Responses to dementia in Less Developed Countries with a focus on South Africa

The global dementia burden is estimated to be 35.6 million people (Alzheimer’s Disease International, 2010), with 4.6 million new cases occurring annually (Ferri et al., 2005). However, as population ageing is occurring more rapidly in the developing world than in the developed world, and an increasing number of people are living to an advanced age in those regions, the increase in the prevalence of dementia will be disproportionately greater in Less Developed Countries (LDCs) (Kalaria et al., 2008; Ferri et al., 2005).

At present an estimated 60 per cent of people with dementia live in LDCs, and this is projected to increase to 71 per cent by 2050 (Ferri et al., 2005). However, increases in prevalence are not uniform: globally, the rates are projected to increase by 100 per cent in More Developed Countries (MDCs) between 2001 and 2040, but by more than a staggering 300 per cent in India, China and certain other Asian countries (Ferri et al., 2005; Prince, Livingston & Kotana, 2007).

Increases in the prevalence of dementia in LAMIC regions (Low and Middle Income Countries), and indeed in all regions, will lead to a substantial public health burden for the countries. In addition, an accelerated urbanisation trend in LDCs is contributing to an increase in diseases of lifestyle, such as diabetes and hypertension — especially in Africa, which are risk factors for dementia.

Scant primary research has been conducted on dementia in LDCs. A lack of primary knowledge about the disease in these countries detracts from an awareness of and policy responses to dementia, as well as management of the clinical and care burden that arises (Maestre, 2008). Although an insidious and disabling disease, the diagnosis and management of dementia, predominantly prevalent in the older population, is not a priority for LDCs’ healthcare systems (Prince, Acosta, Castro-Costa, Jackson & Shaji, 2009). These systems face multiple and competing demands for healthcare, mainly for diseases typically of a developmental nature, such as communicable diseases — specifically malaria, HIV/AIDS and tuberculosis, and reproductive and child health (UNAIDS, 2008; Jackson, 2002). These diseases, and not dementia, are healthcare priorities for LDCs.
With an aim to redress the gap in knowledge and lack of response to dementia in LDCs, the 10/66 Dementia Research Group has established itself at the forefront of dementia inquiries and policy intervention in developing regions. The group contends that although 66 per cent of dementia worldwide occurs in LDCs, only 10 per cent of research on the disease and its effects is conducted in the regions (Prince, 2001). The group has conducted population based surveys (2003–2007) of dementia prevalence and its impact in 14 catchment areas in ten low and middle income countries: Argentina, Brazil, China, Cuba, Dominican Republic, India, Mexico, Nigeria, Peru and Venezuela (Prince et al., 2007). New studies are underway in Puerto Rico and South Africa. In addition to establishing prevalence rates, the studies have documented care arrangements for people with dementia and the impact of the disease on caregivers.

What has been established in these studies is: 1) A need for increased awareness of dementia; 2) The important role that family plays in the care of persons with dementia; 3) A need for increased community support for people with dementia; 4) The lack of healthcare and long-term care services for these people; 5) How onerous the burden of dementia related disability is; and 6) How poor or inadequate, or indeed non-existent, are responses from governments in these countries.

### Increased Awareness

An early lack of awareness of dementia prompted Alzheimer’s Disease International (ADI), headquartered in the UK, to identify awareness raising in the public amongst health workers as a global priority (Graham & Brodaty, 1997). A need for increased awareness, as the organisation points out, resides with policy makers, the medical fraternity, society, communities and families. A common lack of awareness of the disease has been demonstrated in studies in India, for example (Patel & Prince, 2001; Shaji, Smith, Praveen, Lai & Patel, 2003). The studies show that while typical features of dementia may be recognised, these features are frequently attributed to explanations such as chinnan (literally, childishness) (Shaji et al., 2003), nerva frakese (tired brain) (Patel & Prince, 2001) and “weak brain” (Prince et al., 2008). None of the studies found any awareness, in the settings in which they were conducted, of dementia being an organic brain syndrome and indeed a medical condition. Rather, symptoms of the disease were perceived as a normal and anticipated part of ageing. Primary care doctors in these countries have reported, moreover, that they do not encounter dementia cases in their clinical practice. On occasions, it is remarked, as reported in the studies, that as the terms Alzheimer’s disease and dementia are associated with stigma, use of these terms is best avoided, particularly if a person diagnosed with dementia is typically refused admission to an old-age home (Patel & Prince, 2001).

