

Title: Living, Loving, Dying: Insights into Rural Compassion

Authors: Pauline Marsh, Stephanie Thompson, Jon Mond

Abstract

Objective: To improve understandings of the enablers and barriers to maintaining good quality of life for people dying, caring and grieving in rural areas.

Design and setting: In-depth interviews designed on participatory research principles were held with bereaved carers living in a small community in rural Tasmania. Participants had cared for someone until their death within the three-year period prior.

Participants: 19 participants comprising 18 bereaved former carers and one person with a life-limiting illness, and all but four were over retirement age.

Study Aim: To explore experiences of end of life care in a rural community.

Results: Participants discussed the challenges they experienced during end of life caring, including transport into the city for treatment, and access to basic and specialised services. However, they also reported positive aspects of formal and informal palliative care, and described experiences of personable, expert, flexible and innovative caregiving.

Conclusions: The rural location enabled personalised and innovative expressions of care. This research adds new insight into rural end of life palliation, as a complex intersection of supererogation¹, innovation and place-driven care.

What is already known on the subject

- There is unmet need for palliative services in rural areas

¹We use the term supererogation in this paper to refer to acts which might be considered additional to essential tasks.

- Rural Palliative care research is an under-researched area
- Informal, community support plays a vital role in end-of-life care

What this paper adds

- Bereaved carers living in rural areas may have both negative and positive experiences of end-of-life care
- Rural end-of-life care is a complex intersection of supererogation, innovation and place-driven interventions
- The lived experience of rural carers may improve palliative care experiences for others

Keywords

Rural Palliative Care

Health Promoting Palliative Care

Compassion

End-of-Life care

Bereavement

Introduction

The unmet need for palliative services in rural areas is well-documented, stemming from variable combinations of factors such as geographical isolation, workforce shortages, barriers to information and support and higher rates of chronic diseases and cancers ^(1, 2). As remoteness increases, so too do mortality rates - affected by poor access to specialist and primary care services and higher incidences of socioeconomic disadvantage ⁽³⁾. People living in rural populations, therefore, become “doubly vulnerable” ⁽⁴⁾ at the end-of-life (EofL) when there is an increased need for specialised treatments and services. Despite this, rural EofL issues are largely under-researched ^(5, 6). There are limited studies

that address various aspects, such as transitioning to hospital ⁽⁷⁾, commuting ^(8,9), self-care ⁽¹⁰⁾, support needs ⁽¹¹⁾, volunteering ⁽¹²⁾, hospice services ⁽¹³⁾ and living alone ⁽¹⁴⁾. Our study aimed to improve understandings of rural EofL experiences by exploring the ways bereaved carers living in a small community in rural Tasmania provided and received care.

A Health Promoting Palliative Care (HPPC) framework informs our research. HPPC acknowledges the potential for improvements in EofL care when health care services and informal community supports complement each other ⁽¹⁵⁾ - an interrelationship which is particularly relevant to rural communities. HPPC embeds public health principles into EofL care, privileging strategies to minimise the difficulties of dying, caring and grieving; as well as promoting a community development model of care-giving. ^(16, 17) Compassion - a human and tender response to the distress and suffering of others ⁽¹⁸⁾ - is a key component of HPPC as well as an ethical imperative which drives much of EofL care. Sinclair et al. found compassion to be the preferred "care medium" for people experiencing advanced cancer, when asked for their perspectives on empathy, sympathy and compassion. They developed a comprehensive definition of compassion that we also adopt for this research: "a virtuous response that seeks to address the suffering and need of a person through relational understanding and action" ⁽¹¹⁾.

Method

This descriptive qualitative study utilised the single method of semi-structured, in-depth interviews. These were conducted with carers who had looked after someone who had died from a life-limiting illness within the previous three years, or who were still caring for someone in the advanced stages of a life-limiting illness. The study intentionally positions participants as community partners, with the understanding based on participatory research principles, that people have the capacity to

engender meaningful solutions and effect positive changes for themselves and others ⁽¹⁹⁾. The study site was located on the Tasman Peninsula, an area 75km South East of the state capital Hobart (RA3 classification ASGC), in a population facing a higher likelihood of ill health, with an above state average of people over 65 years (22.4%) and in the highest quintile of the Socio-Economic Indexes for Areas (SEIFA) ⁽²⁰⁾. The researchers each have backgrounds in clinical care provision, as well as experience in research with vulnerable population groups. principles of participatory research.

