

Green Templeton College Care Initiative

Thinking about Long-term Care in a Global Context – A Literature Review

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Executive Summary

Due to demographic, technological and social changes, countries all over the world are facing the challenge of a growing ageing population. While the need to provide adequate systems of long-term care for older adults has long been recognised by both governments and academic experts in developed countries, the issue has received, at least until recently, less attention in developing economies. Yet, it is precisely in countries with limited financial resources that the need to introduce effective care policies poses an even greater challenge.

This report presents findings from a literature review of policy documents and academic research on the issue of global discourse on care provision for older adults in low- and middle-income countries.

While care provision for older people does not seem to be a high policy priority at the regional level, international organisations such as the World Health Organization and HelpAge International have been highlighting the need for national governments of LMICs to introduce adequate systems of care for older people. According to these organisations, the introduction of national care systems will not only improve the human rights of vulnerable older adults but will also bring about significant economic benefits.

Care provision for older people in most LMICs is primarily informal, delivered by members of the family (in the majority women) and volunteers. The reasons for this are both pragmatic (absence of adequate state care provision) and cultural (belief that the family is best placed to take care of its older members). Global public discourse recognises the need for care systems to adapt to existing social conditions and cultural beliefs. Informal carers, however, will need to be supported both financially and technically (by improving their knowledge and skills).

A number of emerging innovative models of care for older people have been reported in the literature. Such models will need to be expanded and supported if their sustainability or viability is to be assured.

Thinking about Care in a Global Context – A Literature Review

BACKGROUND

Population ageing is an issue that affects both high-, low- and middle-income countries (LMICs). According to the World Health Organisation (WHO), ‘by 2050, one in five people will be 60 years or older, totalling two billion people worldwide’ (WHO 2017a, Foreword). As a result of a rapidly growing ageing population (due to demographic, technological, and socio-economic changes), the need for long-term care provision for older adults is predicted to rise substantially. Long-term care (LTC) provision refers to care given over a prolonged period to people who are not able to care independently and includes a broad range of services, preferably working in an integrated rather than disjointed way. In this report, the terms ‘LTC’ and ‘care’ are used interchangeably. Care may be provided at home, in the community, or in institutions such as nursing homes or self-managed homes. Meeting the demand for long-term care provision is a topic widely discussed in the high-income countries. The picture in LMICs is, however, less clear, as there is relatively little research on the subject (especially on the policy level). According to WHO’s website, ‘while global data on the need and unmet need for long-term care do not exist, national-level data reveal large gaps in the provision of and access to such services in many low- and middle-income countries’ (www.who.int/ageing/long-term-care.en). The aim of this report is to provide an overview account of long-term care policies and practices in LMICs.

The structure of the report is as follows: first, a description of the objectives and the methods used in the research is provided; this is followed by a description of the results in sub-sections which broadly reflect the initial questions. The third section discusses the main issues arising from the review. The report concludes with a list of recommendations for policy and further research

OBJECTIVES

The main questions that the research sought to answer were:

- What are the dimensions of care that are global, and which are the key actors?
- How is care conceived or problematised as a policy issue (problem) in/for other regions and systems?
- What are the international non-governmental organisations (INGOs) saying and recommending about care as a global issue?
- What is the perception/understanding of the ‘care system’ (i.e. the different constituent elements that need to be in place for a sustainable set of arrangements), and to what extent is the discourse and policy on care connected to that of health?
- What are the international trends and consensus concerning long-term care as a global exigency? In other words, how is care ‘framed’ in public discourse at the international level?
- How are the issues being thought about in the middle- and low-income countries? What where/are the innovations and the key gaps?

METHOD

The report is based on a review of the main literature identified by a series of web searches. . The purpose of the review was to scan academic and policy documents so as to answer the research questions. The researcher scanned the main relevant databases and the websites of the main regional organisations and INGOs. Though not the product of a ‘systematic literature review’, the report provides a comprehensive account of the salient themes relating to the provision of care (conceived broadly as encompassing health and social care) for elderly populations in developing countries. Articles published before 2000 and non-English language publications were excluded.

Databases	Keywords	Websites of International/regional organisations	Websites of INGOs
Web of Science (754 papers of which 26 relevant)	long-term care	World Health Organisation (WHO)	HelpAge International
Google Scholar (38 papers of which 2 relevant)	social care	South Asian Association for Regional Cooperation (SAARC)	CARE International
Scopus (Medline and Embase) (7 papers but only one new)	aging ageing	Association of Southeast Asian Nations (ASEAN)	Age International
Global Health (44 papers of which 19 relevant but only 6 new)	polic* (term used so as to include policy and policies)	Southern African Development Community (SADC)	International Federation on Ageing
International Bibliography of the Social Sciences (IBSS) (46 papers of which 13 relevant)	middle-income countries	Union of South American Nations (UNASUR)	IntraHealth International
	regional health polic*	African Union (AU)	
	global health polic*		
	Developing countries		
	Low-income countries		
	Care for older people		
	Global care polic*		

The keywords were used in various combinations. The searches from scholarly databases yielded 889 articles, of which 48 were relevant. Searches of websites of international and regional organisations yielded 34 documents of which 10 were directly relevant. Searches from INGOs yielded 11 documents of which 3 were directly relevant.