A study in isiXhosa-speaking townships around Cape Town, South Africa (Ferreira & Makoni, 2002) found very little, if any, awareness or understanding of dementia as a medical condition or illness. People interviewed described signs and symptoms typical of the disease, but lacked knowledge that the signs represent a clinical condition. They were also ignorant of care options that might be available to afflicted persons. Indeed, they had their own nomenclature and explanations for the symptoms. Many ascribed them to old age and perceived nothing could be done about them. Others attributed the symptoms to witchcraft: an elderly person who showed such signs was said to be bewitched.

In Africa, medical doctors, largely at the primary care level, lack awareness of and training in treating dementia, and are found disinclined to investigate symptoms of dementia — or to refer patients with the symptoms for investigation. They too, simply ascribe the symptoms to old age. Nurses who screen such patients at the primary level do the same, and inform the patients that no medications are available for their particular ailment.

A general lack of awareness of dementia and potential responses in LDCs leads to the following situations: 1) Few families with an afflicted elder seek help from orthodox healthcare services (Patel & Prince, 2001). 2) No structured training is available or offered to health practitioners on the recognition and management of dementia — at any level within the healthcare service. 3) No constituency is available to place pressure on the government, or policy makers to provide responsive dementia care services (Shaji et al., 2003). 4) Where family members are the main caregivers to a person with dementia, the family receives little or no support or understanding from other individuals or agencies. In the absence of an understanding of its aetiology, dementia is stigmatised and misinterpreted. As a result, demented individuals may be at risk of neglect and
abuse — particularly in households where the family capacity to care for older relatives is under strain and the carers are unsupported (Patel & Prince, 2001). 5) Older people with dementia are often not accepted for residential care and are denied admission to hospital facilities for fear of bed-blocking (Patel & Prince, 2001). 6) Disturbed behaviour in demented individuals, which is common, is particularly poorly understood, and leads to stigma, blame and distress for caregivers (Ferri, Ames & Prince, 2004).

In parts of Africa, persons with symptoms and signs of dementia, especially elderly women who live alone and have certain physical characteristics, are branded as witches — as individuals who may cast evil spells on the community, which result in unexplained events such as lightning and floods. Such women are at a grave risk of having their assets seized, violent assaults and even death (Ferreira, 2004; Kohnert, 2003; Gorman, 2000).

In MDCs, awareness of dementia is growing rapidly, with the media playing an important role in the spreading of information. Reports from Alzheimer’s associations based in the United Kingdom and Australia indicate that considerable media attention has been marshalled, and that the media has been instrumental in making dementia a national health priority in those countries. In LAMICs, public awareness of the disease is far less developed, with very few media carrying items on dementia and ageing. A search by The Times of India in 1999 identified no such articles (The 10/66 Dementia Research Group, 2000). However, in the past decade, Argentina, the Dominican Republic, India, Peru and Venezuela are reported to have succeeded in getting the message out in newspapers, television and radio (Prince, 2009).

In South Africa, media coverage of dementia remains poor, and is mainly linked to a single day in the year — World Alzheimer’s Day (September 15). News items are placed by Alzheimer’s and/or dementia associations in the media intermittently during the year. While the media in LAMICs are receptive to the placement of such articles as part of their role of informing the public and stimulating debate, efforts are required to alert the media in LDCs to the importance of raising awareness on ageing and dementia.

Family Care

Multi-generational co-residence is the norm in LDCs, and in most cases, family members are the primary caregivers to elderly relatives with dementia. A study in South Africa found that 79 per cent of a memory clinic’s clients were being cared for by family members (Kalula et al., 2010). In countries in Southeast Asia, adult children or children-in-law are the most common caregivers to a demented relative (The 10/66 Dementia Research Group, 2004). Even young children in multi-generational households may be a primary caregiver to an afflicted grandparent or great-grandparent.

