

Navigating the path to care and death at home—it is not always smooth: a qualitative examination of the experiences of bereaved family caregivers in palliative care

Elizabeth A. Lobb^{a,b,*}, Kristin Bindley^c, Christine Sanderson^a, Roderick MacLeod^d, Jane Mowl^e

Abstract

Background: Care and death at home are generally thought to be beneficial for families. However, there may be bereavement experiences and support needs, which are specific to family caregivers providing end-of-life care in their home. The Palliative Care Home Support Program in New South Wales, Australia, provides end-of-life care packages for patients who wish to die at home. These packages provide up to 48 hours of specialized supportive palliative home-based care, day or night, by community workers specifically trained for the task, working as part of existing community palliative care multidisciplinary teams. Care packages may include assistance with personal hygiene, carer respite, and domestic assistance. **Methods:** As part of a larger longitudinal mixed-methods study, 28 bereaved caregivers who experienced a home death and/or received the care packages undertook in-depth interviews. Narrative thematic analysis was undertaken to explore their experiences at 6 months post death. **Results:** Twenty-eight caregivers were experienced or planned for a home death and 21 had a package in place. Five themes were identified: “the achievements of a home death”; “taking on the mantle”; “the burden of witnessing the dying process”; “home as our space/their space”; and “resistance or submission to the ideals of best place of care for family caregivers.” **Conclusions:** Bereaved caregivers provided accounts of their interactions with health care providers depicting a complex relationship with the care system. Some families struggled to manage boundaries of home and private space as care needs escalated. Ideals about best care and home death are sometimes conflicted, without easy consensus between patient, family, and service providers. **Significance:** Models of care based on assumptions that home death is straightforwardly beneficial may cause unintended consequences. For future policy, providing care in the private space of the home requires close attention to family concerns and outcomes.

Keywords: Bereaved carers, Home death, Models of care, Palliative care

1. Introduction

In palliative care, the challenge for professional caregivers is not only to achieve a “good death” for the patient, but also to provide

support for the caregivers and family to navigate the path of care, death, and bereavement. Care and death at home are seen as assisting family members’ perceptions of a “good death,” leading to less bereavement-related distress.^[1–4] Features of a “good death” include not being over-whelmed by the physical management of the dying process and the preferred place of death being seen as a “safe place” regardless of its physical location.^[5]

A higher quality of life for patients in the final week of life is underpinned by more palliative care support^[6] and a greater therapeutic alliance with health care providers has been associated with “cascading benefits” for bereaved caregivers including better physical functioning and mental health.^[2] However, some features of a palliative care death may be uniquely traumatizing for vulnerable individuals, with potential impacts during bereavement.^[7] There are also further potential difficult physical, psychological, and spiritual sequelae of caregiving within this setting.^[8]

Management of care- and death-related factors that increase the risk of complexities of grief in bereavement for family members has been reported.^[9] This is counterbalanced by the potential for experiences of a sense of mastery, personal growth, and meaning-making arising from experiences of caregiving.^[6,10,11]

Family caregiving is essential when a person wants to die at home.^[12] In contemporary contexts in Australia, as elsewhere, support for caregivers to provide care and enable a home death comes from both specialist and primary palliative care services

Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article.

Authors’ contributions: JM, EL, CS participated in the research design; EL, JM, CS, KB and RMacL participated in the writing of the paper; JM and KB participated in the performance of the research; JM, CS, KB participated in data analysis.

^a Palliative Care Service, Calvary Health Care Kogarah, New South Wales, Australia, ^b School of Medicine, University of Notre Dame, Sydney, New South Wales, Australia, ^c Supportive and Palliative Care Unit, Western Sydney Local Health District, Mt Druitt, New South Wales, Australia, ^d Greenwich Hospital, HammondCare, Greenwich, New South Wales, Australia, ^e School of Social Sciences, University of New South Wales, New South Wales, Australia.

* Corresponding author. Address: Calvary Health Care Kogarah, Kogarah, New South Wales 2217, Australia. Tel.: +61 2 9553 3093; fax: +61 2 9553 3159. E-mail: address: Liz.Lobb@health.nsw.gov.au (E.A. Lobb).

Copyright © 2019 The Authors. Published by Wolters Kluwer Health Inc., on behalf of the International Psycho-Oncology Society.

This is an open access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CC BY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

J of Psychosocial Oncology Research and Practice (2019) 1:1(e3)

Received: 11 March 2019 / Accepted: 24 May 2019

Published online 9 July 2019

<http://dx.doi.org/10.1097/OR9.000000000000003>

and from sources like trained personal and home care workers. Family caregivers need access to flexible services to support care and death at home, together with ongoing assessment of their needs.^[13]

For specialist palliative care services, care of the family during the illness and death of the patient, as well as provision of bereavement support, are an integral part of their mission.^[14]

