Hard economic times and dementia care by families - Cross Cultural perspective

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Abstract

The authors aimed to review the need to provide quality personal care to patients with dementia as stated in the objective six of the National Dementia Strategy. This review discusses the crucial and helpful roles that families play in the management of dementia patients. Families take a central role throughout the world to provide care for their loved ones and in return they face carer burden, but the comfort and satisfaction of caring for their families is immense. It is also argued that there are cost savings by families in the form of informal care and in doing so they have to give up work which will unfortunately be seen as loss of productivity. It is estimated that informal carers save the United Kingdom (UK) between £15 and £24 billion per year by supporting dependents who would otherwise be institutionalised and these families need much support and training for the service they provide.

Key words: Dementia, carers, family burden

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INTRODUCTION

Dementia is a progressive cognitive decline, which affects not only the individuals but also their families and the wider communities. The National Dementia Strategy (2009) states that the cost to the UK economy is £17 billion a year and projections estimate that within next 30 years the dementia population will double to 1.4 million, this will treble the cost of dementia care to £50 billion a year.

Though some families as informal carers are providing support to their loved ones who suffer from dementia and many others wish to do the same, the support available for this is patchy. It has been found that there are significant unmet needs of these family carers which leads to avoidable crisis situations and expensive long term hospital admissions and care (Alzheimer’s Society, 2011).

A survey conducted by the Alzheimer’s Society (2011) called DEMHOM found that 52% of dementia carers perceived that they have been
receiving insufficient support to enable them carry out the caring role. There are a number of issues with family members taking up the caring role including stress, mental health problems like depression and physical health problems (Schoenmakers, 2010; Charlesworth, 2006).

In different parts of the world mainly in Asian countries and some European countries traditional joint family systems exists and people take pride in living and being part of such a society. The traditional role of a family looking after their elders in the UK sounds strange and is assumed to be non existent but family carers of people with dementia save the UK over £6 billion a year (Full Dementia UK report, 2007).

Some efforts have been made with technology to help family caregivers provide assistance and care for their loved ones. A randomized controlled trial by Eloniemi-Sulkava et al, (2009) was conducted comparing spouses who care for the dementia patients in the community. One group was subject to a multi-component intervention program with a family care coordinator, a geriatrician, incorporation into a support group, and individualized services.

The other arm of the trial was control group who did not receive any intervention at all. At the end of 1.6 years, 25.8% of the control group was in long-term institutional care compared to 11.1% of the intervention group (P = .03). Though Eloniemi-Sulkava et al, (2009) found this was not statistically significant at the end of 2 years; various support systems could be identified to help support to people live in the community for longer. The factors, which will be important to consider, and which are also relevant to the family carers are carer stress, financial burden, training and developing caring skills, both mental and physical health issues.

**AIM**

The aim of this paper is to report on a review of the literature which sought to find out whether providing dementia care in patient’s homes by families and informal carers would be cost effective in hard economic times.

**METHOD**

A literature review of published research in the subject was undertaken with a systematic follow up of reference lists using AMED, BNI, CINAHL, EMBASE, Health Business Elite, HMIC, PubMed and PsychINFO. The key phrases used were: dementia and family care, community support and economic burden of dementia. To facilitate a comprehensive search of the literature, key words were used either singly or in combination. The inclusion criteria consisted of articles published in English and reviews, surveys, reports, official documents and independent studies were included.

Figure 1 Quorum flow chart for methodology of selection of articles
The themes identified come within epidemiological, economic and social care subheadings and each will be discussed in turn.

Results: Epidemiology of dementia care in community:

Current figures according to the National Dementia Strategy (2009) estimate that in the UK there are 700,000 sufferers and similarly the Alzheimer’s society believe there are 750,000 people who suffer from dementia depicting the magnitude of the problem. The UK government spends a huge amount of money in the management and care of dementia patients. This was highlighted in (Alzheimer’s Society, 2011) the ‘Full Dementia UK’ (2007) which is a report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King’s College London, for the Alzheimer’s Society, UK. The report is based on a large number of studies comprehensively looking into various aspects of Dementia in the UK. This report illustrates the number of people supported in residential/nursing homes and at their own homes in different UK countries, which are depicted in the tables 1 & 2 (Full Dementia UK report, 2007):

Table 1: Percentage of older adult UK population supported in residential settings and receiving care at home

<table>
<thead>
<tr>
<th>UK Countries</th>
<th>% of people &gt;65 supported at residential/nursing home</th>
<th>% of people &gt;65 receiving home care service</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>2.5</td>
<td>3.9</td>
</tr>
<tr>
<td>Scotland</td>
<td>4.0</td>
<td>6.9</td>
</tr>
<tr>
<td>Wales</td>
<td>2.8</td>
<td>4.3</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>4.0</td>
<td>2.4 (not directly comparable figure)</td>
</tr>
</tbody>
</table>

In the three UK countries most people who are above the age of 65 years are supported at home by the care services compared to people who are supported in a residential setting.

