

Barriers to linking research and policy: the case of long-term care in low and middle income countries

Peter Lloyd-Sherlock¹

Abstract: This paper sets out a number of issues related to the translation of research into evidence and policy for long-term care (LTC) in low and middle income countries (LMICs). First, it assesses the role research can play in problem definition, including establishing the scale of long-term care demand in LMICs and identifying potential negative consequences of policy inaction. Second, it assesses the role that research can play in identifying and evaluating solutions to the problem, in the form of suitable policies and interventions. Lastly, it assesses mutual accessibility between researchers and policy-makers, paying particular attention to institutional and organisational structures. Applying this framework, the paper demonstrates that the capacity for research to influence long-term care policy is very limited. The paper calls for the establishment of an adequately resourced global institutional hub to support research in this area and to promote knowledge-sharing between academics and policy-makers.

Keywords: Research, long-term care, policy, problem-definition

DOI 10.1515/pophzn-2015-0010

Received 3 September 2015, accepted 9 December 2015

The role of academic research in problem definition

Problem definition is a critical phase in all policy processes (Dery, 2000). More often than not, this does not occur in an entirely neutral, objective and scientific manner. Whilst academic research may play a role in this process, it is usually framed by other effects, including media representations, public attitudes and political considerations (Kingdon, 1984). Academic research does not itself occur in a value-free space. For example, it is strongly influenced by the research funding priorities of non-academic organisations.

Over the past 20 years or so, academic research has, alongside the actions of non-academic organisations, successfully established population ageing as an issue requiring concerted public action in LMICs (UN Population Division, 2013). Studies measuring, estimating, projecting and analysing demographic

ageing abound, and these are mirrored by a rapid growth in the volume of policy literature. Despite this, academic studies and scientific evidence relating to the consequences of population ageing for long-term care in LMICs remain very scarce. The only available estimate for current and future long-term care needs at the global level and for developing regions was published by the World Health Organisation in 2002, based on 1990s data (WHO, 2002). Though better than nothing, the WHO estimate is derived from a simplistic calculation based on various indirect indicators of care demand. This limits its usefulness and credibility for both academics and policy-makers.

In the absence of robust evidence, it is often assumed that there is a simple and direct relationship between population ageing and care dependency. This is embodied in widely-accepted indicators such as the parent support ratio, which is entirely based on assumptions about care dependency at different ages (UN Population Division, 2002). The limited available

*Corresponding author: p.lloyd-sherlock@uea.ac.uk

¹ University of East Anglia, School of International Development

evidence for age-specific functional status shows the weakness of this quick and dirty approach to estimating old-age care needs. Table 1 shows large national variations in levels of reported disability for people aged 70 and over in LMICs. For example, the proportion reporting difficulties with mobility ranged from 40 per cent in China to 86 per cent in the Russian Federation. These findings are broadly in line with comparative studies of high income countries, which also report large national variations (Lafortune et al., 2007). The temporal relationship between population ageing and increasing demand for LTC is not necessarily direct, as the functional status of a given age group can change over time. For example, there is evidence of some improvements in the functional status of older adults in China between 1998 and 2008 (Feng et al., 2013).

Nationally representative longitudinal data on age and function are not available for most LMICs. Consequently, it is not possible to estimate or project levels of current or future demand for LTC with confidence. Where they do exist there are sometimes large disparities in national estimates of long-term care needs, especially in LMICs (Lloyd-Sherlock, 2016). These differences arise because there is not a universally agreed definition of care dependency nor how to assess it. This lack of statistical precision represents an important barrier to establishing and defining the problem of long-term care in these countries, since policy-makers usually have a strong preference for, and are heavily influenced by, apparently reliable “hard numbers” (Allen et al., 2000). There is, therefore, a clear need for credible estimates of current and future long-term care needs based on robust scientific methods. This will provide an essential platform for policy action on these issues.

At the same time, academics need to play a more effective role in defining what long-term care

actually is and how it should be best understood by policy-makers. LTC is a complex concept and relates in different ways to a range of policy fields, including chronic disease management, geriatric health, rehabilitation and social work. Sometimes the term LTC is used inter-changeably with other ones, such as “social care” (Ismail, Thorlby and Holder, 2014). While there may be good reasons for different approaches and emphases, it is essential that academics apply clear parameters to establish a defined field of concern and action for policy-makers.

