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palliAGED Aged Care Standards Insight

February 2020

Living well until death

Professor Jennifer Tieman

As we age, we naturally approach death. An ageing population means that there is an increasing rate of dying in older age, which is reshaping our understanding of the older person's needs and implications for care delivery at the end of life. The changing nature of disease patterns is also affecting how we die as older Australians. Coronary heart disease, dementia, cerebrovascular disease, COPD, and lung cancer are the leading causes of death for older Australians. [1] With age, the likelihood of multimorbidity also increases. Many older people will use aged care services before they die and the longer we live the more likely it is that we will.

What matters to older people

A number of studies of consumer experience and literature reviews have shown that older people want to stay as independent as possible and reside in their home where they have connections to family and friends. They also want to be cared for by those who have a positive attitude and the personal attributes to work with older people, as well as appropriate skills to undertake the work required. [2,3] Even though a person might have some challenges in their health and abilities, they will still have goals that matter, roles and activities that have meaning for them, and the desire to manage their day-to-day life and live as well as they can. This is also true when an older person is coming to the end of life.

A recent qualitative study in Denmark explored what matters to both seriously ill and well older people at the end of life. What mattered to them was being independent and having autonomy; being able to talk about death, dying, and their wishes regarding treatment at the end of life; and living with and managing the chronic illnesses that affected their everyday life. [4] The importance of such personal control was highlighted in a systematic review on dignity, autonomy and control at the end of life. This study found that a person's perceived dignity at the end of life is related to their sense of autonomy and ability to control physical functions and their immediate surroundings. [5] Houska & Loucka's critical review of autonomy at the end of life also noted the importance of "being in charge" and "being normal" as fundamental domains of autonomy. [6] Therefore, as well as facilitating end of life discussions and decisions, we need to consider what are the appropriate supports and services we should be providing that enable people to continuing participate even as they approach death.

How can we support dignity, autonomy, and wellbeing?

While functional decline can be anticipated for people with life-limiting illnesses, the trajectories can differ in shapes and patterns. An analysis of Australian data showed that the pattern of functional decline for the neurological

and dementia cohorts is flatter, showing a prolonged period of low function. [7] This suggests that care needs of older people associated with end of life will need to be addressed over a longer period.

We need to recognise that loss of function, increasing dependence, and a feeling of being a burden may erode the person's sense of self. Therefore, promoting their sense of control and independence and helping them to manage a changing physical body can be powerful. Re-enablement strategies, equipment, and training can all help maintain function and support a continuing sense of accomplishment and contribution in daily living. More broadly, meaningful activities that provide occupation and promote social engagement are necessary. Without these, there are risks of a deep loneliness that older people report arises from a sense of meaningless waiting, a longing for a deeper connectedness, and restricted freedom. [8]

A multidisciplinary approach to care for an older person at the end of life can help to ensure that a comprehensive plan is in place to address not only physical but psychosocial, community, and spiritual needs. This can include referral to specialist services, provision of equipment that enables continuing functional activity and engagement, and workforce strategies that build an understanding of the importance of autonomy and independence for older people at the end of life.

References:

1. Australian Institute of Health and Welfare (AIHW). Older Australia at a glance [Internet]. 2018 [updated 2018 Sep 10; cited 2019 Jan 22].

2. Wells Y, Hillel S, Hunter N, Clune S, Johnstone E, Quintanilla B. Literature review on choice and quality in home-based and community-based aged care. Report for the Australian Aged Care Quality Agency (1.12MB pdf). Melbourne: La Trobe University; 2018.

3. Irlam C. PROJECT REPORT: Measuring Quality and Consumer Choice in Aged Care. Barton (ACT): COTA; 2018 Sep.

4. Hanson S, Brabrand M, Lassen AT, Ryg J, Nielsen DS. What Matters at the End of Life: A Qualitative Study of Older Peoples Perspectives in Southern Denmark. Gerontol Geriatr Med. 2019 Feb 19;5:2333721419830198. doi: 10.1177/2333721419830198.

5. Rodríguez-Prat A, Monforte-Royo C, Porta-Sales J, Escribano X, Balaguer A. Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. PLoS One. 2016 Mar 24;11(3):e0151435. doi: 10.1371/journal.pone.0151435.

6. Houska A, Loučka M. Patients' Autonomy at the End of Life: A Critical Review. J Pain Symptom Manage. 2019 Apr;57(4):835-845. doi: 10.1016/j.jpainsymman.2018.12.339. Epub 2019 Jan 3.

7. Morgan DD, Tieman JJ, Allingham SF, Ekström MP, Connolly A, Currow DC. The trajectory of functional decline over the last 4 months of life in a palliative care population: A prospective, consecutive cohort study. Palliat Med. 2019 Jun;33(6):693-703. doi: 10.1177/0269216319839024. Epub 2019 Mar 27.

8. Edberg AK, Bolmsjö I. Exploring Existential Loneliness Among Frail Older People as a Basis for an Intervention: Protocol for the Development Phase of the LONE Study. JMIR Res Protoc. 2019 Aug 14;8(8):e13607. doi: 10.2196/13607.

palliAGED is funded by the Australian Government Department of Health.

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