The documents were analysed mainly in regard to whether they contained material of relevance to the research questions. In other words, the main concern was to draw a picture of the way in which care for older people is conceptualised as a policy issue at the global level and identify areas for future research, rather than, for example, evaluate the scientific merit of academic studies on care provision. Accordingly, the review is not intended as an exhaustive account of

research on care provision for older adults published to date. Documents that appeared to be repeating points already covered in the report were therefore left out. In addition, although the issue of healthy ageing is very closely related to that of long-term care, the focus of this report is not on healthy ageing but on the narrower topic of care provision for older people.

RESULTS

In this section, the results from the literature searches are presented, organised loosely around the research questions.

Principal Global Care Actors and Global Dimensions of Care

The principal actor in what is known as the ‘global health system’ (the network of global actors whose main or one of their main policy goal/s is health) is the World Health Organisation (WHO). According to one attempt at mapping the global health system, WHO is directly connected to all global health actor types (civil society organisations and NGOs, national governments, academic institutions, professional associations, public-private partnerships and private industry), except philanthropic organisations and multilateral development banks (Hoffman & Cole 2018). WHO works through its five regional offices and in collaboration with a number of academic institutions as well as a plethora of international and national non-governmental organisations and civil society organisations (INGOs and CSOs).

The main INGOs with healthy ageing and care for older people as their principal goals are:

- **HelpAge International** (it is a global network of more than 140 organisations across 80 countries and it campaigns for the rights of older adults to dignified, healthy and secure lives. Global care provision for the elderly is a major concern)
- **International Federation on Ageing** (like HelpAge International, it is in formal relations with the WHO and has a focus on how to protect the rights of older adults across the world)
- **Age International** (campaign for the rights of older people and undertake a number of projects to empower the elderly worldwide)
- **Global Coalition on Aging** (GCOA) representing the business sector.

How is Care Conceived as a Policy Issue at the Global Level?

The WHO Strategy

To date, the WHO *Global strategy and action plan on ageing and health* (WHO 2017a) is the most comprehensive document on healthy ageing across the world, which includes the topic of LTC provision as a global concern. The *Strategy* was adopted at the Sixty-ninth World Health Assembly in resolution WHA69.3; it builds on previous international documents that have guided action on ageing and health since 2002: the *Madrid international plan of action on ageing* (UN 2002); WHO *Policy framework on active ageing* (WHO 2002a); and, the *World report on ageing and health* (WHO 2015). As the authors of the *Strategy* admit, progress to improve the health of older people since 2002 has been ‘uneven and generally inadequate’ (p.2). The *Strategy* aims to address in detail the actions that need to be taken globally to achieve improvements in the health and care of older people, as well as in the process of ageing itself.

The *Strategy* outlines a framework for action for the relevant stakeholders of its member states to coincide with the 15-year period for delivering the Sustainable Development Goals (SDGs) which were adopted by the United Nations General Assembly in 2015 (UN 2015). Specifically, the aim of the *Strategy* is by 2020 to identify gaps in evidence and infrastructure and ensure that member states and other stakeholders have the capacity to undertake a decade (2020-2030) of evidence-based concerted action on healthy ageing. A separate WHO document identified 10 priorities on which the 10 year long research will focus (WHO 2017b). Priority 6 is about ‘laying the foundation for a Long-term-Care system in every country’ and is most directly relevant to the purposes of this report. In order to achieve this priority, WHO will provide support to countries to develop ‘effective, sustainable and equitable’ care systems that meet the needs of older people with significant losses in intrinsic capacity and reduce the burden on caregivers. Three areas of action are identified for this priority: developing long-term-care systems through global, regional and local policy dialogues; mapping existing systems and services on care provision in countries to serve as a baseline with regard to the need, unmet need, type and quality of existing services, legislation, human resources and financing mechanisms; and, provide guidance and technical assistance to countries at any level of socio-economic development on building sustainable and equitable LTC systems (WHO 2017b).

The *Strategy* points out that, in the past two decades, the gap in life expectancy at age 60 years between high-income and LMICs has grown, and identifies five key objectives through which to narrow this gap and generally deliver its broader vision on healthy ageing:

1. Commitment to action on healthy ageing in every country
2. Developing age-friendly environments
3. Aligning health systems to the needs of older populations
4. Developing sustainable and equitable systems for providing long-term care (at home, communities and institutions)
5. Improving measurement, monitoring and research on healthy ageing

Objectives 3 and 4 are particularly relevant to care delivery for older people. They are closely intertwined and are underpinned by the need to establish integrated health care systems that are able to deal more effectively with chronic and complex conditions, compared to existing systems, which work in fragmented ways and which are designed primarily to cure acute conditions. In primary care, for instance, the focus is currently on detection and treatment of diseases rather than on prevention (WHO 2002b). Importantly, the *Strategy* advocates that in the 21st century every country should have in place a comprehensive long-term care system, providing care at home, in the community or in institutions. Such systems will have the potential to free women (typically the main carers) to pursue their goals, reduce inappropriate use of emergency services, help families avoid catastrophic care expenditure, and, by sharing the risks and costs of care across generations, foster social cohesion and solidarity.

As a first step, the *Strategy* identified a number of questions related to healthy ageing that need to be addressed via research and evaluation of policies and interventions in various countries. As part of the action plan 2016-2020, it identified 10 mid-term progress indicators. Examples of such indicators include: number of countries with national plans or strategies aligned to healthy ageing; number of counties with focal points on ageing in health ministries; number of countries that have a long-term care policy or plan or strategy; number of countries with

national policies in place to support comprehensive assessments of the health and social care needs of older people; number of countries with longitudinal national surveys in the public domain on the health needs of older adults. Indicator 8 refers specifically to the percentage of countries reporting to have in place a national policy on LTC. According to the WHO's mid-term progress report, 41% of countries globally report having such a plan. This number, however, is hardly accurate, since the data were collected by March 2018 from 139 of the 194 Member States (www.who.int/ageing/commit-action/measuring-progress/en/).