Care giving may be a source of enormous strain on a caregiver — particularly where little or no formal help is available, as in LDCs. Although the availability of a greater number of co-resident family caregivers in LDCs than in MDCs may be advantageous, the caregivers are generally ill-prepared and ill-equipped for care giving tasks, and are unsupported. They are unlikely to have access to a simple response such as respite care to alleviate their burden. Care giving to persons with dementia without support is also more onerous than care giving to persons with other health conditions. Behavioural problems manifested by demented elders are a main contributor to the burden of care (Ferri et al., 2004).

Persons with dementia who live alone, or live with the spouse alone are potentially more vulnerable as no family member is available to help care for them. The availability of family members in LDCs to help with care giving has been on a decrease due to internal and international migration of employable members, declines in fertility, and women’s increased participation in the workforce (Prince et al., 2007). HIV/AIDS related deaths in sub-Saharan Africa have not only left millions of young children orphaned, but elderly parents of deceased adult children without family support as well (UNAIDS & WHO, 2006).

The majority of LAMICs, particularly low income countries, have no social pension system; neither do they provide any allowance for persons with dementia or their caregivers (Prince et al., 2007). The 10/66 research group’s caregiver studies reported that no demented person received a disability pension (Prince et al., 2007). Further, studies in the Dominican Republic, rural Mexico, rural China and India revealed that where there was no financial support from the state, such as an old age pension, financial help from family members was the main source of income (The 10/66 Dementia Research Group, 2004). Furthermore, diminished household income, wherein a caregiver has to forego
paid employment to care for a demented elder, as well as increased expenditure on the elder's care needs, put a particularly heavy financial strain on affected households in low income countries (The 10/66 Dementia Research Group, 2004). In South Africa, although a small caregiver allowance (Grant-in-Aid) is payable to an older person with dementia to be used by the caregiver, few are aware of and access this grant.

In conclusion, although the prevalence of dementia in LDCs is increasing rapidly, the awareness of dementia as a clinical condition that merits special attention from healthcare and social care providers is severely lacking among both the public and the professionals. Care for dementia patients in these countries is mainly informal, with family members, wherever available, doing the largest part as caregivers, unsupported by formal structures.

Community Support
Given a virtual lack of formal, or government driven responses to the support needs of carers of persons with dementia in the majority of LDCs, the non-government sector (i.e. NGOs) plays a critical role in making available community based care and support to these persons (World Health Organization, 2005). Such services are largely organised and offered by Alzheimer's associations and their agents, which function broadly under the umbrella of Alzheimer's Disease International (ADI) and its associations in 77 countries (Prince et al., 2007). Since 1984, ADI has progressively built and strengthened these associations, and enhanced their capacity to meet the needs of people with dementia and their families. In recent years, new associations of the organisation have been established mainly in LDCs. National associations provide a platform for engagement between clinicians, researchers, caregivers and people with dementia. They raise funds, disseminate information, and act as powerful advocates to the government, policy makers and the media (Graham & Brodaty, 1997). Two national dementia associations in South Africa — Alzheimer’s SA and Dementia SA — engage in formal and informal training and education of carers, towards the achievement of a better understanding of and improved provision of care for persons with dementia. Both associations also run support groups for carers, as a platform for the carers to share experiences, and to learn from and support one another. The groups are typically led by a trained caregiver (Alzheimer’s SA, 2010).

In some cases, NGOs in LDCs operate day care centres for persons with dementia. This form of support often enables a family caregiver to engage in formal employment, and offers the carer brief respite from care giving. However, support groups and day care centres operate mainly in urban areas, whereas the need for such support groups is greater in rural areas.

Responses of Healthcare Systems
In a large number of LDCs, primary healthcare services often fail to meet the healthcare needs of older persons in general and persons with dementia in particular (Patel & Prince, 2001; Shaji et al., 2003; Prince et al., 2007). Healthcare services for older clients in these regions tend to be clinic based, and focus on acute and “treatable” conditions — hence, exclude dementia. Even the basic curriculum for training of health professionals in the diagnosis and management of dementia is underdeveloped. Thus, a paradigm shift, beyond a mere preoccupation with simple, curative intervention, to one that encompasses long-term support and chronic disease management is the need of the hour. Given the frailty of many older people with chronic health conditions, greater outreach of care services, and assessment and management of patients in their own homes are urgently called for.

