

# Caring for those who care for others: Finding a unique Arab vision to lead care for family carers of people with dementia

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## Abstract

The article discusses the predicted estimates for dementia prevalence with population trends for ageing across the Arab states. As some states show rapid population ageing, the priority is to embrace research methods and the practical application of care implementation for people. This should be approached through communities and national strategies in ways that only Arab tradition finds suitable. To this end those influencing health and social policy must plan resources and training to offer the maximum support. This will require education to be responsive and sensitive in the training of professionals as well as across primary, secondary and tertiary levels of health services. It is essential that these training initiatives include a focus upon the creation of multidisciplinary teams both in appropriate settings with home-based services at the centre. Such needs and developments represent huge challenges to national and community-based health services across Arab states. Whilst many Middle Eastern countries have incorporated international influences and agencies to coordinate care, it should not be assumed that future care needs will be implanted with external or international ambitions for health and social care provision. The response should utilise only, where appropriate, international input where it benefits the region and as an overarching priority structure its own culturally embedded community dementia care and family carer support.

**Key words:** Dementia prevalence, population ageing, carers rights, stigma, health and social care policy, dementia care planning

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## Change driven by the Vulnerable

Everyone is familiar with the mantra that the French Revolution was initiated by 'the storming of the Bastille'. However, it doesn't take a particularly forensic mind to ponder how, on the morning of July 14th, 1789, thousands of French people, oppressed by an archaic and unsympathetic government, managed to raise the required arms and weaponry to initiate change. In fact, long before they reached the Bastille, the French people took to Les Invalides, the hospital built by command of Louis XIV and the patronage of Madame de Pompadour to care for and house ageing people and crippled soldiers. Les Invalides had an enormous store of rifles and weaponry in its basement. Staffed by carers and patients who bore the brunt of appalling poverty and forgotten wars, these were the people who readily handed over the weapons and offered their sympathetic assistance to arm the hordes prior to their 11 a.m. arrival at the Bastille. This is the overlooked truth of the six-year revolution; despite long standing social evils afflicting the French people, it took the weakest and most vulnerable with their loyal carers to make a brave decision to open the armoury and hand out the weapons.

Since this example of action for revolutionary change in 1789, around the world the role of mainly informal, unpaid carers of people with chronic and terminal illness is always admired and equally, at the same time, never met with sufficient resources to make their daily caring for others an easy one. Arab culture is suffused with caring for one another within the family from the cradle to the grave and, apart from that being the way things are done, it is the way that is preferred for the future (Sibai, 2010).

## Middle Eastern Population Ageing and Diversity

The Middle East is a heterogeneous region where cultural, political and religious life exists in a fusion of diversity whilst embracing the significant international impact of foreign workforces. In 2004, the year where stable statistics were reliable for all the Arab states, the GCC states were inhabited by 12.5 million foreigners, constituting 37 percent of the total population (Kapiszewski, 2006). In Qatar, the United Arab Emirates (UAE), and Kuwait, foreigners make up the majority; for example, in the United Arab Emirates they accounted for over 80 percent of the population. (Kapiszewski, 2006). This breadth and tolerance are features that affect policy making in the running of day to day affairs. Beyond drawing broad categories, there are many particular microcosmic differences and patterns to life between obvious religious practices, economic privileges and cultural traditions. This diversity pervades most aspects of life including health and social care. Certain concerns exist, as they do in every other region of the world, over how these needs can be best met whilst fostering the family at the heart of that care. Compared with countries outside, the population of the Middle East is younger, although regional variation does exist in the

percentage numbers over the age of 65, for example, a stark extreme exists between Lebanon having 10% and the United Arab Emirates having only 2% (Hajjar et al., 2013). The percentage of elderly people in the Middle East therefore, is expected to increase with improvement of the health care delivery in the area. This means that the Middle Eastern population is ageing; in some states rapidly, and in others, at a more sedate rate.

As family centred care in the home is preferred, the trend for smaller families across the region will lead to fewer potentially supportive adult dependents available to absorb full care needs. Linked with this is the changing nature of employment. The post-industrialisation across Europe and elsewhere changed the ability of adult dependents to care for their parents due to having to emigrate and relocate for work. This began the rise in the West of care homes and retirement homes allowing state care provision mixed with private business seeking to make a profit from old age and disease. It is inevitably likely that traditional patterns of family responsibility will change with economic development across Arab life. The desire for education has led to two dominant expectations; good employment as a reward for that education and a desire to see Arab states run by their own people. Special plans and provisions must therefore be made in order to maintain the care practices which will endure in accordance with tradition. This tradition stands in contrast to demands for foreign profits and international cultural trends which have set the status quo elsewhere. It is against this backdrop that the global statistics in dementia demand focus from both the younger generations and all policy, health and social experts in the field.

## Dementia Prevalence

A worldwide study of epidemiologic data collected by a team at Kings College realised consensus estimates of dementia prevalence in fourteen of the World Health Organisation regions (Prince et al., 2013). The panel of experts estimated a projected benchmark of 24.3 million people with dementia in 2001. Of this group 60% are living in low and middle income countries. Statistically it is observed that each year, 4.6 million new cases of dementia are predicted. These numbers are reported to almost double over every twenty years until reaching 81.1 million by 2040. More recently figures cite that by between 2010 and 2050 the total number of dependent people with dementia worldwide will almost double from 349 million to 613 million (Prince et al., 2013). This must be set against an estimate of the numbers of older people with needs for care will virtually treble from 101 to 277 million (Prince et al., 2013). Whilst this body of extensive research provides only estimates of dementia prevalence, it has been used as an international springboard and benchmark to realise the extent of the condition. Dementia therefore, is likely to touch every family drawing concern to their needs and pulling on social and health resources in ways never seen before. It is critical that support in every nation state across the world is enhanced from all quarters.

