

Uncovering an invisible network of palliative care

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Credit: Vlada Karpovich from Pexels

Day-to-day palliative care in the community is mainly delivered by an "invisible network" of extended family members, friends and neighbours, Flinders University research shows.

Using data from the South Australian Health Omnibus Survey from 2001 to 2007 where more than 3,000 South Australians participate in in-depth interviews each year, the study aimed to identify the key people, besides health professionals, who provide end of life care and support, including bathing, feeding and administering medications, to those dying at home.

Co-author Flinders Professor David Currow said extended [family members](#), neighbours and friends accounted for more than half (55.9 per cent) of the 2,028 identified hands-on caregivers, providing more hands-on care than first-degree relatives.

"As expected, one cohort of caregivers was those usually identified in the medical records; first-degree relatives, including spouses/partners, parents, adult children or siblings," Professor Currow, based in the Discipline of Palliative and Supportive Services, said.

"Yet we also identified a larger cohort of 'invisible' contributors to end of life care – extended family members, including grandparents, aunts, uncles, nieces and nephews, as well as friends, neighbours and community members," he said.

Professor Currow said the reason why extended family members, neighbours and friends provided the majority of care was because "in caring for someone at the end of life, it is a time the dying person's whole network comes together to provide support and care for the person who is dying and for each other".

He said the invisible network was far more likely to undertake their role for shorter periods of time when compared with first-degree relatives.

"This means the invisible network really contributes in the last weeks and months of a person's life in a way that has not been quantified

before."

Other findings showed men were just as active in providing care as women. Importantly, the invisible network also spanned all age groups, with more than one third of caregivers under the age of 35.

Professor Currow said the research highlights the need for [palliative care services](#) to create specific ways of identifying and engaging all those who provide care for someone at the end of life to ensure each person receives adequate support as they take on demanding roles.

"Most [palliative care](#) studies rely on reports from the spouse or identified next-of-kin, which has limited the ability to identify the broader social networks of support.

"These networks are crucial in supporting long-term caregivers for people at the end of life, especially when a person's care needs become more intense, but they are mainly invisible to the health team, which is of great concern.

"Changes to the medical record to identify the extent of potential social support is one way to help teams reposition the focus of their psychosocial care."

The research, titled Uncovering an invisible network of direct caregivers at the end of life: A population study, was undertaken by Flinders University researchers Dr Kate Burns, Professor Amy Abernethy, Professor Currow and Ms Lora Dal Grande from the University of Adelaide and published in the peer reviewed journal Palliative Medicine.

More information: The complete study is available online: pmj.sagepub.com/content/27/7/608.full

Provided by Flinders University

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