The total cost of dementia care to the UK economy is £17.03 billion, which equates to £25,472 per person per year. The annual cost break down with the severity of dementia (Full Dementia UK report, 2007):

Table 2: The annual cost of dementia care in the community per person

<table>
<thead>
<tr>
<th>Placement - severity</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community – Mild dementia</td>
<td>£16,689</td>
</tr>
<tr>
<td>Community – Moderate dementia</td>
<td>£25,877</td>
</tr>
<tr>
<td>Community – Severe dementia</td>
<td>£37,473</td>
</tr>
<tr>
<td>Care home</td>
<td>£31,296</td>
</tr>
</tbody>
</table>

Table 2 shows the annual cost of dementia care in the community and it is particularly important to note that, as the severity of dementia increases more input is needed to manage and care for dementia patients. The cost of managing severe dementia in community has been found to be more than caring for dementia patients in their own homes.

The informal care input from the family and other carer’s was about 36% of the total cost (Full Dementia UK report, 2007). The projections made by the Alzheimer’s Society and the National Dementia Strategy suggests that there will be a rise in dementia population in the future and this will have an impact on the care provided by the families and informal carers.

As the life style, demographics, family compositions, labour force participation, geographical mobility are changing constantly the informal care givers are shrinking (Moise, Schwarzinger, Um, 2004) and the projections of the future care provided by the informal carers depending on the current statistics will show unrealistic results.
Impact of economic factors on family carers of dementia:

Dias et al., (2004) indicated the impact of economic strain among Indian caregivers as a result of high proportion of dementia caregivers giving up work to care which was coupled with the increased likelihood of high health care costs. It is estimated that informal carers save the UK between £15 and £24 billion per year by supporting dependents who would otherwise be institutionalized (Alzheimer’s Disease Society, 1993). Though this saving is coming at a cost of loss of wages and work and limited respite to the carers. It has also been reported that out of the total cost of £17 billion towards the late onset dementia most of it is accounted for the accommodation costs and informal care (Full Dementia UK report, 2007). Gray and Fenn (1993) found that 65% of total care cost (excluding informal care) is attributed to residential or nursing home care, and 25% to hospital based care. These huge costs could be cut but more investment would be needed to support the family and informal carers. The costs of caring informally for someone with Alzheimer’s dementia is higher overall in European countries and it can be calculated as the sum of lost working days (valued at the average wage rate) and caregiver time (valued at GNP per capita) (Jonsson & Wimo, 2009).

In a study Hunter, et al. (1997) suggest that Alzheimer’s disease is and has been a challenge for care providers and purchasers. They argue that the direction for now seems to be less towards long term institutional care in most developed countries and there has been a shift in caring for Alzheimer’s disease patients at home. If patients with dementia are kept in a home environment it will lead to lesser public and private expenditure on institutional care.

The cost of caring people with dementia will eventually rise as many studies have projected, at the same time there is a need to support the informal carers who are committed to perform their duties some times at the expense of loss of wages, stress, carer-burden and loss of recreation due to caring role.

Social and cultural care factor influencing dementia care by families:

Many cultures have different living standards, norms and variations by which they recognize themselves as a unique society in this world. Joint family system still exists in many countries like rural India, though it is being rapidly challenged. An observational study by Pillai and Verghese (2009) concluded that social engagement, marriage, living with someone to avoid loneliness might be protective for development of dementia. In India innovative thinking had led people to train lay health workers to provide home-based care for people with dementia under the supervision (Dias & Patel, 2009). There is a lack of resources in health services in India and family or informal carers exclusively provide social care for dementia patients. There has also been argument on the burden faced by the families who care for people with dementia and the lack of services to support these family carers. Due to lack of resources and structures in the healthcare system in India families who support people with dementia have to face challenges at all levels of their caring role. In more advanced countries like the UK it is possible to provide the needed support to these families who provide the caring role for people with dementia.

Dementia is a progressive condition and the stages vary from mild to severe and late stages. The demands on the family and informal carers would increase as the condition progresses towards more severe stage (Hu et. al., 1986). The care of dementia patients could be best managed at home when support from the families and informal carers is available in the mild to moderate stages of dementia. When patients develop Behavioral and Psychological Symptoms of Dementia (BPSD) in more severe stages then they would eventually have to be supported in care home settings. Chui et al., (2009) explored the use of Internet as the medium to provide care and support to caregivers of dementia patients. The new Internet technology could be used to support families and informal carers by providing simple instructions and tips in managing distressed behaviors in patients with dementia.
Ho et al., (2003) reported that in Chinese Canadian women caregivers were concerned about the negative effects of Western culture on traditional values regarding caregiving. Chui et al., (2009) argued that the above findings suggest that Chinese caregivers may need support services tailored to their ethnic-cultural belief systems. Due to the expanding multicultural societies in Britain it is important to understand different cultures, their care giving roles and in the values and customs associated with the role. The Internet-based Caregiver Support Service (ICSS) system was built to address these issues and to provide easy accessibility through the use of technology. The personalized e-mail was sent to patients and therapeutic intervention occurred through a password-protected, secure web site. The embedded e-mail function supported text-based exchanges between each caregiver and a designated therapist. Experienced clinicians like occupational therapists and social workers were involved in the process of psychosocial and psycho-educational intervention. The therapists responded to each caregiver using standard therapeutic strategies such as empathic understanding, validation of emotions, reactions to difficult caregiving situations and emotional support. In this study Chinese Canadians are studied using ICSS. A questionnaire based survey was conducted on 28 users together with a follow up in-depth interview on 10 others. Though the sample was too small to draw significant conclusions they found more burden in people who have not used the system compared to people who have used ICSS and they also found improvement in burden (Chiu et al, 2009).