Regional policies on care

WHO recently published the first document of a series of future publications on regional LTC policies and practice, covering the region of sub-Saharan Africa (WHO 2017c). The report highlights the fact that, despite some progress in the region, focused work on LTC has been largely absent, reflecting the low policy priority accorded to the issue. Provision of LTC is left primarily to families in the absence of support and guidance on what constitutes appropriate care or how it might be best provided. The result is that millions of vulnerable older people have their basic needs neglected or suffer abuse and violation of their fundamental rights. This lack of LTC provision also places a huge burden on caregivers, who are primarily female. It often perpetuates household poverty by limiting opportunities for education and employment for sub-Saharan women and girls. Despite the existence of huge resource limitations on governments in providing LTC, the document includes examples of emerging models of good practice from four countries in the region (see below).

One area on which research on care for the elderly in LMICs has been focusing is that of dementia. Authors of the 10/66 Dementia Research Group point out that, despite its growing prevalence, dementia is not a high priority in international or regional health policy documents. Despite the fact that the impact of dementia on the individual, the family, and society can be huge, it is a relatively under-prioritised condition in research, policy, and practice. Even where international policy guidelines exist, resource limitations in LMICs are a major obstacle to policy implementation at the national level (Prince, Acosta *et al.* 2008).

Our research on current health policies *at the regional level* found little evidence of regional approaches targeted specifically at improvements in care provision for older adults. Echoing the WHO *Strategy*, there are declarations about the need to promote healthy ageing. A recent document by the Association of Southeast Asian Nations (ASEAN), includes 'promotion of healthy and active ageing' as one of its health priority issues (ASEAN 2018). The emphasis here seems to be on prevention of health deterioration in old age, which would lead to a reduction in the need for formal care provision for the elderly and cost containment. Similarly, beyond general declarations about ensuring every citizen's right to health, respect and dignity, searches of the African Union and the Union of South American Nations (UNASUR) websites did not reveal any detailed strategies on tackling the care needs of an ageing population. The South Asian Association for Regional Cooperation (SAARC) lists 'social affairs' (which includes 'health and population activities') as one of its areas of cooperation. A look at the website, however, did not reveal a focus on LTC provision for older adults as one of the current key themes. The emphasis at present seems to be on combating HIV/AIDS and tuberculosis, infectious diseases such as Severe Acute Respiratory Syndrome (SARS), and gender and children related issues.

The 10 countries comprising ASEAN collaborate closely with three other Asian countries (China, Japan and South Korea) forming what is known as ‘ASEAN Plus Three’ (APT). APT countries represent a wide spectrum of economic development and LTC policies, from high income Japan that in 2000 implemented the first LTC insurance in Asia, to poorer Indonesia with a relatively younger population and a virtual absence of LTC policies. Life expectancy in countries such as Japan, Singapore and South Korea is among the highest in the world, whereas at the other extreme life expectancy in Myanmar, Lao PDR and the Philippines is amongst the lowest. Authors point out the central role that family plays in caregiving in Asia while, at the same time, the gradual decline in fertility and changes in family structure due to socio-economic change put a strain on the family’s ability to provide care for older members (Yeung & Thang 2018). Current practices of care provision for older people in some of these countries are described below.

An important consideration regarding the issue of global health policies (including LTC for older adults) is the approach followed by the high-income countries towards LMICs. Given that the EU and the US are two of the biggest donors of development aid, it is helpful to examine their policies on global health.

The EU global health policy

One question concerns the extent to which there has emerged a well-formed common ‘EU’ approach to global health. According to one study, since 2000 the European Commission (an international donor in its own right) has been increasingly forging an ‘EU approach’ to global health, while at the same time EU member states (especially the largest ones like UK, Germany and France) have been trying to maintain their own individual policies, and have released their own global health strategies. While acknowledging the need for more research on the topic, the authors of a recent study conclude that a common ‘EU’ vision for global health appears to be lacking and express doubts about the likelihood of a common policy emerging in the near future, given existing differences between the EU central institutions and its individual member states. (Steurs L, Van de Pas R *et al.* 2018). In addition, given the difficulties that EU countries themselves are facing on how to tackle pressures created by their own ageing populations, neither the EU Commission nor its individual member states seem to have a policy referring specifically to global care for older adults.

The US global health approach

The US is another key player in global health diplomacy. For instance, it played a key role in creating the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) in 2002; it launched the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) in 2003; it introduced the Global Health Initiative (GHI) in 2009; and it was involved in the development of the Global Health Security Agenda (GHSA) in 2014. US involvement in global health diplomacy, however, seems to be focusing on issues relating to security (e.g. infectious disease) and investment, rather than on ethically driven considerations about protecting the rights of older people by improving care provision across the world.