Major barriers to older people's access to healthcare in LDCs include poverty, low education, frailty and lack of transport. Widespread endemic poverty, and low levels of awareness and knowledge due to poor education, translate into families of older persons with dementia being unlikely to consult a health practitioner about the person’s condition — despite associated disability and strain on informal carers. Encouraging help-seeking for such cases requires dissemination of information in communities: by the government, by healthcare providers and through the media. However, efforts to increase a demand for dementia care services need to be accompanied by reforms in the healthcare system and its services, so that help-seeking is indeed met with a supply of better prepared and more responsive services.

Health services in LDCs are generally ill-equipped to meet the needs of older persons. Centralised hospital-based services provide limited care to a small number of patients with serious mental illness; for the rest, the burden of care falls on the family, the community and traditional healers. Healthcare, even at the primary
care level, is clinic-based: the older person must attend a clinic to obtain care, which often involves a long and costly journey, and a lengthy waiting time at the clinic — all of these constitute barriers to help-seeking for demented older clients (Prince et al., 2007). Even if such clients are able to travel to a clinic, the assessment and treatment they receive is likely to be oriented towards acute rather than chronic conditions. At times, a diagnosis of dementia may be made specifically to exclude an older patient from receiving care. In Soweto, a township in South Africa, nurses at a community clinic are trained to discriminate between dementia and delirium, whereupon they will refer delirium cases to a hospital for treatment of the underlying acute disorder, and dementia cases are sent home for family care (Prince et al., 2007; Patel & Prince, 2001). In Goa, psychiatry interns are advised not to admit older people with dementia for fear that their families will be reluctant to take them back home (Prince et al., 2007; Patel & Prince, 2001).

The role of medical specialists in responses to dementia within the healthcare system also needs consideration and planning. Most LAMICs have an insufficient number of specialists (psychiatrists, neurologists, elder-care physicians) dedicated to dementia care to be able to provide needed dementia services nationwide (Prince et al., 2007). Of all countries participating in the 10/66 studies, only Venezuela (with 24 psychiatrists/100,000 population), Argentina (13/100,000) and Cuba (11/100,000) have resources similar to those found in MDCs (WHO, 2005). Certain other Latin American countries like China, India, Nigeria and South Africa (2, 1.2, 1, 0.2 and 0.1/100,000, respectively), have far fewer resources. The majority of sub-Saharan African countries have less than one psychiatrist per million population (WHO, 2003). Brazil with approximately 250,000 physicians of which approximately 170,000 in active practice, has only 500 physicians with geriatric medicine credentials. This ratio translates into one geriatrician per approximately 37,000 elderly Brazilians (Garcez-Leme, Leme & Espine, 2005).

South Africa has fewer than ten geriatricians and fewer than five specialists in old-age psychiatry for a population of 3.8 million persons aged 60 years and above. This paltry number of specialists is far too small to play any significant role in frontline care for people with dementia. The responsibility for redressing the inadequate national clinical response to dementia in LDCs must lie initially at the primary care level. The 10/66 research group is testing the effectiveness of training community healthcare workers to identify people with dementia (Shaji, Kishore, Lal & Prince, 2002; Jacob, Senthil, Gayathri, Abraham & Prince, 2007), and to implement and provide a brief intervention to educate and train caregivers (Prince et al., 2007). In South Africa, a 6-item Cognitive Impairment Test was developed, modified and culturally adapted in disadvantaged communities around Cape Town (Brodrick, 2002), for the use of health personnel at clinics to identify people with signs of dementia who may then be referred to a tertiary care institution for assessment.

Tertiary level assessment centres for persons with signs of dementia, such as memory clinics, are typically run by a multi-disciplinary team which offers comprehensive assessment and management of clients, as well as counselling and support to the primary caregiver and his/her family. Memory clinics have been established in some LDCs (see e.g. Shaji, Iype & Praveen, 2009), and according to an article published in Expressindia, “Memory clinics are being established in that country [India] with help from the state” (www.expressindia.com), but no inventory is available of memory clinics in these regions. One may assume nevertheless, that memory clinics are operated in several Asian and Latin American countries, but this is not the case in sub-Saharan Africa, where the facilities exist only in South Africa and Nigeria. Nonetheless, memory clinics are typically urban based, attached to a tertiary care hospital, and neither have the capacity to screen the number of clients who may potentially be referred to them for assessment and management, nor offer any service to potential clients in rural areas.