Table 1 also indicates considerable scope for reducing age-specific care dependency through interventions that enhance lifelong health and functional status, and there is evidence that China has achieved this to some extent (Feng et al., 2013). In other words, it is possible to frame the LTC problem in a more positive, proactive light (with reference to prevention and health promotion) instead of a negative, reactive one (responding to need and minimising financial liability). The fact that LTC remains framed almost entirely negatively by policy-makers points to a failure of academics to convey this important message.

Academic research can also contribute to LTC problem definition by assessing the extent to which current needs are already being met and prospects for the future. Here again, the availability of academic evidence is very limited, often leading to stylised assumptions and extrapolated claims. The evidence falls into two categories. First, there are indirect indicators of the capacity and predisposition of different societies to provide care. These look at a range of trends including reduced fertility rates, increased female participation in paid work and growing population mobility. Whilst we have reliable data on these trends for most LMICs, there is less complete information on their consequences for the willingness and availability of family members to

Table 1. Disabilities for population aged 70 or over, 2007-10 (% of total population).

	Any disability (%)	Difficulty moving around (%)	Difficulty with self care (%)	Difficulty with cognition (%)
China	85.4	40.4	19.7	68.0
Mexico	79.7	54.3	31.3	54.6
Russia	98.1	85.6	56.4	74.7
South Africa	86.0	51.7	24.8	67.6

Source: He et al. (2012).

provide care. The limited evidence is usually derived from small qualitative studies which do not lend themselves to wider generalisation. Moreover, these studies often reveal that the effects of these wider social trends on the provision of care are nuanced, and vary across groups and contexts (Aboderin, 2004; Kreager and Schröder-Butterfill, 2015; Gomes da Conceição and Montes de Oca Zavala, 2004). The complex relationships identified in these studies are not easily translated into clear policy messages, and run up against an established bias of policy-makers towards supposedly more authoritative quantitative evidence. In the absence of evidence about the effects of social trends on care-giving, there is a tendency for policy-makers to fall back on generalised assumptions about enduring cultural norms of intergenerational support and family solidarity.

The second way to assess how far current LTC needs are being met is by directly mapping patterns of formal and informal care provision. Here, the evidence is very limited, especially for poorer countries. The lack of data both results from and reinforces limited academic research. In terms of formal care services, there are several reasons why information is so scarce. First, most LMIC governments have a relatively minor role as direct formal LTC providers, with services provided mainly through NGOs, as well as private and religious organisations. Monitoring and regulation of these service-providers is often very limited and the information obtained is rarely complete or reliable (Phillips and Chan, 2002; Redondo and Lloyd-Sherlock, 2009). Second, there is considerable institutional fragmentation of responsibility for managing and overseeing LTC, which acts as a barrier to data collection. This includes confusion between the roles of mainstream health-service providers (who are sometimes *de facto* formal LTC providers of last resort) and various social service agencies. It also includes a tendency for states to administer and oversee LTC services at the local government level. Data management tends to be weaker at this level than at national government level, and there is evidence that formal care provision varies markedly across different local governments (Camarano et al., 2010; Cheung Wong and Leung, 2012). This makes it very difficult to provide a reliable national picture.

Obtaining credible evidence about the quality and quantity of informal LTC is equally challenging. Few established household surveys in LMICs include items that refer to these forms of care-giving.

Also, eliciting reliable information about family care-giving practices is highly problematic, since responses (especially to quantitative surveys) are strongly influenced by cultural norms of acceptable behaviour (Yanxia Zhang and Yeung, 2012; Sinunu et al., 2009). Put simply, household members will not necessarily admit to themselves, let alone to an outsider, that the care they provide is inadequate. Likewise, dependent older people may find reporting poor family care is stigmatising or, if family members are present in the interview, unsafe. Without recognising and overcoming these challenges, it is likely that surveys will significantly understate the failings of informal LTC. This plays into the default policy discourse of enduring family solidarity.

To summarise, the role of research in problem definition has been very limited. In part, this is due to a lack of routinely collected data for academics to work with, as well as the low priority given to this issue by funding agencies. This is reflected in the limited volume of available research in LMICs. A comprehensive review of published studies on LTC found that only 6 per cent were focussed on LMICs, the countries which contain two-thirds of the world's older population (Lloyd-Sherlock, 2014).

Putting the limited and fragmentary evidence (including more anecdotal sources such as media reports) together, there are indications of a large and growing gap between need for LTC and the provision of adequate services. There are also indications of the harmful consequences of policy-makers failing to take action (another key part of the problem definition process). These include a growing body of studies which identify high levels of stress experienced by mainly female family carers (Prince et al., 2012). By contrast, there have been almost no studies quantifying the effects of policy inaction on areas such as unnecessary hospitalisations.¹ Most notably, there is very little research on the consequences of policy inaction on dependent older people themselves, in terms of quality of life, exposure to abuse and preventable mortality.