In close consultation with the local GP, a purposive sampling strategy identified eligible participants. A written invitation was mailed to 31 people, and an additional five were contacted by telephone (total 36) at which point the researchers emphasised the aims of the research and the value they placed on learning from the person's experience. We conducted 17 interviews with 19 participants (in two instances there were two people present, both partners), and of these, 17 were bereaved carers, and all but four were over retirement age. The majority of interviews took place in participants' homes, apart from three in various other chosen locations and three via telephone. Each were guided by a modified version of the Quality of Dying and Death Index, ⁽²¹⁾ adjusted to prompt conversation. For example, the interviewers might inquire if the participants felt they were able to spend time alone with the person they had cared for. Each took between 45–90 minutes. More detail about the methodology informing this study is the subject of a separate publication (22).

Data was analysed using thematic analysis techniques. ^(23, 24) The two researchers who undertook the interviews firstly strengthened their familiarity with the data through re-reading, listening to audio-recordings and reviewing their notes made immediately following the interviews. Independent of each other the researchers conducted an initial coding exercise in order to identify recurring codes (from content, issues raised, observations, reflections and experiences) which were then organised into

major themes and subthemes. Themes were consolidated and verified through a collaborative process of discussion, re-reading and revision between the two researchers, until no new themes or sub-themes emerged. The themes and subthemes were then verified independently by a third researcher, in reference to the original transcripts. Ethics approval was obtained from the Social Sciences Human Research Ethics Committee (H16379).

Results

Analysis generated six theme domains. The themes encompass: the various supports that people utilised to die at home; issues of isolation; the impacts that difficult relationships can have on the dying experience; experiences of losing or maintaining control; talking about death and dying; and the variations of grief and bereavement that participants experienced. Additional quotations to those in this section are contained in Table 1, Additional Results Data.

1. Support to die at home

Participants received assistance provided by a range of formal and informal services, and many noted the professionalism and expertise of local services. Some thought the care was more personalised and of higher quality than what they would expect to receive in the city, which they attributed to longstanding community connections and personalised approaches:

[The local staff] were brilliant ... and ... the compassion from the staff was amazing. [The GP] put his arm around [my partner] one day and said "I love you, [X]" and that just meant so much to him, you know? I don't think he – it's rare he would have heard those words - and to have heard that when he was in that state was pretty special. And you felt that [the GP] did have a ... genuine caring and humanity. Int12

Others, however, reported difficulties accessing not only specialists, but also basic care services. People rang multiple providers, either having no result or being “handballed” until they found a provider that serviced

the region. People who were not referred to the specialist palliative team had even more restricted access to supports:

So, there was no palliative care...Who provides the help? That's all we wanted to know. And then everybody kept saying, "well we only do this bit though. We only do that bit though". Int7

When the care required was beyond the capacity of family or friends - "it was the hardest thing I've ever done in my whole life" (Int17) - or not available through formal providers in the area, then people could not stay at home to die, despite wishing to.

There was a big gap...where they couldn't get anybody down here to do [podiatry] and the hairdresser and that sort of thing. ... Little things like that which are important (Int 9)

An absence of services sometimes led to creative informal caring interventions. For example, one man modified a ride-on mower to provide transport for his friend with neurodegenerative disease. When one carer needed help herself, she was showered by her friend: "the funniest shower I ever had". Family members uncomfortable with being inside camped in the backyard, and shared cups of tea on the back porch.

2. Isolation

Physical distances, coupled with the nature of illness progression, meant some people were unable to stay connected with others. It was particularly difficult to maintain close contact with younger family members who had moved away from the area. As a result, some carers stated they did not know who, or how, to ask others for help. Furthermore, specialist treatments, including chemotherapy and radiotherapy services, were at least a 90-minute drive and participants felt that they spent longer periods in hospital as a result. Hospitalisation was itself an isolating experience.

Travelling long distances was frequently reported to be stressful and tiring, and city accommodation not always available or desirable. Stories of rogue private operators, ineligibility for community transport, mix ups with timings and collection points were not uncommon. So difficult was the travel, some people chose to refuse treatment or appointments:

He thought about what the two doctors said to him and thought there was no point in having treatment because he couldn't travel in the car. Int19

Conversely, people felt that a small community generated a sense of closeness and social connectivity:

I think because everyone knew everyone, I think there was no question of, you know, being in touch. So, I felt very privileged by that ... how you would manage without them I don't know, because they would make sure that when we got back [from treatment in town] that the fires were lit and the place was warm and that's an extraordinary gift.

3. Difficult people, difficult relationships

The isolation of caring was exacerbated for those who were living in difficult relationships. Several participants became carers of previously abusive spouses, parents or ex-partners, and the history of abuse exacerbated the intensity of the caring role. The intensity of the caring relationship was heightened by a history of disharmony, abuse or violence.

