THE GROWING NEED FOR LONG-TERM CARE

ASSUMPTIONS AND REALITIES

60+ COUNTS

Growth in the number of older persons is a global phenomenon: virtually every country in the world will experience a substantial increase in the size of the population aged 60 years or over between 2015 and 2030.

Source: United Nations (2015). *World Population Ageing 2015.*

With increasing age and longevity, the risk of chronic disease rises along with that of age-related disabilities from chronic diseases such as pulmonary disease and diabetes to age-related loss of hearing, sight and movement (arthritis), cognitive illnesses such as dementia and Alzheimer's to injuries from falls. The incidence rate of disability from each of these varies considerably by country based on longevity and access to appropriate healthcare and rehabilitation services.

As the number of older persons continues to grow along with their longevity, the need for long-term care will increase significantly for those aged 80 and over, and in particular for older women who live longer.[1] The number of older persons age 80 and above is estimated to grow from 125 million in 2015 to 434 million in 2050.

Due to the rise in life expectancy and the growth in the number of older persons, the incidence of mental health diseases such as dementia and Alzheimer's continues to grow, leading to a further source of increased demand for long-term care.[2] The incidence of dementia is projected to grow from 47 million worldwide in 2015 to 75 million in 2030.[3] For instance, in the United States, nearly 40 per cent of the population aged 85 years and older suffer from Alzheimer's and dementia.

However, the type and amount of long-term care needed will in large part depend on the health status of individuals as a result of the standard of healthcare received, and social and economic experiences over the life-course.

In practical terms, long-term care covers a wide range of services and situations from in-home help with basic activities of daily life such as bathing, dressing, meals and/or more complex health care related services, attendance at day care centres, to care within an institutional setting. The vast majority of older persons in all countries receive care services within their own homes and from informal carers (mostly unpaid female family members). In some cases, paid informal care is available but is unregulated and often associated with poor wages and lack of benefits for the care-givers. Some older persons purchase or receive government subsidized or free health and/or social

[1] United Nations General Assembly, *Report of the Secretary-General on follow-up to the Second World Assembly on Ageing*, 26 July 2012 (A/67/188).
[2] United Nations General Assembly, *Report of the Secretary-General on follow-up to the Second World Assembly on Ageing*, 19 July 2013 (A/68/167).
[3] World Health Organization, *World Report on Ageing and Health* (Geneva, 2015).

services at home or had earlier purchased private insurance on the open market. A smaller number receive care in residential institutions or retirement communities.

The importance of a comprehensive discussion on the provision, quality and funding of long-term care for older persons concerns not only the well-being of older persons themselves, but also the well-being of informal caregivers and families, and ultimately the sustainability of Government health care and social service systems.

> "Long term care encompasses activities undertaken by others to ensure that those with a significant ongoing loss of physical or mental capacity can maintain a level of ability to be and to do what they have reason to value; consistent with their basic rights, fundamental freedoms and human dignity."
>
> *Source: World Health Organization (2015). World Report on Ageing and Health.*

Long-term-care – It's not just a developed country issue

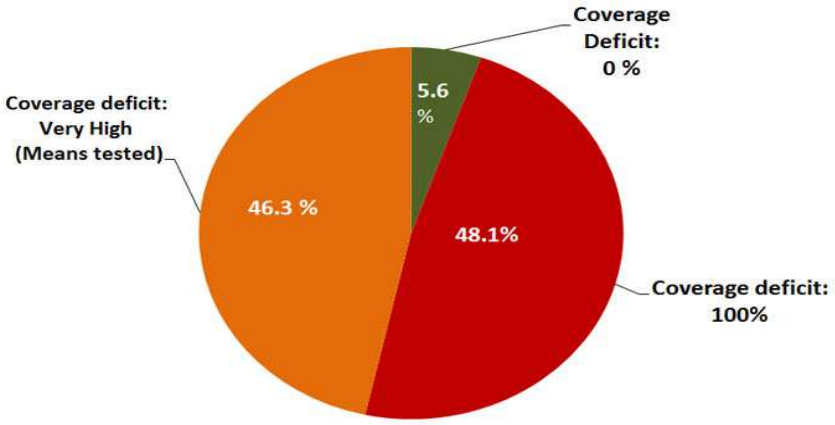
Currently, the highest levels of care needs are in low- and middle-income countries and at lower ages due to lower longevity rates combined with higher rates of chronic non-communicable diseases. This will only continue to increase as populations age in these countries unless there is a sharp improvement in healthcare services throughout the life-course (including at older ages) to address this growing rate of non-communicable disease and age-related disabilities.[4]