¹ One exception to this is a 2001-2007 survey of hospital inpatients aged 60 and over in Rio de Janeiro, which found that 2,260 had been in hospital for over a year. Of these, around a quarter were recorded as being in hospital due to a lack of family support (Romero et al., 2010).

The role of academic research in identifying and evaluating suitable policies and interventions

In the research-policy nexus, finding good solutions is just as important as identifying problems. To be attractive to policy-makers, these solutions should be easily understood, demonstrably affordable and based on evidence of effectiveness in similar settings. These interventions are often validated or even championed by international agencies, such as the World Bank or large NGOs. This has been the case in other areas of social policy related to older people, such as the extension of non-contributory social pensions. However, the prospects for identifying comparable “solutions” to the LTC “problem” are much less promising.

First, there is little consensus about effective LTC policy and good practice in high income countries. Within these countries there has been a general shift away from directly state-run residential services towards more pluralistic forms of provision with an emphasis on care in the community (Colombo et al., 2011). There is also some consensus about the usefulness of new concepts such as “ageing in place” and “person-centred care” (Morley, 2012). However, patterns of formal care provision are highly diverse, and in all countries there are concerns about both the fiscal sustainability of current arrangements and their effectiveness in delivering adequate services. As such, policy-makers in LMICs are less inclined to see high income countries as a point of reference for suitable policy models compared to other areas of public policy, such as pensions. This reluctance to engage with western models is reinforced by the view of many LMIC policy-makers that their own cultures are inherently more caring and based on solidarity. Indeed, they sometimes see the extension of formal care services in western countries as undermining family solidarity by letting relatives off the hook. Regardless of the validity or otherwise of these cultural depictions, this misses the point that high income countries do offer a range of useful LTC policy lessons, both in terms of what to do and what not to do. Indeed, the diversity of high income country experiences extends the range of available evidence that can be applied to other settings.

Second, institutional fragmentation of the provision and oversight of LTC in individual countries

hinders both the sharing of interesting examples of policy experimentation among policy-makers and feeding these examples back to academics. Faced by these obstacles to directly access to policy experience, academics may prefer to focus on other issues. These barriers to feeding back lessons from policy on the ground reduce the evidence base from which researchers can formulate solutions and evaluate practice. This is reinforced by a general lack of research funding for developing solutions tailored to the needs of LMICs and for sharing these experiences.

Mutual accessibility between researchers and policy-makers.

Engagement and effective dissemination play a key role in translating academic insights into policy action. This requires mutual accessibility between the two fields, but opportunities for such engagement are very limited for LTC in LMICs.

One critical gap is the marginal interest that potentially influential international organisations take in this issue. In the late 1990s, the World Health Organisation established a global programme of LTC research, which generated a number of outputs, but this was discontinued after 2002 and is only now being reinstated (WHO, 2002; Brodsky, Habib and Hirschfeld, 2003a; Brodsky, Habib and Hirschfeld, 2003b). The OECD has an ongoing programme on the financing and quality of LTC, but this is primarily focussed on high income countries (OECD, 2011; Lafortune et al, 2007; OECD, 2005). Among international development agencies, concerns about income poverty and development finance have led to a strong focus on the provision of pensions and social protection (Lloyd-Sherlock, 2010).

By contrast, international development agencies have almost nothing to say about LTC issues and have paid more attention to the role of older people as carers for other family members with HIV/AIDS than to care for older people themselves (IFRC, 2005). The lack of interest among international agencies in this issue is critical because of the key role these organisations play as bridges between academic research and policy thinking. Put simply, most policy-makers do not read academic journals and few academics have close, continual engagement with policy-makers. Unless this critical gap is addressed, the scope for linking research to policy and for comparing national experiences will remain constrained. WHO’s new report on ageing and

health makes a small step to addressing this challenge, by including a dedicated chapter on ageing and social care (WHO, 2015). Also in 2015, ILO published a report on the long-term care workforce (Scheil-Adlung, 2015). To build on these limited developments, this paper calls for the establishment of an adequately funded global institutional hub to support research in this area and policy learning.

Currently, there are no strong networks of academics with shared interests in LTC in LMICs. Researchers work in different disciplines, publish in different journals and, largely, attend different conferences. One potential exception to this is the International Long Term Care Policy Network, organised jointly by the London School of Economics (LSE) and the University of Kent. This group organises regular international conferences, but participation in the network is almost exclusively limited to researchers interested in high income countries. An underlying reason is that the volume of academic research on these issues in LMICs falls well short of the critical mass necessary for more coordinated networks, such as a specialist journal or conference events. Establishing a global institutional hub could play a helpful role in kick-starting this interaction.