I could hear her through the bedroom wall berating my father and belting...she belt him with a stick and he came out with a black eye one morning Int1

As people became frustrated with their illness, or experienced increased pain or anxiety, their anger also increased and was often directed at the carer.

It was very, very difficult... I was the only support in his life...He just progressively got worse and worse where looking after him sort of became harder and harder and harder. Int 12

Abuse that had hitherto been private or concealed was suddenly public, on transfer to hospital or residential aged care, or as formal service providers became more frequent visitors to the house.

4. Control

While some carers felt in control when they were able to look after someone dying at home, for many there were feelings of loss of control over life and the future.

I'm still annoyed the lymphoma chose [my husband] because he hasn't taken drugs, he hasn't been an alcoholic, he's kept fit and healthy and I just feel God let us down. Int11

Participants needing treatment in the city felt particularly powerless:

You go through the whole hospital thing, and it's like you got to forget everything you know because ... you got no control, that's what I learnt the most. I had no control what was going to happen...there's a lot of struggle and there's a lot of fear. Int10

5. Talking about dying

Commonly, participants had not discussed dying or death prior to the onset of a life-limiting diagnosis. Sometimes this was attributed to a history of shallow communication or to a hopeful sense of immortality.

[My husband] didn't say very much at all until one day I was laying on the bed with him and he just took my hand and said, "I've had it, haven't I?". And I said, "Not quite." What else could I say? "Not quite yet". Int4

Disease progression meant less opportunities or inclination for discussion.

He was a very communicative person and wasn't afraid of talking about such things. But towards the end, I think the disease took over and he became much quieter. He didn't talk a lot towards the end ... But I think, ... he was too worn out and too tired. Int2

Concerns that talking about death in a small community would impact on privacy were noted. Health professionals were pivotal in prompting

discussions about death, whether at point of diagnosis, first visit from the Palliative Care Team or when treatment options had been exhausted.

6. The complexities of bereavement

Informal and formal supports during bereavement were reportedly provided by palliative care providers, local medical services, social workers, rural mental health services, GPs, friends, family or community groups. Some sought solitude, while others support from family or close friends only. Non-verbal coping methods were common: gardening, cooking, caring for others, being busy, going out in the boat, meditation, travel, and online support groups.

People talked about how difficult bereavement was. They reported that they lost not only someone close to them, but the death had resulted in the loss of pets, property, their own physical health, eyesight, teeth, and mental health:

It was the most difficult time of my life, without a doubt. In fact, I'm still recovering from it. It's exhausting... I'm not out in the garden like I used to be. I'm hoping that it's going to come back soon. Int 12

Community groups that were not specifically bereavement care providers, nevertheless provided effective bereavement support:

I suppose my biggest support network here has been the craft group ... I'm a fairly private person but I think, even if there had been a [formal support] group I don't think I would have felt too comfortable going along and I think I would have gone and sat quietly. I don't think I would have opened up. Int6

People also found comforting spiritual connections with deceased their loved one in spaces they had previously shared:

I don't want to go anywhere...I can't go anyway...it seems almost that I can't go anywhere because [my deceased husband] is still here. ...That's what the garden is doing I think, because we still work on it together. Int11

Discussion

Applying a HPPC lens to the data, end of life care in a rural community can be seen to be characterised by compassion which is expressed in relational and innovative ways. Despite challenges associated with lack of services, social and geographical isolation and the demands of travel, and although issues of privacy and over-stepped personal boundaries plague rural communities⁽¹²⁾, a feature of this research were the expressions of caregiving that were steeped in compassion, both formal and informal services went beyond what was required of them to ensure people were well supported. As observed by Sinclair et al, people respond to suffering through relational acts of understanding and action⁽¹³⁾, and in this research they did so with a particularly rural slant.

Some experiences of the local medical, nursing and allied services revealed a welcomed responsiveness and flexibility, including things like after-hours visits from the GPs and community nurses, as well as home visits from city-based services and the opportunities carers were given to undertake some of the clinical tasks. Not all carers felt this way, and some raised issues about the fragmentation of care and absence of particular services. It is possible that these experiences could be considered evidence of the lowering of expectations that characterises rural populations. Brazil et al. (2013), for example, found no statistically significant differences between urban and rural caregivers experiences of formal services in Canada, but rural residents lowered their expectations about access to care and services and accepted access limitations⁽⁵⁾. Nevertheless, evidence of supererogatory compassionate caregiving is also present in rural health literature. For example, Duggleby and colleagues note that people living in rural areas feel a strong sense of connectedness with their formal healthcare providers⁽²⁵⁾ and Sinclair et al. found “small supererogatory acts of kindness” which had

immense impacts on patients with advanced cancer and health care workers
(13)