Even where specialist assessment of such persons is conducted, the provision of drug therapy for dementia is a challenge in most LDCs. Dementia drugs that are used to improve cognitive function and treat underlying depression and/or behavioural disorders, are exorbitantly expensive in LDCs, and beyond the reach of the majority who might benefit from them. In South Africa, drugs that modify cognitive function are neither on essential drugs lists for public healthcare facilities, nor supported by all private health insurance companies. In any case, the majority of South Africa’s population has no health insurance cover, let alone persons with dementia, to access the drugs through health insurance.
Disability, Dependency and Long-term Care

The incidence of disability is typically higher in the older population, with older individuals more likely than younger persons to have multiple physical, mental and cognitive disorders, and co-morbidity (Sousa, Ferri, Acosta & Albanese, 2009). Demographic ageing and the health transition has led to an increase in chronic morbidity, causing a substantial increase in the number of older persons who will live longer and be at the risk of dementia — itself a disability. An adequate response to these trends calls for policies to: a) prevent disability and thus dementia through the control of chronic diseases; b) limit disability through more active community based rehabilitation; and c) manage disability through universal access to long-term care (Sousa et al., 2009).

A study in Goa, India, showed that old-age homes in that country, as a rule, do not admit people with a permanent disability and specifically exclude persons with dementia. Ostensibly, they claim, they do not have the facilities or manpower to care for high dependency individuals (Patel & Prince, 2001). In South Africa, long-term care facilities are sparse and unevenly distributed between urban and rural areas, with most facilities being concentrated in urban areas (Drower, 2001); the majority of older persons, who reside in rural areas, are thus excluded from residential care if they need it. The growing number of persons with dementia and the diminishing availability of family caregivers will translate into a heightened demand for residential care, which is sorely under-catered for in these countries and LDCs.

The policy on ageing in South Africa promotes deinstitutionalisation and limits state subsidised residential care to no more than 2 per cent of frail older persons who are in need of 24-hour nursing care (Follentine, 2006). In Brazil, long-term care is under-developed, and nursing homes are almost exclusively located in major metropolitan areas — mainly supported by religious institutions and not by the state. Of these, a few admit only the most demented or terminally ill older people (Garcez-Leme et al., 2005).

Those frail older persons in LDCs who continue to live at home, even if well-cared for by family, are at a high risk of abuse and neglect — an increasing trend (World Report on Violence and Health, 2002). All the more, if a demented person lives alone, it is a clear signal for his/her relocation to long-term care. Hence, the expected increase in the prevalence of dementia in all countries signals an urgent need for governments to develop a dementia care policy or plan.

Government Responses to Dementia

An extensive search of the relevant literature was unsuccessful in identifying any government policy on dementia care in LDCs. Government responses to the condition and the burden of care on families may be assumed therefore to be sparse, if at all. It is possible, moreover, that several governments may contend that dementia care is a family responsibility — as proved by the lack of policy responses to address the dementia burden in these countries. Indeed, many LDC governments tend to have policies that bolster traditional family care arrangements — often supported with legislation. Some of these governments “encourage,” or may even coerce families into shouldering responsibility for the financial support and care of older family members (Prince et al., 2007).

A WHO report on long-term care policy (WHO, 2003) notes that wide variation exists in how the responsibilities of individuals, families and the state in dementia care are viewed. It further contends that each community could and should determine the types and levels of assistance needed by older people and their caregivers, as well as their eligibility for, and the financing of long-term care support. In practice, LAMIC governments typically avoid involvement in the provision and financing of long-term care (Prince et al., 2007). A few, if any, have comprehensive long-term care policies and plans. Limitation of resources is arguably a major obstacle to LDCs having comprehensive policy and plans for this purpose. However, the lack of government attention and indeed, poor responses to dementia may also be explained by a lack of awareness of the disease and its impact; a relative lack of, or ineffective advocacy and lobbying; and, above all, a lack of political will to address this issue. It may be time therefore, given the demographic and health trends, that LDC governments’ attention be drawn to the need for a comprehensive “Alzheimer’s Plan”. An Alzheimer’s Plan, as France has, may not be a solution for dementia care in many LDCs in the short term. However, sowing the seeds of a need for such a plan would be a start to the development of a comprehensive dementia strategy.
Responses Going Forward
Dementia has a uniquely devastating impact on an individual’s capacity for independent living — even when the afflicted person resides in a multi-generational household, as in LDCs. This condition is commonly overlooked when policies for the prevention and treatment of chronic diseases (including dementia) are proposed — even in the WHO’s Global Report on Innovative Care for Chronic Conditions (Epping-Jordan, Pruitt, Bongoa & Wagner, 2004). In most LAMICs, care of persons with dementia is likely to improve if it is incorporated in the management plan for chronic conditions.