What do INGOs Say about Global Care

The searches of the main INGO websites show that HelpAge International is the main organisation which has care for older people as its focus. The organisation published the

Strategy to 2020 on the topic of ageing as a global issue in which it acknowledges that, despite the topic receiving increasing attention since the *Madrid Plan of Action* of 2002, it is still of relatively low priority amongst agents of international development (HelpAge International 2015). Similar to the WHO *Strategy*, the *Strategy to 2020* focuses on the more general topic of global ageing rather than the narrower topic of provision of LTC for the elderly as a separate subject. The *Strategy to 2020* puts forward four main general goals: a) to ensure financial security and social protection for older adults; b) to ensure the right of older women and men to adequate health, nutrition and care services; c) to achieve the right of older people to safety and security, free from discrimination, violence and abuse; d) to work to enable older people to take part in decision making, becoming themselves agents of change. Clearly, all four of these goals are directly applicable to care provision for older people.

Another publication by HelpAge International also deals with the broader theme of healthy ageing rather than provision of LTC for older people, which is discussed in chapter 4 of the document. (HelpAge International 2017). The publication repeats a number of arguments made in the WHO *Strategy*, such as suggestions to rebalance healthcare systems from curative to preventive services and the need for integration between health and social care. It also advocates the provision of a universal basic income for older adults and the support of informal carers through the provision of an adequate array of external services. In addition, it draws attention to the need for better regulation of the private sector residential and domiciliary care services.

Perceptions of the ‘Care System’

There is agreement, both in academic literature and in policy documents, that caring for older people entails a holistic approach, which encompasses health care needs as well as providing help with performing daily activities. In other words, provision of care for older adults includes both health care and social care. At the system level, a holistic approach involves the delivery of integrated as opposed to fragmented care (Nuño, Coleman *et al.* 2012; Kruk, Nigenda *et al.* 2015; Briggs, Valentijn *et al.* 2018). In practice, this means close co-operation between a number of relevant institutions and sectors (e.g. primary and secondary care, social care, residential and community care, family members and other unpaid carers). Importantly, some authors point out that prevention of illness, despite its crucial importance, is still a neglected component of healthy ageing, and emphasise that education about prevention of ill health needs to be an integral part of the care system (Lloyd-Sherlock 2000; Zolnikov 2015).

The WHO *Strategy* clearly adopts the holistic approach to care provision for older people, advocating the integration of a wide range of care services such as health promotion and disease prevention, screening, early detection and acute care provision, and ongoing management of chronic conditions. It suggests the more widespread use of assistive technologies and a re-orientation of financial incentives towards achieving the best possible trajectories of functioning rather than the provision of specific interventions. It also recommends that every national care system place emphasis on self-management and that services be patient-centred and situated close to home (either in people’s homes or in the community).

In one study, the authors conducted in-depth interviews with relevant policy makers and stakeholders in order to form a complete picture of the ‘ideal care system’ in the context of

high-income economies e.g. U.S (Miller, Booth *et al.* 2008). According to the authors of this study, the main features of the ‘ideal care system’ are: establishing systems of consumer-centred care serving people with diverse characteristics and preferences; putting in place regulatory systems which ensure that providers of care are accountable; ensuring that care systems are governed by the principle that long-term care is both a quality-of-care and a quality-of-life issue; producing quality information to enable consumer preferences; ensuring the supply of a motivated, capable and sufficient workforce; ensuring continuous government commitment in the area of care provision.

In summary, the ideal care system is person-centred, professionally rewarding, integrated, affordable, accountable, home- or community-based, and consumer directed. According to the study, an ideal care system should also be supportive, comprehensive, dignified, culturally appropriate, innovative, responsible, safe and secure. Importantly, the authors draw attention to the absence of a long-term care system in the US and the absence of a vision of what LTC ought to be (p. 455). They also identify an over-emphasis on institutional care as opposed to the option preferred by patients of home- and community-based alternatives.

Framing LTC as a Global Exigency

The WHO *Strategy* adopts the definition of LTC used in the *World report on ageing and health*: “the activities undertaken by others to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity” (WHO 2017a, p. 18). As we saw above, the approach taken in the *Strategy* encompasses a wide range of topics related to healthy ageing, which are underpinned by general principles such as viewing healthy ageing as a human right, achieving gender equality, preventing discrimination on the basis of age, achieving equity, and intergenerational solidarity. The *Strategy* clearly recognises that provision of care in old age is part of the wider theme of healthy ageing.

The topic of healthcare as a global exigency has been analysed in the academic literature via the use of analytical ‘frames’. Although such analysis has not been applied specifically to the topic of LTC, since global healthcare encompasses this, it is worth examining public discourse on care as a global issue via the application of framing analysis. One approach is Labonté and Gagnon’s six frames of analysis of global health diplomacy – security, development, trade, global public goods, human rights, and ethical/moral reasoning (Labonté & Gagnon 2010). As is evident from the definition of LTC adopted in the WHO *Strategy*, the call for improving global care provision for older people is couched primarily in terms of human rights and ethical reasoning.

A similar ‘framing analysis’, distinguishing between four frames (social justice, charity, investment, and security) has been used to analyse EU documents on global health policy (Steurs L, Van de Pas R *et al.* 2018). Having examined policy documents issued by the European Commission and some EU individual member states, the authors point out that, while the European Commission and some member states (e.g. Belgium and Denmark) stress the social justice frame, other member states (UK, Germany and France) place more emphasis on the investment/economic and security frames. Despite references to social justice and the importance of health as a human right, the latter countries focus on investment and security as a justification for global health. The social justice frame implies a high degree of

‘voluntariness’ and ‘optionality’, whereas the economic and security frames add an element of urgency, thus raising the topic higher on the policy agenda and, by relating it to the country’s direct self-interest, increasing its legitimacy and acceptability to their electorates. Importantly, the authors caution against over-emphasising the security and investment frames at the expense of social justice, for fear of ignoring areas of global health less relevant to the donor countries’ self-interest. Care provision for older people may be precisely such an area.