Finally, the institutional fragmentation of policy responsibility for LTC, as described earlier in this paper, acts as a further barrier to linking with academic research. First, it is often unclear with whom academics should be engaging. In the absence of a single authority, effective engagement requires working with multiple, poorly integrated stakeholders located within different agencies, locally and nationally. Few academics have the resources or patience to do this.

Concluding comments

Meeting the growing demand for LTC represents a major and growing policy challenge for all countries, be they high, middle or low income. In LMICs, it is a relatively recent phenomenon and policy-makers lack obvious models or frames of reference. Theoretically, this should represent both a need and an opportunity for academic researchers to exert influence over policy-making. In practice, academic research on these issues remains limited and there are substantial barriers to engagement with stakeholders. This encourages policy-makers to fall back on generalised assumptions (such as the inherent strength of family networks) and

to prioritise other issues. Researchers have made little progress in persuading policy-makers in LMICs that LTC is a public, as well as a private, issue. Nor have they sufficiently demonstrated the consequences of policy inaction, including the exploitation of unpaid family carers, harm to older people and the economic costs of avoidable hospitalisation. In the absence of strong research engagement, for many countries LTC policy remains a low priority, evidence-free zone.

References

- Aboderin, I. (2004). Intergenerational family support and old age economic security in Ghana. In: P. Lloyd-Sherlock (Ed.) *Living longer: Ageing, development and social protection*. London: Zed Books/United Nations Research Institute for Social Development.
- Allen, M., Bruflat, R., Fucilla, R., Kramer, M., McKellips, S., Ryan, D., & Spiegelhoff, M. (2000). Testing the persuasiveness of evidence: Combining narrative and statistical forms. *Communication Research Reports*, 17(4):331-336.
- Brodsky, J., Habib, J., & Hirschfeld, M. (2003a). Key policy issues in long-term care. Geneva: World Health Organisation.
- Brodsky, J., Habib, J., & Hirschfeld, M. (2003b). Long-term care in developing countries: Ten case studies. Geneva: World Health Organisation.
- Camarano, A., Kanso, S., Leitão e Mello, J., & Fernandes Carvalho, D. (2010). As instituições de longa permanência para idosos no Brasil [*Long-term care facilities for the elderly in Brazil*]. In: A. Camarano (Ed.) *Cuidados de longa duração para a população idosa: Um novo risco social a ser assumido?* [Long-term care for the elderly population: A new social risk to be faced?] Rio de Janeiro: IPEA (Instituto de Pesquisa Econômica Aplicada/Institute for Applied Economic Research).
- Cheung Wong, Y., & Leung, J. (2012). Long-term care in China: Issues and prospects. *Journal of Gerontological Social Work*, 55(7):570-86.
- Colombo, F. et al. (2011). Help wanted? Providing and paying for long-term care. Paris: OECD Publishing.
- Dery, D. (2000). Agenda setting and problem definition. *Policy Studies*, 21(1):37-47.
- Feng, Q., Zhen, A., Gu, D., Wu, B., Duncan, P., & Purser, J. (2013). Trends in ADL and IADL disability in community-dwelling older adults in Shanghai, China, 1998-2008. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 68(3):476-485.
- Gomes da Conceição, C., & Montes de Oca Zavala, V. (2004). Ageing in Mexico: Families, informal care and reciprocity. In: P.Lloyd-Sherlock (Ed.) *Living longer: Ageing, development and social protection*. London: Zed Books/United Nations Research Institute for Social Development.
- He, W., Muencrath, M., & Kowal, P. (2012). Shades of gray: A cross-country study of health and well-being of the older populations in SAGE countries, 2007-2010. Washington DC: United States Census Bureau.

