Flinders University

Research Centre for Palliative Care, Death & Dying

What do unpaid carers need when end-of-life and palliative care are part of caring?

Carers matter! While we talk about their economic contribution to our economy, it is the essential physical and emotional support that they give to someone who is ageing or coming to the end of their life that matters.

We know that demand for unpaid carers is going to grow as our population ages. We need to have policy, service and systems support that enable people to care and to continue caring. State and federal governments have recognised the challenge and institute policy reviews and refreshed carer strategies. But is this enough?

Why a round table?

The Research Centre for Palliative Care, Death and Dying (RePaDD) has a specific research focus on carers and seeks to build the evidence for change. Earlier this year we convened a research roundtable bringing together, carers, advocates, policy makers, services, researchers and health and care professionals in the context of ageing, caring, palliative care needs and end of life. The aim for this roundtable was to

- Continue the conversation with and about unpaid carers
- Amplify the voices of carers and their priorities and needs
- Focus on the possibility of research addressing concerns and issues, and
- Develop a research agenda and generate evidence that supports unpaid carers.

Over 40 people participated.

The voice of the unpaid carer came first

A panel of carers with lived experience and carer advocacy organisations framed the day’s discussion. They told us that carers need to be involved in and lead research about carers and that carers are survey fatigued. Sharing carers' stories is a critical way that can help people understand their lived experience.

Carers also told us they need to be supported to be involved. And they reminded us that carers are diverse, and researchers must take the challenging path of engaging with hidden voices, including those who do not speak English and those living in rural and remote areas. A repository of caregiver stories, including video stories, was suggested as an initial step.

So, what did we learn?

A strength-based approach in research that acknowledged the unique insights and contributions of carers was considered essential. Applied and participatory research that incorporates implementation science and human rights theories and frameworks were also recommended. Funding to test novel ideas is needed. Meaningful engagement with carers’ advocacy organisations facilitates relationship building and an understanding of cultural issues when working with carers.

Carers experience many transitions while caring: from occasional to full time, from home to hospital to aged care, from partner to care provider. We need to recognise and respond to these transitions and what they mean to unpaid carers.

Research around carers' rights and workplace support could help them balance work and caring responsibilities. Technologies and digital solutions could support connection and transitions if co-designed with carers.

Carers also need continued support after the death of the person they cared for. This includes grief and bereavement assistance, as well as financial and employment aid, to help carers cope with personal loss and the loss of identity and purpose.

What needs to be done?

The participants saw RePaDD as having specific responsibilities arising from the round table. First, we need to share the findings with participants facilitating ongoing connection and exchange. Second, we need to find funding to continue carer participation. Third, we need to ensure that carer stories and voices are seen on the RePaDD website. Finally, we need to formalise a research agenda that acknowledges carer priorities and needs and which enables carer engagement.

We have already started by sharing a report and findings from the round table with participants. It will also be made publicly available on the RePaDD website. We welcome interest from carers, organisations and researchers who wish to contribute to a research agenda that will support unpaid carers of older adults, individuals with palliative care needs, and people coming to the end of their life. Email us: RePaDD@flinders.edu.au