As in the case of other high-income countries, the discourse in the US on global health diplomacy is couched in the frame of investment and security rather than social justice and human rights (Kickbusch 2002; NASEM 2017).

Another ‘framing analysis’ of health policy documents from four regional organisations (ASEAN, EU, SADC and UNASUR) found an absence of a unified approach to global health care (Amaya, Rollet *et al.* 2015). According to the authors, ASEAN places emphasis on health as a security regional issue, due perhaps to the re-emergence of highly contagious diseases, such as influenza. On the other hand, SADC views health as a driver for development, which can be explained by the impact the HIV/AIDS epidemic has had on development in the region. For UNASUR, health is also seen as a driver of development but the social justice frame is also prominent in the policy documents. Finally, documents from the EU utilise both economic and moral frames. The EU considers aid for health as a tool to fight poverty, support development, and achieve the Sustainability and Development Goals. Moreover, the EU sees investment in health in non-member states as having the potential to open new economic opportunities and markets to the region.

Main Issues Related to Long-term Care Provision in LMICs

As mentioned already, our searches of published documents on regional and national policies on care provision for older citizens in LMICs indicate that the topic is not a high policy priority. This confirms previous research on the topic (Zhang & Wei-Jun 2012). Existing publications point to the fact that care provision for older adults in LMICs is primarily informal rather than formal. In other words, it is usually not provided in formal institutions (publicly or privately funded), as it is perceived to be primarily the domain of the family (Lloyd-Sherlock 2014; Zhou & Walker 2016).

According to one study in Thailand, spouses and children constitute 90% of caregiving in the country and 95% of caregivers either co-reside or live very near care recipients (Knodel, Teerawichitchainan *et al.* 2018). A shrinking in family size and worker migration are resulting in gaps in caregiving, which will need to be filled by formal state institutions and/or private LTC provision. Current challenges in provision of LTC relate to shortages in trained and skilled home care volunteers as well as funds to support such volunteers. According to another study conducted in two similar countries (Thailand and Costa Rica), governments in both countries trained older volunteers from local communities to make home visits to impoverished and vulnerable older people and to facilitate access to health services and other social services (Lloyd-Sherlock, Pot *et al.* 2017). The authors point out that, despite some evidence of benefits to the physical and mental health of older people, a large burden of unmet care needs and signs of a growth of unregulated private services still exist. They point to the scope for low- and

middle-income countries to develop large-scale networks of community-based long-term care volunteers and invest in community long-term care services.

A study from the Philippines shows similar patterns of LTC provision to those of Thailand, with co-resident or nearby living family caregivers dominating the scene. The authors highlight their concern about the country's ability to provide adequate LTC in the face of changing demographics and greater geographical mobility of younger generations (Abalos, Saito *et al.* 2018). Using data from China, South Korea, Japan and Taiwan, another study examined the strains under which the 'sandwiched generations' find themselves in providing care both for children and for their elderly (Tan 2018). Usually, care for younger and older generations in the family falls on women, which points to the need for adopting a gendered perspective of caregiving.

Another theme is the frequency of elder-to-elder caregiving in many LMICs, an area of research that is rather under-investigated. Carers in this case are also older women, providing care for their ailing elderly spouse, children suffering from AIDs, or orphaned grandchildren. According to one study conducted in Tanzania and Indonesia, inter-generational care support is considered to be the ideal form of caregiving and care receiving (van Eeuwijk 2014). The author points out that, although the intra-generational form of caregiving does not comply with social norms and cultural expectations about caregiving in the two countries, the model of an elderly wife providing care for her old spouse complies with prevailing gender norms. The same study also shows that, in addition to kin caregivers, a number of non-kin caregiving institutions exist in the two countries in which older persons take care of economically and socially neglected frail and elderly citizens. Such institutions provide much needed complementary care. Moreover, by being part of international programmes, these institutions have the potential of becoming models for adoption elsewhere.

A study from China draws attention to the importance of providing person-centred institutional care for older adults, in the form of empowerment and social support (Wang, Wang *et al.* 2018). The study was conducted in 2011-2012 using predominantly quantitative methods (questionnaires and statistical analysis) in nine non-profit residential care providers in Shanghai. According to the authors, the results agree with previous studies showing that China's formal LTC system is still in its early stage of development, challenged by limited funding and under-prepared workforce. The study found that residents' perceived quality of life (QOL) was described as moderate, which is low compared with the findings of a similar study in Taiwan. There were shortcomings in both quantity and quality, while staff seemed to lack awareness of providing suitable activities that would contribute to higher experience of QOL. The authors stress that, despite its crucial importance, implementing a programme of empowerment and social support in residential care is challenging. They suggest that the focus in residential facilities be shifted to more personalised care provision rather than solely pursuing institutional efficiency. Facilities should cease to be 'total institutions' where residents are less connected to the wider society and are being treated alike. It is imperative for caring staff to provide social activities and educational programmes that will increase residents' autonomy and enable them to manage chronic diseases more effectively. Facilities should provide more opportunities for networking within and outside the facility, and create a home-like environment for residents as well as take into consideration their individual needs. The authors conclude that, for successful implementation, more funding is needed to increase staff

and develop a high quality workforce in the sector, with the knowledge and skills to provide resident-centred care.

