SUPPORTING INFORMAL CAREGIVERS OF PEOPLE LIVING WITH DEMENTIA

KEY MESSAGES

- Most care for people living with dementia is provided by informal caregivers who include spouses, adult children, daughters- and sons-in-law and friends. Women are far more likely to be the caregivers in all countries. However, changing population demographics may reduce the availability of informal caregivers.

- The provision of care to a person with dementia can result in significant strain for those who provide most of that care. The stressors include physical, emotional and economic pressures. Support is needed to enable informal caregivers to continue in their role for as long as possible. Support includes information to aid understanding, skills to assist in caring, respite to enable engagement in other activities, and financial support.

- A range of programmes and services have been developed in high-income countries to assist family caregivers and to reduce strain. However, research on their effectiveness in different social, cultural and geographical contexts is limited. There is an urgent need to develop and implement an array of low-cost or no-cost government-supported services within an accessible infrastructure, so that even those with significant barriers to accessing services will be able to do so if motivated.

- Information and education campaigns for the public – including people living with dementia, their caregivers and families – aimed at raising awareness, improving understanding and decreasing stigmatizing attitudes should help overcome barriers to accessing and using services.

The position of informal caregivers is one of the key issues in dementia. Among chronic disease conditions, dementia has a large effect upon disability and needs for care. The impact of the disease on their families, partners, neighbours and others in their networks is considerable.

All over the world, the family remains the cornerstone of care for older people who have lost the capacity for independent living. In high-income countries, the vital caring role of families, and their need for support, is often overlooked. In lower- and middle-income countries the reliability and universality of the family care system is often overestimated.

Family caregivers can be defined by the relationship (spouse, adult children, daughters- and sons-in-law, friends, neighbours), living arrangements (co-resident with the care recipient or living separately) and care input (regular, occasional or routine). Family caregivers can be involved in providing “hands-on” care or – also a very significant role – in organizing care delivered by others, sometimes from a distance.

HOW DEMENTIA CARE DIFFERS FROM OTHER DISEASE AREAS

Dementia caregiving varies from other health issues in the duration of disease, progressive nature of disability, the fact that many caregivers are themselves old with possible disease or disability, and the lack of disease modifying treatments. In the home setting, family caregivers are confronted with multiple tasks that evolve throughout the disease process. Typically, the level of support increases as the disease progresses, starting with support for instrumental activities of daily living (household, financial and social activities) and expanding to include personal care and eventually almost constant supervision. The extent and types of care needed and their progression over time, depend on many factors such as the clinical profile (types and severity of cognitive impairments and challenging behavior, which may vary by subtype of dementia), the presence of comorbid physical and psychological problems, the custom and habits of the person with...
dementia, the person’s personality and significant relationships. Symptomatic features of dementia will vary considerably from person to person within and between the different diseases that result in dementia, and the caregiver’s role will vary accordingly.

Dementia care is difficult and requires time, energy and, often, physical exertion from the caregiver. As the disease progresses slowly, family members often provide care for many years and are under high levels of stress for long periods of time. The effects of high stress levels are intensified by the chronic fatigue associated with providing long hours of care without periods of relief.

The majority of family caregivers are women, according to this study in several lower- and middle-income countries (Table 1).

**CAREGIVING IS A SOCIAL ISSUE**

Caregiving and support is not the responsibility solely of the family and others in the immediate network of the person with dementia; it should also be a concern for communities, governments and society as a whole. However, the role of family caregivers is often neither supported nor properly acknowledged.

**HEALTH AND ECONOMIC IMPACT**

Family caregivers of people living with dementia are more likely to develop major depression, anxiety disorders, and physical health disorders among others and they have a higher mortality rate compared to the general population. Providing dementia care can become a full-time job without adequate support. Caregivers may be forced to quit work, cut back on work, or take less demanding jobs in order to provide care.

In the United States of America in 2010, nearly 15 million family and other informal caregivers provided an estimated 17 billion hours of care to people living with dementia, a contribution valued at more than US$ 202 billion (Alzheimer Association, Facts and figures 2011).

**TABLE 1** Household living arrangements and characteristics of the main caregiver for people with dementia at 11 sites in Latin America, China and India. Source: World Alzheimer Report 2009, table 2.3, p. 55