Global availability of formal long-term care

Globally, the availability of formal long-term care services is low. Forty-eight per cent of older persons are not covered by any type of formal provision of services; 46 per cent are excluded from any coverage that does exist by some form of means testing; and only 5.6 per cent of older persons worldwide are covered by legislation that provides coverage for all.[5] This is reflected, for example in statistics for the United States that show 123 informal care givers per older person versus 6.4 formal care givers.

[4] Ibid.
[5] Xenia Scheil-Adlung, "Long-term care (LTC) protection for older persons: A review of coverage deficits in 46 countries", ESS Working Paper, No. 50 (Geneva, International Labour Organization, 2015). Available from http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---soc_sec/documents/publication/wcms_407620.pdf.

Global estimates of coverage deficits in LTC: Proportion of the world's population not protected by legislation, 2015



Source: ILO estimates 2015, OECD 2011, World Bank, 2015 (population data in 2013), in Scheil-Adlung (2015).

Furthermore, there is a critical shortage of trained personnel. In 2015, it was estimated that there was already a global 13.6 million shortfall of formally employed caregivers. The shortage is most severe in the Asia-Pacific region, where the largest numbers of older persons reside and from where many caregivers leave to work in developed countries.

In fact, in countries where long-term care is lacking, the inappropriate use of acute care hospital services and emergency rooms is higher, and costs are therefore higher, too. Even in developed countries, cases of older persons residing for long periods in hospital beds due to lack of long-term care placement arrangements are not unusual.[6]

Informal care

The majority of caregivers are informal, and most also receive little to no training and/or practical or financial support to help ensure sustainability or quality. The great majority are still family members. However, due to smaller family sizes and economic and social changes, older persons in some urban areas of developing countries such as China currently rely upon a large number of untrained and poorly-paid home care workers among women with low levels of formal education. On the other hand, both China and other countries in the region such as Viet Nam are also cultivating other alternatives such as volunteer social organizations, community-based care and mutual support groups.[7]

[6] Denis Campbell, "NHS hospitals face record level of 'bed blocking'", *Guardian*, 24 January 2014. Available from http://www.theguardian.com/society/2014/jan/25/nhs-hospitals-bed-blocking-figures.
[7] United Nations Economic and Social Commission for Asia and the Pacific, "Long-term care of older persons in China", SDD-SPPS Project Working Paper Series: Long-term Care for Older Persons in Asia and the Pacific (Bangkok, UNESCAP, 2015). Available from http://www.unescap.org/resources/long-term-care-older-persons-china.

Gender dimension of informal care

The giving and receipt of care is overwhelmingly a female issue. The majority of caregivers (both informal and formal) are women and, due to the fact that women live longer, they are also the majority of care recipients too. The ILO points to gender discrimination as inherent in the reliance on unpaid care by female family members and cites the hidden costs of informal care that lead to higher rates of poverty and low social protection coverage rates for those out of the formal workforce. Even within countries that provide financial incentives to family care givers and have low rates of institutionalisation, studies are showing that the pressure in reconciling care and labour force activities is overwhelming the availability of family care and that more community services are urgently needed to address the growing problem.[8] There is little widespread study of the economic cost to societies of the overreliance on informal caregivers that causes, among other things, loss in productivity and labour market distortions, particularly for women.