As with studies from Asia, which highlight the importance of cultural expectations on caregiving practices, especially that women are the primary caregivers for older adults as well as for children, studies from LMICs in Latin America also point out that, culturally, the family, rather than formal carers, is expected to be the primary caregiver for older relatives. A number of studies show that the cultural expectation is that women (daughters, granddaughters, daughters-in-law) are the primary care givers (Gomes & Montes de Oca 2004; de Oca Zavala, Sáenz *et al.* 2012; Lloyd-Sherlock, Mayston *et al.* 2018). The issue often becomes how responsibilities for caregiving roles for older relatives are negotiated and decided upon within wide family networks. A useful analytical framework for examining caregiving for aged adults in LMICs (as well as high-income countries) is therefore ‘bargaining’. A qualitative study conducted in Mexico and Peru examined processes of family bargaining related to care (Lloyd-Sherlock, Mayston *et al.* 2018). It concluded that care arrangements were strongly framed by cultural norms for both men and women. Interestingly, this study found that in cases where men were identified as the main carer, this was related to having authority and overall responsibility (e.g. organising care and financial resources) rather than provision of hands-on help with daily activities. Significant as the burden of taking organisational responsibility may be, it is nevertheless different from direct care provision, which is often seen as an extension of domestic work and therefore the domain of female members of the family. The other important finding of this study is that, when it came to bargaining, care dependent people appeared to have little involvement in decision-making about their care. As the authors point out, care dependent older people may lose status and power as they become dependent, which is arguably the time when they are most in need of power and influence.

Another issue in assessing the state of care provision in LMICs, is care for people affected by particularly debilitating conditions, such as dementia and stroke. Researchers have drawn attention to the fact that knowledge about dementia across a significant part of the population in many LMICs is limited. They point out that a number of misconceptions (e.g. that dementia is a normal and inevitable part of the process of ageing) persist. Moreover, lack of knowledge about the condition often results in stigma being attached to it (Brainin, Teuschl *et al.* 2007; Prince, Acosta *et al.* 2009; Prince, Brodaty *et al.* 2012; Cieto, Valera *et al.* 2014). Some authors mention that in India, for instance, the condition is often attributed to neglect by family members, abuse, and lack of love. Symptoms are often misinterpreted as deliberate misbehaviour on the part of the sufferer, and sufferers are frequently excluded from residential and hospital care. Families of dementia sufferers are also most likely to be financially disadvantaged as caregivers stop work in order to care (Prince, Acosta *et al.* 2008).

In recent years, policy makers and academic writers urge countries to launch public awareness campaigns that are adapted to their specific cultural contexts, and to increase knowledge about the conditions of children and young people (Prince, Acosta *et al.* 2008; WHO 2017d; Wright & O’Connor 2018; Cahill 2019). In addition, authors argue that media campaigns and education should be complemented with putting in place appropriate infrastructure for risk reduction and help seeking (Cations, Radisic *et al.* 2018). According to researchers, steps to improve care for dementia in LMICs need to focus on improvements in diagnosis, provision of information, regular needs assessments, and carer support. Emphasis should be placed on carer training and availability of respite care. Primary care teams should be at the centre of care

provision with emphasis on management of chronic conditions and community outreach. Care delivery should therefore be integrated with care for other chronic diseases and community-based support (Prince, Acosta *et al.* 2009).

Innovative Models of Care

The WHO report on LTC provision in sub-Saharan Africa (WHO 2017b) points out that, although organised provision of LTC is patchy in the region, there are still some emerging models in different parts of the region. Most organised care is provided in urban centres and two predominant models can be distinguished: charitable care for the most destitute older people (typically provided with few resources by faith-based, civil society or public welfare bodies); and private services for those able to pay, provided mainly in residential homes. Within this region, national efforts to develop LTC systems exist only in Mauritius, Seychelles and South Africa.

The report includes four examples of emerging innovative models (Kenya, South Africa, Ghana and Tanzania), led by non-governmental organisations (NGOs), community-based, or private sector bodies. In Ghana, the Care for Aged Foundation operates in an area with a disproportionately high number of neglected older people. The organisation provides individualised care plans based on initial assessments and developed in collaboration with the older people they serve and their families. Young people in the same community pay home care visits to older people to fulfil the care plan. The young carers work on a voluntary basis but they benefit from free health care at specific partner facilities. Services are resourced through cash and in-kind donations such as geriatric training, medical supplies and supervisory support. Currently, the organisation provides regular home visits to 160 people and health care, when required, to 400 people. Well-established donors provide the bulk of direct monetary aid. The organization has also formed alliances with educational and health care facilities and government authorities such as the Ministry of Health and Department of Social Welfare, as well as chiefs and traditional authorities in its geographic area of operation. Expansion of services beyond the existing geographical area would require substantial additional resources. Although the organisation is struggling to attract and retain volunteers because of its inability to offer payment, the example illustrates how organised home-care services can be provided in a manner that is culturally acceptable and integrated with the health care services.

In Kenya, a nursing agency is an example of how private companies are being formed to provide organised LTC services to those who can afford to pay for them or who have medical insurance that covers home-based care. The agency was formed in 2012 and provides professional services at clients' homes. It offers personal care, specialised home health care, nutritional advice, psychosocial support and disease management services. It employs approximately 140 personnel, half of whom are health professionals, the rest being patient attendants assisting clients with activities of daily living. Care plans are highly personalised and adapted over time. This example is illustrative of the type of good-quality, multidisciplinary, integrated and personalised long-term care that can be provided to those who have the resources to pay for it. This factor, however, substantially limits the number of people who can benefit from the services offered by this agency.