<table>
<thead>
<tr>
<th>11/66 dementia research group study site</th>
<th>Number</th>
<th>Household living arrangements</th>
<th>Characteristics of the main caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Alone (%)</td>
<td>Spouse only (%)</td>
</tr>
<tr>
<td>Cuba</td>
<td>316</td>
<td>6.3</td>
<td>10.2</td>
</tr>
<tr>
<td>Dominican Republic</td>
<td>235</td>
<td>8.5</td>
<td>10.2</td>
</tr>
<tr>
<td>Venezuela</td>
<td>140</td>
<td>5.7</td>
<td>4.9</td>
</tr>
<tr>
<td>Peru (urban)</td>
<td>129</td>
<td>1.6</td>
<td>9.4</td>
</tr>
<tr>
<td>Peru (rural)</td>
<td>36</td>
<td>13.9</td>
<td>8.3</td>
</tr>
<tr>
<td>Mexico (urban)</td>
<td>86</td>
<td>14.0</td>
<td>9.3</td>
</tr>
<tr>
<td>Mexico (rural)</td>
<td>85</td>
<td>16.5</td>
<td>11.1</td>
</tr>
<tr>
<td>China (urban)</td>
<td>81</td>
<td>2.5</td>
<td>34.5</td>
</tr>
<tr>
<td>China (rural)</td>
<td>56</td>
<td>3.6</td>
<td>8.9</td>
</tr>
<tr>
<td>India (urban)</td>
<td>75</td>
<td>4.0</td>
<td>13.3</td>
</tr>
<tr>
<td>India (rural)</td>
<td>10</td>
<td>15.1</td>
<td>5.7</td>
</tr>
</tbody>
</table>

http://www.who.int/mental_health/neurology/dementia/en/
The 2010 World Alzheimer’s Report estimated the total cost of Alzheimer’s care worldwide at US$ 604 billion, of which the costs of informal care (unpaid care provided by families and others) and the direct costs of social care (provided by community care professionals and in residential home settings) contribute similar proportions (42%) of total costs worldwide, while direct medical care costs are much lower (16%) (1).

The global economic impact of caregiving for dementia has been estimated in detail, based on a systematic review of the world literature, for the World Alzheimer Report 2010. A summary on informal care inputs (hours per day) is presented in Table 2. Where estimates were not available for a particular world region they were imputed from findings from a neighboring region with similar characteristics. The caregiver time was quantified as:

- assistance with basic Activities of Daily Living (ADL), such as eating, dressing, bathing, toileting, grooming, and getting around (sometimes referred to as personal care);
- assistance with combined ADL, including also Instrumental Activities of Daily Living (IADL), such as shopping, preparing food, using transport, and managing personal finances;
- supervision to manage behavioral symptoms or to prevent dangerous events.

### BARRIERS TO ACCESSING CAREGIVER SUPPORT SERVICES

The barriers to accessing caregiver support services are the same as those identified for accessing dementia-appropriate health and social services in general. These barriers include negative attitudes to diagnosis and treatment, lack of appropriately trained health workforce and of the infrastructure to scale up services, low help seeking due to dementia being considered part of ageing or stigma, lack of public policy initiatives, and lack of funds for dementia services, research, and training.

Caregivers also face additional barriers when seeking services for themselves. In many low- and middle-income countries, no support services are routinely available for family caregivers. Even in high-income countries there are barriers to access and uptake, including lack of recognition of the caregiving role, poor understanding of dementia, and cultural influences on caregiving, such as taking for granted that this will be done by the family and especially by female family members.
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STRENGTHENING CAREGIVERS

Strengthening caregivers requires provision of information resources and training, support and respite, and financial support.

● **Information, resources and training:** Information needs to include understanding the characteristics and course of the disease and what resources are available to families, along with training in how to care for people with the disease and how to prevent and deal with challenging behavior.

● **Support and respite:** There are a number of strategies for supporting caregivers, including counselling and long-term support, caregiver retreats, respite care and family meetings that include the person with dementia. It is urgent to implement strategies that are successful and replicable, focusing on both best practices and promising ones.

● **Financial support:** Caregivers need financial assistance in order to be able to provide appropriate care and to continue the caregiver role in the long term. A few models are in place worldwide such as the long-term care insurance in Japan. Some other countries like Germany provide caregiver benefits. In addition to caregiver benefits, disability benefits for the person with dementia and social pensions also have a part to play.

Strengthening caregivers is needed. National and subnational dementia plans from various countries make this point over and over again. Even though the specifics may vary by income level of a country, the theme remains the same. In Scotland this is taking the form of a guarantee of one-year of post-diagnostic support for the person with dementia diagnosis and their family, while in Finland it is taking the form of creating information centers for caregivers of people living with dementia at the municipal level all over the country. In Mauritius, the care strategy includes basic training to informal caregivers, a feature we see all over the world.

In addition, several caregiver interventions have been found effective through rigorous evaluation. Outcomes included reduced caregiver strain and psychiatric morbidity among caregivers. Innovative technology might play a role in the development of caregiver interventions. At present, the World Health Organization (WHO) is working on iSupport (Box 1), an information and communication technology based platform for caregivers that will be developed in multiple languages. Lastly, programs such as the mhGAP intervention guide highlight the role of health care providers to acknowledge and support the caregiver role while dealing with a person with dementia in their clinical practice.

**References**


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**BOX 1. iSUPPORT: AN E-HEALTH SOLUTION TO SUPPORT CAREGIVERS AND PEOPLE WITH DEMENTIA**

WHO has partnered up with international experts in caregiving and dementia to develop a comprehensive, online education portal called “iSupport”. The portal is aimed at relieving the burden of caregiving by emphasizing self-help, skills training and support for caregivers of people living with dementia. iSupport will be made available via a secured internet connection on personal computers, tablets and smart phones.