A different kettle of fish: bringing our dying home

The Caring at End of Life Project

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Background

80% of people say they want to die at home

Approx 16-20% of people in Australia do so

Most die in institutions despite most *dying* being done at home

While probably not possible for 80% surely we can do better than 16-20%?
How are ordinary people supporting each other to care for someone dying at home?

How can we capture their narratives, making them public and illuminate the space of the possible?

What role/s are service providers in EOL playing?
how is caring for someone at home the same/different in the context of intellectual disability?
Caring can be isolating and a burden, but not necessarily so

The sociological literature moves beyond a biomedical model of the caregiver based on alleviating the assumed long-term burden of caring, to a portrayal of the embodied and lived experience of caring (Sadler & McKevitt, 2013, p. 50)
Who did we speak to?

<table>
<thead>
<tr>
<th></th>
<th>Urban</th>
<th>Regional/rural</th>
<th>Total participants</th>
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</thead>
<tbody>
<tr>
<td>Focus Groups: Caring networks</td>
<td>5</td>
<td>8</td>
<td>84</td>
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<tr>
<td>Interviews: Carers</td>
<td>19</td>
<td>7</td>
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<td>Interviews: Outer Network Members</td>
<td>6</td>
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<td>Focus Groups: Service Providers</td>
<td></td>
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<td>88</td>
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<tr>
<td>Total</td>
<td>30</td>
<td>26</td>
<td>215</td>
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</tbody>
</table>
Who did we speak to?

39 caring networks where 33 people died at home

Period of care: 4 weeks to 25 years

 Majority between 3 months and 1 year

Main causes of death: cancer, motor neuron disease; respiratory failure, emphysema, heart failure, dementia, Alzheimer's.
How did we speak to people?

- Creative methods: photovoice and participatory network mapping
  - In depth interviews
  - Focus groups
Before caring
(FG 8: regional)

After caring
Love, intimacy, joy, pleasure

I felt really honoured and privileged...the person that’s giving actually gets a lot out of it
In home EOL caring develops children's death literacy

Pamela: It’s an amazing learning experience for all of our kids... three-year-olds actually learnt to care (FG 3: Urban).
We had a great grandfather (who died) before our grandmother died and I was emotional about that and it was kind of the same but when I came into this it was a little bit easier. I’ve experienced not a lot of funerals but a few funerals and I’ve been emotional but it wasn’t hard and it didn’t feel scary or anything. It had to happen... you can’t hide it from someone because otherwise they’re not going to know. They’re not going to know at all who is there before them. It wasn’t scary. I think everyone around me made it a lot easier.

[focus group member, aged 13, regional].
Rippling out

‘up-scaling’ of social capital i.e. external, bridging and linking networks.

the pharmacist managers story...
the nurses story...
Home.
It’s more than where the heart is!

Home exists with/in larger environments inhabited with people, trees, flowers, creatures, sounds, smells, and sensations such as the sun on your skin.

These places are not passive.

Environments impact our ability to both care and be cared for.
Pulling it all together

Home is where people can learn about dying and death. Here, it is a community event where each person has a role to play.

This learning builds death literacy: an outcome of engagement in, and participation with, the care of the dying and each other.

This experience is transformational at individual, network and community levels. It is this transformation which we define as ‘death literacy’
How do people develop death literacy?

I think too that no matter what you’ve been explained, no matter what, it’s still completely different to what you’re experiencing.

[focus group member, regional]

You can’t do things for somebody and then expect them to know... They’ve got to be able to do it. If they’re hands on it’s a different kettle of fish.

[outer network member, regional]
So, being part of a caring network is transformational for individuals can build social capital and contributes to people’s death literacy
Re-orientation of Practice/s

From a predominantly protective and paternalistic model of care provision

To negotiated care between providers and informal carers.

Underlying premise: that caring networks have a range of already existing competencies. The role of the service provider is to understand these and supplement them with their own practice wisdom and resources.
For More Information

Caring at End of Life (CAEOL) Project 2012-2015

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References