Elder abuse

A large proportion of cases of abuse and neglect of older persons occurs within situations of care dependency, whether within the home or an institutional setting. This includes issues of neglect, physical and sexual abuse and financial, psychological and emotional abuse. While physical and sexual abuse are easily categorised, what passes for "normal operational practice" are often violations of the rights of older persons, such as use of restraints, locking of doors, social isolation, inappropriate use of medication and regimented enforcement of schedules.[9]

Age discrimination in access to long-term services

The unequal treatment of older persons versus younger disabled cohorts in accessing similar care services has been raised as an age discrimination issue, particularly in light of the adoption of the Convention on the Rights of Persons with Disabilities, which is often cited as a possible source of human rights law for older persons. In many countries, older persons with disabilities are not entitled to the same care allowances and benefits as younger persons with disabilities.[10] For instance, in France there are different benefit schemes for a disability acquired before and after age 60, with the old age disability benefit being less generous. This is refererred to as an example of intersectional discrimination – on the basis of age and disability.[11]

A recent study in Norway pointed to the unequal distribution of resources between younger and older persons in need of care. The study notes that some of the employees of the municipal authorities responsible for allocation of resources had an unconscious bias against persons over age

[9] United Nations General Assembly, Report of the Secretary-General *on Follow-up to the Second World Assembly on Ageing*, 24 July 2016 (A/69/180).
[10] Age Platform Europe, "Age Platform Europe position on Article 19 of the UNCRPD", March 2016. Available from http://www.age-platform.eu/images/stories/Publications/papers/AGE_input_CRPD_Art19.pdf.
[11] Age Platform Europe, "AGE response to OHCHR questionnaire on article 5 of the UNCRPD", 1 June 2016. Available from http://www.age-platform.eu/images/AGE_input_CRPD_article_5.pdf.

60 with disabilities. These assumptions were often linked to ingrained ageist views which hold that priority that should be given to younger people with more "potential" for future development.[12]

Policy responses and challenges in face of growing need

Care provision

A great deal of misinformation and assumptions abounds about the availability of resources and care for older persons. Most people believe there is much more government support for the provision of care services than there actually is. Even more assumptions are made about the ability of families to care for older relatives despite evident changes in all countries such as growing migration for employment, the increasing number of women in the workplace, the need for more than one wage earner in families and smaller family sizes.

Unmet need for care

Source: AGE UK, *Agenda for Later Life 2015: A great place to grow older* (London, Age UK, 2015). Available from http://www.ageuk.org.uk/professional-resources-home/policy/agenda-for-later-life/.

In some countries such as Algeria, India, Russian Federation and Chile there is legislation enforcing family responsibility for long-term care, with the State stepping in, in certain cases, only in the absence of family members.

In nearly every country, to differing degrees, the underlying question of who is responsible for the provision of and financing of care for older persons is a negotiated balance that involves issues of cultural expectations and the specific political and social environment, as well as availability of funding. The ILO asserts, however, that the right to social security and health care also includes the right to long-term care, which clearly puts the onus on Governments to provide a comprehensive policy framework.

WHO further notes that throughout discussions on Government or family responsibility and the proportion thereof, little attention is paid to quality of care or the quantification of the benefits of care provision and funding by the State–only the cost to gross domestic product (GDP).

[12] Heidi Gautun and Anne Skevik Grodem, "Prioritising care services: Do the oldest users lose out?", *International Journal of Social Welfare*, vol. 24, No. 1 (January 2015).

Who pays?