## Meeting the Concerns of Chronic Ill Health at Home

A raft of international standards and treaties spearhead family support and boost rights and cultural support across the globe. The UN Convention on the Rights of Persons with Disabilities (CRPD) is an international treaty that contains a comprehensive range of complementary and interrelated civil, cultural as well as political and socio-economic rights which refer to those affected by chronic health problems. Amongst these other rights is the right to respect for private and family life (Article 8, ECHR) as unpaid caring responsibilities have an impact on the autonomy as well as the physical and mental wellbeing aspects of quality of life. These are also linked to an adequate standard of living (Article 11, International Covenant on Economic, Social and Cultural Rights, ICESCR) and the right to work (Article 6, ICESCR) as unpaid carers are also recognised. However, as recognition through legislation connected to caring for people with chronic health conditions and their unpaid carers has burgeoned over the past two decades, it often has but abstract significance in the day to day role of carers.

Caring for family kin with dementia, including fictive kin (caring for someone we are not directly related to through blood) can, even when the care giving is not regarded as burdensome, lead to chronic stress exposure (Papastavrou et al., 2007). It is well documented to have strong associations with physical health decline, mental health reduction and poor quality of life (Rose-Rego et al., 2007). These factors threaten the quality of care given to those within the family with dementia having knock-on impacts on those with dementia. One issue which is well recorded in the literature is the stigma involved in dementia (Behuniak, 2011; Kitwood, 1990; Kitwood, 1997; Kontos, 2003). Stigma is variously defined as affecting the perception of the individual who may be exposed to disqualification from full social acceptance by exhibiting any attribute understood to be deeply discrediting. Stigma is contingent upon the bearer possessing some concern as to what others think about them reflecting their 'moral career' (Goffman 1963). It can also be reliably thought of as shame. Stigma forms two broad categories in the care of others and these belong to the person with the discredited or stigmatised condition and the person who cares for them as they may also attract a reduced respect in society for the role they occupy in assisting. It is therefore necessary that in order to reduce stress and strengthen relationships, partnerships should be established that seek to understand and support those with dementia but just as critically, their carers, whatever the form of care provided.

## Managing Domestic Expectations within Diverse Communities

In several Middle Eastern countries, state organisations, charities and religious associations have occupied a role in care for vulnerable groups. Some international groups provide care traditionally focused on institutionalised templates and Western ideals which may be contrary to Arab and Islamic preferences (Sibai, 2010). The majority of vulnerable frail, severely ill or disabled older people traditionally remain in their homes. As a consequence, there is an increasing demand for home-based care, however, the desire to see this assistance remains underdeveloped and is not well integrated by any state to date (Sibai, 2010). To see this happen, pilot studies and focus groups can be rapidly set in motion with a view to instituting community nurses and social response teams who will be in existence currently. They can be trained in new perspectives and underpinning their roles will be universities and colleges broadening the educational programmes in order to educate new practitioners. They should appear across multi-health disciplines to strengthen their cohesion in communities. Family care facilitators can assist families with emotional and practical support so that knowledge and confidence in their care roles are not lacking. Stigma related to caring for others as well as the stigma involved in having to live with a chronic condition must be dealt with in national and local strategies so that all people feel valued and educated about the nature of diagnoses. With awareness of conditions affecting vulnerable people, there is no need for people to fear others or fear rejection by others.

It is therefore an urgent priority of planners, policy makers and professionals in the field that an informed understanding of the needs of any community is rapidly gained and utilised. Western stereotypes of the Arab region must not be implanted from any caricature of what they imagine may be appropriate based on a mixture drawn from the current collective psyche. These often do not flow compatibly with local communities and government policies. These represent bold demands but bracing times surely lie ahead. The socio-political ferment and evolving societal attitudes toward women's rights, family structure, and the alienation of nomadic habits must be challenged to find the right balance for the generations ahead. For the sake of caring for others, a prescient challenge lies not merely in producing data that is rich, diverse and sensitive in order to generate new knowledge and practice but providing hands-on support for those providing that care for their own families.

How elastic the Arab world will have to be to sidestep all of the potential tensions and conceptual problems in approaching top to bottom care is yet to be fashioned. But it is surely desirable that integration is based upon only what traditional life seeks to retain and what works best. There is an ever pressing need to define health policy programmes that will reduce the burden of ageing populations on society and the economy. There is also a need to ensure the availability of social services for older persons and promote their continuing participation in a

socially and economically productive life. The changing economic and shifting migration patterns lead to the projection that the provision of long-term care will be an important part of health care planning as each state strives to borrow and blend from internationally compatible templates and inspire with domestically driven ideas.

What should we hope to see spread across the Middle East as we head towards the middle of the 21st century? Surely it must be meeting the good news of increased life expectancy by providing groundwork for future geriatric and disability services as well as instituting retirement and rehabilitation centres. These must be staffed by passionate and sensitive staff. There must be a depth of home care agencies married to values Arab people dictate. Palliative care programmes must be infused with the belief that in seeking out those who experience illness and frailty, provision will always be given to us to prevail for them. Overarching all of these ingredients is a concern for empowering those who do the caring and that that concern should ensure a lack of stigma attached to addressing all of our human vulnerabilities. More than this, local customs must precede any international investment in social and health care provision. International strategic tensions and ambitions which may preoccupy the bold and ambitious should never go before those who are invested in experiencing the deepest and darkest extremes of joy and pain, life and loss. The pressure to change often comes from those regarded as having a barely visible presence in society. It is only through the vision and bravery of often humbled and sick people who struggle to be heard, as those lining the beds and corridors of Les Invalides long ago, that new horizons can be shaped and realised.

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