In South Africa, Rand Aid is a registered not-for-profit organisation in Johannesburg that serves a dual function: it provides a range of upscale retirement accommodation and long-term

care to older people who can afford it. This generates a source of income that is used to assist other older people in need. Residents in the residential villages buy the right to live in the village and their estates receive 80% of the initial purchase price on their demise. In addition, residents pay a monthly fee for services that are available to them, regardless of whether or not they use them. Services offered include 24-hour security, nursing care, garden and domestic services, physiotherapy and podiatry. Besides the residential properties, there are two LTC facilities. In one of these facilities, residents pay for their board and lodge in full. The other facility receives a small government subsidy but is funded mainly by the organization through a cross-subsidy of a portion of the 20% of the life rights purchase price. The LTC facilities offer multidisciplinary and personalized care by encouraging residents to be involved in their care planning and exercise autonomy in their day-to-day lives. The subsidised long-term care facility accommodates 180 older people in need of 24-hour nursing care.

In Tanzania, HelpAge International is implementing the Better Health for Older People in Africa programme in the country (2014 - 2017). The project, funded by the Department for International Development of the United Kingdom, aimed to improve access to home-based services for poor older people in need. The programme supports approximately 4,500 older people in four districts and is delivered by 425 trained volunteers who are supervised by registered nurses and clinical officers. Volunteers live in the area they serve and are selected in consultation with older people's fora and local community and health leaders. Care plans are developed in consultation with clients, and include assistance with activities of daily living such as eating, dressing, and bathing; bed sore management; medication assistance; companionship and support; and escorts to medical appointments. Clients have access to psychosocial support networks and programmes that enable them to socialise, prepare and eat meals together, discuss their health needs and learn from health workers about nutrition and exercise. This care model relies primarily on volunteers, with training, supervision and support financed by donors and local governments.

Another WHO publication included a detailed account of LTC policy direction in ten developing countries within the context of key socioeconomic and epidemiological indicators: China, Mexico, Costa Rica, Thailand, Republic of Korea, Lithuania, Ukraine, Indonesia, Lebanon, and Sri Lanka (Brodsky, Habib *et al.* 2003). The authors highlighted a number of broad trends emerging in developing countries. For instance, some countries made serious efforts to provide home-based LTC, including home health, personal care, and homemaking (Lithuania, Republic of Korea, Ukraine). Provision of home health was usually linked to the health system, especially primary care (Costa Rica, Republic of Korea, and to some extent China, Lithuania, Mexico, and Ukraine). Provision of family guidance was highly emphasised in some countries (Costa Rica and Republic of Korea). Personal care and homemaking services (where present) were targeted towards the very poor and those without families. Institutional LTC was provided more extensively in Lithuania and Ukraine, and to some extent in China, Lebanon, the Republic of Korea, and Sri Lanka. In the rest of the countries, publicly-financed institutional LTC was hardly provided. As in industrialised countries, service integration between the health and social systems was hardly evidenced in these countries. In some countries (Lithuania, Ukraine) the aim was to shift institutional LTC into community care. In countries such as Mexico, Sri Lanka, and Ukraine, NGOs were playing an important role in developing LTC. Volunteer participation was present in some countries, although not necessarily with appropriate training. The role of volunteers was emphasised in China,

Indonesia, Sri Lanka, and Ukraine, but training was provided only in Indonesia, Sri Lanka, and Ukraine. As regards level of training of LTC staff, there was a broad variation among these countries.

The role of volunteers in providing LTC is also the focus of a case study in East Java, Indonesia. According to this model, volunteer women assist in providing medical check-ups and organise peer groups for the elderly in three areas in East Java. The study found that community-based services were both accessible by and culturally acceptable to the care recipients. The authors highlight the importance of incorporating cultural and religious values in the care services and draw attention to the challenge of sustaining, let alone expanding, community care services that rely predominantly on volunteers for their provision (Pratono & Maharani 2018).

Another model that has emerged in some countries in East and Southeast Asia is that of Older People's Associations). A study of such associations was conducted in four countries (Cambodia, China, Myanmar, and Vietnam), funded by HelpAge International, Age International, WHO regional office of Western Pacific and the EU (Howse 2017). According to this study, despite model variations among countries, there are a number of common features which justify regarding them as instances of a single, community-based approach aiming at improving the wellbeing of older people and their communities in developing countries in the region. Their most salient features include: they are membership organisations that are led or managed by older people; they offer a number of activities or benefits across multiple domains, derived from limitations in state involvement, and lack of income security of many of the members; they offer help and support to the most vulnerable in the community; they act as advocates for the interests of older people at the local level; they depend on the ability and willingness of members to contribute time and resources to the organisation; they act as 'pressure groups' in demanding appropriate services from local authorities; they do not work in isolation from each other, but as part of a national network. This network has the task of campaigning for the support of policy makers in promoting the interests of older people.