As this and other studies show, physical and emotional EofL support is predominately sought from and provided by family and friends, community workplaces, churches, neighbours and others ^(10, 18) and often counter balances access limitations. It also provides care different to that of formal care services. Consistent with other rural areas, ⁽⁹⁾ participants in our study described a myriad range of ways compassion was expressed: chopping wood, cooking meals, filling the freezer with food or providing transport. More innovative measures included: modifying a ride-on-mower to enable a friend some independence; insisting that a bereaved friend join them at craft group; moving the bed in the middle of the lounge room so a dying man could feel part of the family; supplying home-grown plant-based pain relief; continuing to garden with a partner after he had died; and, continuing to go camping with friends despite severe pain and discomfort. These actions are creative, individually-tailored expressions of compassion, and largely non-conforming to formal caregiving practices.

The most extreme expression of compassion was demonstrated by people who provided care in dysfunctional and even violent relationships. Despite very troubled relationships, people still took on the caring role, some travelling from town to look after ex-partners or in-laws from whom they had been estranged. The reasons why are complex, and beyond the scope of this discussion. However, the reasons how people are able to care in this manner may be partly attributed to the benefits that flow to the carer from displays of compassion. Rainsford and colleagues argue that caregiving that is compassionate better enables carers to cope ⁽⁶⁾. Compassion characterised by maintaining dignity, receiving support from others, feeling appreciated, providing spiritual support, and a focus on hope ⁽⁶⁾ may assist carers to experience personal growth and satisfaction, ^{(26) (27)} significant challenges notwithstanding.

At the end of life and in bereavement, place is a complex intertwining of physical symptoms, tangible support, emotional support and emotions ⁽²⁹⁾. In this research, the rural location was central to facilitating expressions of compassion and innovation. Rural place-driven compassion manifested in a variety of ways, including gardening sessions that extended from dawn to dusk, or going out on the water with a friend once a week. Friends, neighbours, gardens, boats, dogs – and various other factors emblematic of place – all contributed to the context of EofL care in the rural environment. Alternatively, smaller communities can provide much needed privacy and solitude. The spatial-spiritual connections that were observed – i.e. the connections between a living person and a deceased person – acknowledge the important function of place in enabling personal bonds to remain after death. ⁽³⁰⁾ The potential healing and restorative qualities associated with rural places – such as access to nature, greenery, wildlife and gardens – are entrenched in poetry, mythology and historical writings, as well as contemporary research ^(6, 9, 27). When participants valued dying in a peaceful rural environment above ready access to radiation or other medical treatments, a finding evident in other literature ⁽²⁸⁾, they compromise symptom control to remain at home. In this way they demonstrate trust in the therapeutic capacity of place over and above that of other treatments.

The study confirms that bereavement is difficult and exhausting. It can be isolating, debilitating and all-consuming. Nevertheless, the results also illuminate the myriad of ways that people in the community live with grief, and support each other in bereavement. Kellehear states that an understanding of the ways in which communities mobilise grief support may help to strengthen a public health approach to EofL care ⁽¹⁸⁾, and Abel and colleagues argue that a collaboration between formal services and “less controllable and auditable activities” could be “formidable” ⁽¹⁶⁾. As Rosenberg et al. claim, the challenge for HPPC is for formal services to

truly partner with communities to co-design palliative care in ways that respond to community assets, strengths and limitations. ⁽¹⁵⁾ Our rural snapshot exemplifies the value in care partnerships that allow both formal and informal caregivers the space to express and practice compassion during bereavement, in relational and creative ways.

Limitations of this study are that the experiences of medical, nursing and allied health staff are absent, and their voices would add to the richness of the findings and analysis. The majority of participants reported a good relationship with the local rural GP, and although we heard from some people who were very unhappy with care they received, or a lack of care, there is potentially an over-representation of satisfied participants which creates a slant to results. Future research in rural areas, which includes formal and informal carers and people in the palliative stage of their condition, is recommended to continue to build on the knowledge and understanding of rural palliation. Comparison studies with urban communities also would be beneficial.

Conclusion

This research enriches understandings about rural HPPC from the perspectives of people living in a rural area of Australia who cared for someone until their death and who were continuing to grieve. Their experiences demonstrate the appropriateness of a HPPC approach that is focussed on enhancing inter-relationships and community compassion. Participants constructed a nuanced profile of rural compassion, as comprised of complex intersections: geographical isolation and therapeutic space; personalised, innovative care and a lack of basic services; community-wide support and private expressions of grief.

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