Would reframing aged care facilities as a 'hospice' instead of a 'home' enable older people to get the care they need?

Authors:

Phillips, J.L.
Professor Nursing (Palliative Care)
Director Centre for Cardiovascular and Chronic Care
Faculty of Health, University of Technology Sydney
Sydney, NSW, Australia

Currow, D.C.
Professor of Palliative and Supportive Services,
Palliative and Supportive Services,
Flinders University,
Daw Park, SA, Australia

Correspondence:

Phillips, J.L.
Professor Nursing (Palliative Care)
Director Centre for Cardiovascular and Chronic Care
Faculty of Health, University of Technology Sydney
Sydney, NSW, Australia

'Home' is a concept that is central to our sense of self. It is about belonging and having an environment that is uniquely one's own, reflecting one's personality and provides security (Collier, Phillips, & Iedema, 2015). In hospice and/or palliative care, the concept of 'home' is important to many people in terms of where their care is provided and, for some, also where they actually die (Agar et al., 2008). Most people indicate that institutional care beyond an acute illness is a less preferable place of care and that they ideally want to spend as many days as possible at home. Whilst spending as many days at home is desirable, it is not always possible, especially in the context of advanced age, dementia and/or fragility. With the current policy emphasis on supporting people to remain at home, the transition to permanent care typically occurs once all possible options have been exhausted. This policy reform has markedly decreased the average length of residential care stay in the last two decades (Australian Institute of Health and Welfare, 2015).

Given the need to match the place of care with the provided care, many older people who cannot return home are often discharged from hospital to a residential aged care facility for the last weeks of their life. It would be inappropriate for them to stay in a high acuity medical facility when residential aged care better matches their current care needs. However, can this now be called their 'home'? Given their decreasing energy and engagement with the world around them, there is little or no opportunity for these older people to make the transition and even start to identify this as their 'home'. This is in contrast to someone who has made the transition to care in a skilled nursing facility from a community care setting, is admitted to an acute care facility, and returns to the skilled nursing facility. For this person, care at the end of life may well be seen as care at 'home'.

However, the number of older people who now live for the longer term in residential aged care is diminishing. Whereas, once the transition to a hostel or nursing home was predominately driven by an individual's social welfare needs (Angus & Nay, 2003), today's admissions to permanent care is driven by older people's complex medical, nursing, social and behavioural care needs. Consequently, most people admitted to an aged care facility will remain there until they die, and require increasingly intensive nursing care as death approaches (Phillips, Davidson, Kristjanson, Jackson, & Daly, 2006). Given the acuity and complexity of the health of these older people, many of whom are living with several comorbidities, fragility and advanced dementia, is it appropriate or useful to persist in referring to residential aged care facilities as 'home'?

We contest that an Australian residential aged care facility in 2016 has never looked less like a home. Referring to it as a resident's 'home' is outdated and may inadvertently restrict this vulnerable population's access to the expert nursing and medical care they require. An older person's transition to a skilled nursing facility is also a change in in their official residence. While this address change may be considered by the community and many people living in these facilities to be 'home', in reality, there is little that is homelike about these facilities other than the interior décor, which is increasingly more akin to a hotel chain than a 'home'.

Until the introduction of the 1997 legislation, the division of labour in aged care facilities resembled a Victorian household. The resident was relegated to the role of child; the direct care workers providing invisible downstairs help; the registered nurses were the up-stairs servants; the director of nursing the woman of the house; and the GP the head of the household (Game & Pringle, 1983) However, since the repeal of the legislation mandating registered nurse to resident ratios, the number of registered nurses employed in aged care has been dramatically reduced. At the same time, the number of less skilled and unregulated direct care workers has escalated, as have the needs of the older people living in these

facilities (Australian Institute of Health and Welfare, 2014, 2015). As a consequence, the bulk of direct care is now provided by the unskilled section of the aged care workforce, who are least educated and prepared to deal with the challenging behaviours and complex care that many older people living with comorbidities and advanced dementia now require. An unintended consequence of population aging is that the Australian aged care workforce has become a major provider of aged-palliative care, which will only increase in coming years. As palliative care demands a skilled response, this has major implications for the configuration of the aged care workforce and for funding the provision of aged-palliative care services. If residential aged care is truly a 'home, would the most vulnerable members of the household be left afterhours with the household staff least able to meet their complex care needs?

If an institution providing nursing care can no longer be called 'home' for the elderly, more specifically in the context of providing hospice level care, consideration of the language used to describe these facilities for a specific group of people is required. These people are typically older, frailer and admitted to an acute care facility with a change in clinical condition, which once stabilised, achieve acceptable symptom control but are on an increasingly steep trajectory of physical decline. Their need for physical care cannot be met in a community setting, often because of either a lack of a resident caregiver (Gill, Laporte, & Coyte, 2011) or the frailty of the people who would want to provide their care.

To persist in calling an aged care facility a 'home' makes it difficult for aged care workers to provide the level of care required by these older, frailer Australians. It also perpetuates the status quo that ensures the aged care accreditation standards are not reflective of the palliative care needs of older people living with a life-limiting illness, such as advanced dementia. It also ensures that funding allocated to aged care is not commensurate with residents complex aged-palliative care needs.

As governments and other funding agencies focus more on place of death, pretending that this is a validated marker of excellence in end-of-life care, there is a need to be cautious about automatically labelling a death in a residential aged care facility as a community or 'home' death. Were we to ask people in this circumstance, it is not clear that they would see these facilities as 'home' in any sense in which we use the term.

If we acknowledge that aged care 'is a place of rest for a traveller on an arduous journey', then we could stop pretending that these permanent care facilities are residents' homes, and rename, and staff and fund them as hospices. Instigating this level of reform would enable the aged care sector to be reconfigured to provide the type of care that our most vulnerable elders need, that is aged-palliative care services. Referring to aged care facilities as hospices, would also send a clear message to the public as to the role of these facilities and address expectations about the level and type of care they can expect and demand.

References

- Agar, M., Currow, D. C., Shelby-James, T. M., Plummer, J., Sanderson, C., & Abernethy, A. P. (2008). Preference for place of care and place of death in palliative care: are these different questions? *Palliative Medicine*, 22(7), 787-795.
- Angus, J., & Nay, R. (2003). The paradox of the Aged Care Act 1997: The marginalisation of nursing discourse. *Nursing Inquiry*, 10(2), 130-138.
- Australian Institute of Health and Welfare. (2014). *Palliative Care Services in Australia* 2014. Retrieved from Canberra: no URL?

- Australian Institute of Health and Welfare. (2015). Residential Aged Care and Home Care 2013–14. Retrieved from http://www.aihw.gov.au/aged-care/residential-and-home-care-2013-14/#toc
- Collier, A., Phillips, J. L., & Iedema, R. (2015). The meaning of home at the end of life: A video-reflexive ethnography study. *Palliative Medicine*, 29(8), 695-702.
- Game, R., & Pringle, D. (1983). Sex and power in hospitals: the division of labour in the 'health' industry. In R. Game & D. Pringle (Eds.), *Gender at work*, Sydney, Australia Allen and Unwin
- Gill, A., Laporte, A., & Coyte, P. C. (2011). Predictors of home death in palliative care patients: a critical literature review. *Journal of Palliative Care*, 29(2), 113-118.
- Phillips, J., Davidson, P. M., Kristjanson, L. J., Jackson, D., & Daly, J. (2006). Residential aged care: The last frontier for palliative care. *Journal of Advanced Nursing*, 55(4), 416-424.