Another study claims that larger households would witness less caregiver burden compared to smaller households (Prince, 2004). The caregiver burden among these families is looked upon as resilience which is part of life in many Asian families. There has been a shift from this concept more recently because of the families moving from the more rural to urban areas in search of jobs and good quality of life and also many people migrating to different countries in pursuit of better life style leaving a gap in this care providing role.

‘Job satisfaction’ and ‘Companionship’ were the two very positive aspects to caring for spouses with Alzheimer’s disease in a cross-national study by Murray et al. (1999). This study showed that the carers gained satisfaction from making their spouse as comfortable as possible. They had to learn new skills to deal with difficult situations and were happy with the achievement. Around 16% were satisfied about ‘doing their best’ for their partners and 12% felt that they could provide the care and affection given in the past and this played a major part in their motivation. Staying together was the most rewarding aspect for 15% of spouses, 16% patients appreciated the effort their spouses were making and this was the motivation factor for the carers to go on. Singing, playing jokes and any other pleasurable activity was also found to be cherishing (Murray, et. al., 1999). A study undertaken in Japan suggested that “the positive values attached to personal dependency may make care giving more expected and less onerous” (Arai & Washio, 1999).

It seems that the satisfaction and comfort the carers derive from looking after their loved ones is much more stronger than the burden they are faced with. This is further strengthened by the fact that the families who are in a position to return all the favours and affections they previously received from their loved ones were now willing to do the same.
DISCUSSION

There is a need to think in more than one direction when discussing care provision to dementia patients; particularly as hard times are ahead because the economy is shrinking (Booth, 2009). There have been indications that the economy is improving but it is still slow and unpredictable. If appropriate support is provided to the families they will feel more confident in continuing their commitment to their families. It is suggested that family carers feel valued, satisfied and comfortable in providing care for their loved ones (Murray, et. al., 1999). The concepts of ‘job satisfaction’ and ‘companionship’ are more important to many families than the stress they face in providing care to their loved ones. As the statistics suggest that 2.4 – 6.9% of older adults are supported in their own homes there is a much greater need for these families to be appropriately supported and trained in caring for the elderly. Caring for loved ones is a process which evolves as a whole, people care for their families who suffer from dementia and over a period of time a sense of altruism develops to care for others and society as a whole. In a study (Barr-David, 1999) the care givers’ capacity for caring was found to be at the core and to unfold in three phases:

1. Development of caring capacity for the care recipient.
3. Development of caring capacity for others.

The experience of care giving will prompt people to get into caregiver role for humanity and expansion of sense of self (Barr-David, 1999). A number of social factors influencing the care of the elderly by families have been suggested by various researches in different parts of the world. The issues of respect for the elderly, dignity of the family structure as a whole, responsibility of families towards their elderly, family values and honor in looking after the elderly, have all been highlighted as important means of providing informal support for the elderly and particular for those with dementia. Although these concepts might be viewed as ‘altruistic’ and potentially be viewed as culture-specific to the confines of geographical boundaries, there are a number of families in the UK who provide such support for their elderly.

‘The Independent’ in 2008 published a story of a 65-year-old man being cared by his wife for 13 years. He was diagnosed with Alzheimer’s just after taking early retirement. Despite medication and being physically healthy he could no longer talk, walk, wash or feed himself.

As his wife says:

“Looking after him is my job; it is a 24-hour-a-day job which saves the Government lots of money. I do have help from the NHS and social services. Carers get him up in the morning, again at lunch and in the evening at weekends. During the week my sons and various friends help me to get him ready for bed or sit with him if I want to go out. It is tiring but I’m absolutely committed to looking after him. It really bothers me that you have to fight for basic things like incontinence pads and lifting equipment. Everyone should get support to stay at home as long as possible” (The Independent, 2008).

This story is true for many people in similar situation but what is evident is that people are committed to care for their families but need appropriate and prompt support and should not have to ‘fight for basic needs’. The carer burden faced by the families providing excellent care to the patients with dementia needs to be addressed by providing them with the most basic necessities including physical and mental health well-being of carers, access to financial and social resources.
Limitations: This review is not an exhaustive analysis of economic downturn and crisis for patients with dementia and their care. There were various aspects of caregiver burden that were not focused on here because this is a widely researched subject already. More in depth empirical research is needed in this area and this review must be looked at as a preliminary work.

CONCLUSION

In hard economic times families and informal carers provide the personalized and high standard service. Dementia patients do value this service and are better looked after by family members and informal carers, though this will depend on the stage of dementia and presence of BPSD. Family members feel comfortable and satisfied in providing care for their loved ones. Families are committed to this job but would need support and timely help when needed.

REFERENCES


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