To introduce or strengthen responses to dementia, and to enhance the quality of care and quality of life of persons with dementia and that of their caregiver, actions are needed at various levels. Drawing on the 2006 Kyoto Declaration, “Minimal action required for dementia care” of the Alzheimer’s Disease International (Access Economics, 2006), some of these actions are as follows:

**Awareness**
In LAMICs the major part of dementia care is provided by Non-Governmental Organisations (NGOs). Governments in these countries should support NGOs and other community organisations in public education on dementia by using effective tools such as multimedia, to promote preventive strategies, early recognition and help-seeking behaviour. The education will help to engender positive attitudes towards the management and care of dementia, and to combat stigma. Encouragement of the formation of structures such as clinic committees and hospital boards will help to facilitate community participation in decision-making on health issues of concern to the local community.

**Increased family support**
Family members of persons with dementia and their community should be involved in policy formulation on dementia care. Governments and international organisations should support and equip caregivers through the provision of accessible education and training programmes for carers and for the establishment of self-help support groups under the guidance of relevant NGOs and other community based organisations (CBOs). These bodies have an important role to play in the mobilisation of community action and advocacy around health issues. Multi-disciplinary teams should be established for home assessment, and home-based care and support.

**Develop human capacity**
Health professionals should be appropriately trained and equipped to diagnose and manage dementia at primary and other levels of care, and to refer clients for assessment and/or care as indicated. Dementia should be included in training curricula for health professionals at all levels of care and incorporated in the management plan of chronic conditions.

**Policy formulation**
Governments should promote the development of national policies and programmes in line with current knowledge and human rights for the inclusion of dementia in healthcare services, social programmes and benefits. Accessibility to essential drugs for the treatment of dementia and associated symptoms should be improved.

**Research**
Governments and other funding bodies should support research on dementia to improve awareness, recognition, management, support and preventive strategies.

Ultimately, the most cost-effective way to enhance dementia care in LAMICs will be through support for persons with dementia, and their informal and formal carers. Such a goal may only be achieved through a multi-pronged approach with the co-ordinated involvement of communities, healthcare providers, educators, funders, policy makers and politicians.

**Conclusion**
Worldwide, the burden of dementia is increasing significantly, but to a far greater extent and at a far more rapid pace in the developing world. LAMICs and LDCs by and large have no dementia care policies, programmes and strategies for community and/or family support, and no specific education in place. These countries do not have dedicated health services for dementia, and memory clinics, where they exist, have largely not been initiated by the government, but established by tertiary level healthcare institutions. A major part of dementia care services is rendered virtually entirely by NGOs.
Little is known, if indeed something is to be known, of initiatives or government policies aimed at supporting the management of dementia. It must be speculated therefore, whether such inaction is only due to a lack of awareness of the present and future burden of dementia, or due to a lack of political will to be informed of the imperative and to respond concretely and timely — or both.

NGOs’ efforts to lobby with their government for responses to the burden of dementia have typically drawn little success; their efforts need to be supported and intensified. Research has an important role to play in the generation of evidence of the impact of the burden of dementia on society and individuals, and to support NGOs’ advocacy efforts. Research too needs to be supported and expanded.

Healthcare professionals widely lack interest in specialisation in ageing, and are neither adequately trained in the management of dementia. Linkages between the three pillars of education, training and service provision in this regard need strengthening.

Finally, given the advances made in dementia care policy and practice in the developed world, one may question whether a scarcity of resources in LAMICs and LDCs is the only impediment to expanded and appropriate care responses to dementia. We contend that another set of factors is at play: a lack of a sense of urgency of the growing need for care and support engendered by dementia. Addressing those factors systematically must be our task at hand.

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