- IFRC: International Federation of Red Cross and Red Crescent Societies (2005). HIV/AIDS in southern Africa takes toll on grandparents caring for orphans. 13 July 2005, accessed 1 September 2015 <http://www.ifrc.org/en/news-and-media/news-stories/africa/south-africa/hiv-aids-in-southern-africa-takes-toll-on-grandparents-caring-for-orphans/>
- Sharif Ismail, Ruth Thorlby and Holly Holder (2014) Focus on: social care for older people. Reductions in adult social services for older people in England. London. The Health Foundation and the Nuffield Trust http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/140326_qualitywatch_focus_on_social_care_older_people_0.pdf
- Kingdon, J. (1984). *Agendas, alternatives, and public policies*. Boston: Little, Brown. 240p.
- Kreager, P., & Schröder-Butterfill, E. (2015). Differential impacts of migration on the family networks of older people in Indonesia: A comparative analysis. In: L. A. Hoang & B. Yeoh (Eds.) *Transnational labour migration, remittances and the changing family in Asia*. London: Palgrave MacMillan.
- Lafortune, G., & Balestat, G. (2007). Trends in severe disability among elderly people: Assessing the evidence in 12 OECD countries and the future implications. *OECD Health Working Papers*, no.26. Paris: OECD Publishing.
- Lloyd-Sherlock, P. (2010). Ageing and international development. In: D. Dannefer & C. Phillipson (Eds.) *The SAGE handbook of social gerontology*, pp.379-388. London: Sage Publications.
- Lloyd-Sherlock, P. (2014). Beyond neglect: Long-term care research in low and middle income countries. *International Journal of Gerontology*, 8(2):66-69.
- Lloyd-Sherlock, P. (2016) Managing the 'cost' population ageing in low and middle income countries: health and social care. In UNFPA Investing in an ageing world. UNFPA, forthcoming.
- Morley, J.E. (2012). Aging in place. *JAMDA: Journal of the American Medical Directors Association*, 13(6): 489-92.
- OECD: Organisation for Economic Cooperation and Development (2005). Ensuring quality long-term care for older people. *OECD Observer Policy Brief*, March 2005.
- Phillips, D., & Chan, A. (2002). National policies on ageing and long-term care in the Asia-Pacific: Issues and challenges. In: D. Phillips & A. Chan (Eds.) *Ageing and long-term care: National policies in the Asia-Pacific*, pp.1-22. Singapore: Institute of Southeast Asian Studies and Ottawa: International Development Research Centre.
- Prince, M., Brodaty, H., Uwakwe, R., Acosta, D., Ferri, C.P., Guerra, M., Huang, Y., Jacob, K.S., Llibre Rodriguez, J.J., Salas, A., Sosa, A.L., Williams, J.D., Jotheeswaran, A.T., & Liu, Z. (2012). Strain and its correlates among carers of people with dementia in low-income and middle-income countries. A 10/66 Dementia Research Group population-based survey. *International Journal of Geriatric Psychiatry*, 27(7):670-682.
- Redondo, N., & Lloyd-Sherlock, P. (2009). Institutional care for older people in developing countries: Repressing rights or promoting autonomy? The case of Buenos Aires, Argentina. *Journal of Population Ageing*, 2(1-2): 41-56.
- Romero, D., Marques, A., Barbosa, A., & Sabino, R. (2010). Internações de idosos por cuidados prolongados em hospitais do SUS no Rio de Janeiro: Uma análise de suas características e da fragilidade das redes sociais de cuidado. In: A. Camarano (Ed.) *Cuidados de longa duração para a população idosa: Um novo risco social a ser assumido?* [Long-term care for the elderly population: A new social risk to be faced?] Rio de Janeiro: IPEA (Instituto de Pesquisa Econômica Aplicada/Institute for Applied Economic Research).
- Scheil-Adlung, X. (2015) Long-term care protection for older persons: A review of coverage deficits in 46 countries. Extension of Social Security Working Paper No.5. ILO, Geneva.
- Sinunu, M., Yount, K.M., El Afify, N.A. (2009). Informal and formal long-term care for frail older adults in Cairo, Egypt: Family caregiving decisions in a context of social change. *Journal of Cross-cultural Gerontology*, 24(1): 63-76.
- UN Population Division (2002). World population ageing: 1950-2050. New York: United Nations Publications. <http://www.un.org/esa/population/publications/worldageing19502050/> accessed 6. August 2015.
- UN Population Division (2013). World population ageing 2013. New York, United Nations. <http://www.un.org/en/development/desa/population/publications/pdf/ageing/WorldPopulationAgeing2013.pdf> accessed 5 August 2015.
- WHO: World Health Organisation (2002). A long-term care futures tool-kit; pilot edition. Geneva, WHO and Washington, DC: Institute for Alternative Futures. <http://www.who.int/chp/knowledge/publications/ltctoolkit/en/> accessed 5 August 2015.
- WHO (2015). *World report on ageing and health*. WHO, Geneva.
- Yanxia Zhang, W.-J., & Yeung, J. (2012). Shifting boundaries of care in Asia: An introduction. *International Journal of Sociology and Social Policy*, 32(11/12): 612-32.