The global average public expenditure on long-term care is less than 1 per cent of GDP. It is highest in Europe, but varies widely among countries, for example, from a high of 2 per cent in the Netherlands and Norway, to 0 per cent in Slovakia. In North America it stands at 1.2 per cent in the United States, and 0.6 per cent in Canada

Mandatory public long-term care insurance systems are in place in Germany, Japan, the Republic of Korea, Luxembourg and the Netherlands, which see ongoing adjustments in benefits and premiums to ensure sustainability of the systems. However, for the majority of older persons who want to or even can access any type of formal care services, they must utilize savings, or "spend down" their assets to qualify for government-funded services–either institutional or in home. There are also often different Government funding mechanisms and qualifying rules for social and medical in-home care services, with more burden generally put on the individual to self-fund "social" care in support of activities of daily living. Such out-of-pocket expenditures can have adverse financial outcomes both for the older persons themselves and often, their families. Finally, while a limited market exsits in some developed countries for self-insurance policies against possible long-term care costs in the future, the take-up rate is low and policy premiums expensive.

Hidden costs to family

In Sweden, for example, a policy of "ageing in place" and keeping older persons in their own homes as long as possible has led to evidence of a reduction in residential care space, which has not translated into an increase in the provision of formal homecare services, but rather an increased reliance on informal unpaid family care. In addition, unpaid family care remains more common among families of older people with less education and, therefore, cutbacks in formal services affect working class families more negatively.[13]

Time for global debate?
Key overarching policy that must be addressed

The overarching policy development considerations should be the views and preferences of older persons themselves regarding the type and location of care, the quality of care provision (formal and informal), and the tangible and intangible "costs" to Governments, the individual and families in the provision of care. In this respect, it has been suggested by some that long-term care might be reframed as a societal and political public good, the neglect of which only leads to higher social and economic costs.[14]

Countries are at different stages of discussion of the policy implications of these issues. Many are recognizing that the reliance on the traditional family structure for caregiving functions is under great stress due to economic and social changes, smaller families and migration of family members.

[13] Petra Ulmanen and Marta Szebehely, "Consequences of reduced residential eldercare in Sweden", *International Journal of Social Welfare*, vol. 24, No. 1 (January 2015).
[14] World Health Organization, *World Report on Ageing and Health* (Geneva, 2015).

In all countries, policy and programme responses deemed appropriate are subjet to ongoing debate and adjustment.

Above and beyond this, key policy issues for discussion might include:

Identification of sustainable sources of funding and practical support for the provision of care services, including the provision of financial and/or practical support to family/informal caregivers;

An examination of the gender and societal implications of reliance on informal care provision;

Consideration of/movements towards the integration and coordination of social and health care services to provide a continuum of care;

Ensuring the implementation and monitoring of effective regulations and standards of care, and awareness-raising and enforcement of the rights of care workers;

Ensuring equality of access and provision of care services for all ages, based on need.

For further detailed reading

- World Health Organization. *World Report on Ageing and Health*. Geneva, 2015.
- Political Declaration and Madrid International Plan of Action on Ageing: United Nations. *Report of the Second World Assembly on Ageing, Madrid, 8-12 April 2002*. United Nations publication, Sales No. E.02.IV.4, chap. I, resolution 1, annex II.
- Scheil-Adlung, Xenia. Long-term care (LTC) protection for older persons: a review of coverage deficits in 46 countries. ESS Working Paper, No. 50. Geneva: International Labour Organization, 2015.
- United Nations, General Assembly. Report of the Secretary-General on the follow-up to the Second World Assembly on Ageing. 24 July 2014. A/69/180.
- United Nations, General Assembly. Report of the Secretary-General on the follow-up to the Second World Assembly on Ageing. 26 July 2012. A/67/188.
- Ilinca, Stefania, Kai Leichsenring and Ricardo Rodrigues. From care in homes to care at home: European Experiences with (de)institutionalisation in long-term care. Policy Brief (December). Vienna: European Centre for Social Welfare Policy and Research, 2015. Available from: http://www.euro.centre.org/data/1449741582_83911.pdf.
- United Nations, Human Rights Council. Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover. 4 July 2011. A/HRC/18/37.