT, Dua T, Harper M, et al. Mental health of older adults, addressing a growing concern. *Mental Health and Older People*. World Mental Health Day, October 10 2013. World Federation for Mental Health 2013.
22. World Health Organization (WHO). *Mental health and older adults*. Geneva: World Health Organization; 2013.
23. Saxena S, Paraje G, Sharan P, et al. The 10/90 divide in mental health research: trends over a 10-year period. *Br J Psychiatry*. 2006;188:81-82.
24. Shah and Lindsay. In: Ames et al. (eds). *Dementia*. London: Edward Arnold (Publishers) Ltd; 2010.