DISCUSSION

Throughout the world, a convergence of socio-economic, technological, and demographic factors has led to an increase in ageing populations and the need for national governments to put in place appropriate systems of LTC provision for older people. Although the issue requires urgent action, it has not so far received due attention at the international or regional levels. As we saw in the previous sections of this report, both the WHO and HelpAge International acknowledge that the topic of ageing (which includes LTC provision for older adults) as a global exigency is still of relatively low priority amongst agents of international development (HelpAge International 2015; WHO 2017a). Providing appropriate LTC to older people raises many challenges in economically advanced countries, putting an added strain on existing welfare systems and increasingly featuring prominently in national public debates. The UK is an example of an advanced economy where the issue of financing care provision has recently been the focus of public debate (see BBC Panorama, *Who Cares*, 29 May 2019 at www.bbc.com). The problem is magnified in LMICs with significantly fewer resources and greater prevalence of deadly infectious diseases (e.g. HIV/AIDS, malaria), which, due to their more immediate urgency, tend to take precedence over LTC provision for older adults. In addition, scholarly research on the topic of LTC policy tends to focus disproportionately on

high-income countries, a bias which, according to one author, reflects ongoing neglect by policy makers (Lloyd-Sherlock 2014).

As we saw, international documents on care provision for the elderly take as a starting point the need to deliver care which maintains, as much as possible, older people's health, security and dignity (HelpAge International 2015). Although these dimensions of care are universal and should therefore apply to every care system across the world, this does not mean that there is only one care model which would fit all countries. The WHO *Strategy* acknowledges that there is no single system of LTC that can be applied in every country, not even those with similar resource constraints. It recommends that national long-term care systems be adapted to the specific economic and cultural contexts, taking advantage of existing health and social care delivery systems. The *Strategy* also emphasises that, in order to achieve an efficient and equitable system of long-term care, appropriate governance structures need to be put in place for overseeing development and monitoring progress. Governments need to play a crucial role in making sure that all the relevant components are in place, including a regulatory framework, training and support for carers, service co-ordination, and mechanisms for provider accreditation and monitoring of quality.

Although the *Strategy* is rich in ambitious goals, it contains limited information about concrete proposals on how these goals can be achieved across the world, especially in LMICs. Despite the *Strategy's* good intentions, it is difficult to assess the feasibility of the ambitious proposals contained in it, especially in contexts of multiple pressures which are facing the health care systems of developing countries (e.g. HIV/Aids, Ebola virus, limited resources). What is crucial in achieving these goals is country willingness to adopt them and compliance with implementing them. In the end, successful implementation of policies depends on commitment by national governments and willingness to create the required capacity on the ground (Van Langenhove & Kingah 2014). The hope is that documents such as the *Strategy* will serve as targets to which national governments can aspire. For governments willing to establish effective care systems for older adults, the *Strategy* provides comprehensive suggestions and guidelines.

Our review of the literature reveals that, despite its urgency, care provision for older adults is not a priority at the international or regional levels of public discourse and development. Applying a 'framing' analysis to the issue of global care provision shows that the prevailing 'frame' is that of human rights and moral reasoning. The rhetoric which sees care provision for older people as a universal human right, laudable as it is in itself, does not effect adoption of adequate care provision by national governments. As various authors point out, human rights depend on political will and government legislation to enshrine and protect them. One of the main problems with using the human rights paradigm in global health policy is that effective international legal mechanisms for enforcing human rights are still to be realised (Austin 2001).

In addition, even where national governments seem to be making genuine attempts at introducing adequate systems of LTC for older people, LMICs often rely on foreign aid for the success of such attempts. Given the increasing pressures for care provision for older adults that ageing populations create in high-income countries, however, the governments of such countries may find it difficult to rely solely on the human rights paradigm to convince their electorates of the desirability of allocating funds to care provision for older adults abroad. An emphasis on the 'investment' frame (pointing to new possible economic opportunities and

markets for donor countries), together with the social justice paradigm, may be easier to sell to the electorates of major donor countries.

Even in developed countries, adequate long-term care provision for older adults is often lacking. The US is a case in point, where an absence of an overall vision of what LTC ought to be seems to be the norm and an over-emphasis on institutional as opposed to the patient-preferred options for home and community-based alternatives prevails (Miller, Booth *et al.* 2008). In many LMICs the issue of care for older adults has not yet been put on the social policy agenda. In many such countries the family (especially female members) is still the primary caregiver. With demographic and socio-economic changes, however, such countries will have to make serious efforts to put in place national care systems. As with developed countries, LMICs countries will need to prioritise the aspects of care provision expected to be most efficient in their individual cultural contexts (Howse 2007). For instance, national governments, especially in resource-challenged countries, will need to be convinced that prioritising prevention and putting in place integrated health and care systems are likely to be more cost-effective steps, compared with existing practices. Some INGOs have increasingly been arguing for the necessity of shifting the emphasis from the moral to the economic paradigm of care delivery for older people, especially in LMICs (HelpAge International 2017).

It is encouraging that a number of innovative models exist from an array of LMICs. Such models should be supported and expanded nationally (or internationally), since not only are they adaptations to the prevailing cultural practices of the countries in which they emerge, but they can also serve as examples which could provide solutions to the care pressures in high-income countries. Elder-to-elder care or the emergence of Older People's Associations are only two of many such examples of models that have the potential to be expanded. It is often pointed out that, while people who need care are by definition dependent on their caregivers, they also tend to be the least consulted about the nature of their care. It is important that care provision (be it informal or formal) becomes person-centred as far as possible. As we saw, some researchers draw attention to the need to move away from care facilities which operate like 'total institutions' where residents are less connected to the wider society and their individuality is being ignored (Wang, Wang *et al.* 2018). Care institutions should instead focus on providing a range of social activities (both within and outside the facility) and educational programmes that will contribute to maintaining residents' autonomy, and enable them to manage chronic diseases more effectively.

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