However, there may be bereavement experiences and support needs which are specific to family caregivers providing end-of-life care, although this remains under-researched.^[15] A strong relationship between the delivery of lower quality of care, for example, the patient's physical, psychological, spiritual, and informational needs not being adequately addressed, and higher levels of complicated grief has been reported^[16] with utilization of palliative care found to buffer the effect of fear of death on the complicated grief of caregivers.^[16] When compared to home deaths, hospital deaths have been associated with worse quality of life for patients and a higher risk of psychiatric illness including prolonged grief disorder for bereaved caregivers.^[2] Of concern however, a recent study of >25,000 palliative care patients in Australia found that although all patient symptoms improved and >85% of patients had no severe symptoms before death, when comparing all symptom outcomes by place of death, hospital patients are 3.7 times more likely than home patients to have no severe symptoms.^[17] Consequently,

“there is need for research to better understand the effects and outcomes of care provided in the home, and its impact on family caregivers.” [MacLeod, P26]

This knowledge will help clinicians support caregivers, patients, and their families in making decisions about end of life and where they want to die and improve service provision.

In 2013, the Palliative Care Home Support Program (PCHSP) was funded by the New South Wales Ministry of Health.^[18] The program provides end-of-life care packages for patients who wish to die at home or remain at home for as long as possible. These Supportive Palliative Care Packages (SPCPs) provide up to 48 hours of specialized supportive palliative home-based care, day or night, by community workers specifically trained for the task, and who work as part of existing community palliative care multidisciplinary teams.^[19] The 48 hours may be used consecutively or spread over several days and may include assistance with personal hygiene, carer respite, and some domestic assistance.

Care provided under the PCHSP is determined by the patient and their family in consultation with the palliative care clinician, palliative care community nurse, or the primary care team. The program is promoted with referrals by approved health professionals from each Local Health District. There is no charge to patients or families for the packages.

The current study examines the experiences of participants who experienced or planned for a palliative home death and who received a SPCP and those who did not receive a SPCP (n=28).

2. Methods

The study employed a narrative research framework to examine experiences through in-depth interviews at 6 months post loss. These interviews formed part of a larger longitudinal mixed method study of 81 bereaved caregivers recruited following both “expected” palliative (N=61) and “unexpected” coronial (N=20) deaths. (To be reported elsewhere). The study complies with the standards for reporting qualitative research.^[20]

2.1. Data collection

Bereaved caregivers were sequentially recruited from 2 specialist palliative care services 4 to 6 months after the death. Potential participants were sent a letter from member(s) of the management team introducing the study. Upon consent, the researcher (JM) telephoned the participant to arrange a time for the interview, which took place at a venue of their choice. Recruitment stopped when there were sufficient numbers of caregivers who experienced a death at home and/or received the SPCP and saturation of themes was reached.^[21]

The Human Research & Ethics Committees of The University of Notre Dame, Australia, and South East Sydney Local Health District, Prince of Wales Hospital, Sydney, approved the study. During the interview, the researcher (JM), an experienced bereavement practitioner, was responsive to participants' concerns and provided opportunities to stop and flagged difficult questions so that they could be avoided if wished.^[22]

2.2. Analysis

Interview data were audiotaped and transcribed verbatim. Initial analyses began after interviews. A narrative analysis strategy allowed themes to be identified across individuals and held a case-centered commitment to keep the individual account intact and allow nuanced analyses.^[23] Critical theory, which addresses the language and situation of power, provided a lens through which to explore the dominant discourses about home care, death, and grief implicit in the narratives of bereaved caregivers.^[24,25]

Analysis steps included initial data immersion where 5 researchers (JM, KB, EL, CS, RMacL) read a subset of transcripts, from which a preliminary thematic framework was developed to enable systematic attention to story “strands” of narratives. Two researchers (JM, KB) read the remaining transcripts alongside the thematic framework. A detailed analysis focused particularly on stories of illness, caregiving, death events, and palliative care experience within and across cases, to identify themes. Network mapping^[26] was utilized to review themes and sub themes/codes as conceptually situated in relation to one another. The diverse background of the researcher team including social workers/bereavement counselors (JM, KB), palliative care clinicians (CS, RMacL), and a behavioral scientist/bereavement counselor (EL) provided reflexivity to ensure adherence to themes. Additionally, participants were provided an opportunity to review themes and provide feedback and 7 participants responded endorsing the themes and providing additional clarification. Interviews were on average 60 minutes' long (range 35–80 minutes).

3. Results

Of the 28 caregivers who participated in an interview (Table 1), 12 had experienced a home death with a SPCP in place, 8 planned for a home death with a package but the death occurred in hospital, and 1 had a SPCP and died in an aged care facility. Eight had planned for and achieved a home death without a SPCP in place. One of the deaths was subsequently reported to the Coroner/Medical Examiner as the Primary Health Care Practitioner declined to issue a death certificate.

Five themes were identified: “the achievements of a home death”; “taking on the mantle”; “the burden of witnessing the dying process”; “home as our space/their space”; and “resistance or submission to the ideals of best place of care.”

Table 1**Sociodemographic characteristics of participants (n=28).**

Employment	n=22
Mean age	62.42 (SD 16.42) range 12–92
Sex	
Male	7
Female	21
Main carer	
Yes	24
No	4
Package recipient	
Yes	23
No	5
Relationship to deceased	
Husband/male partner	4
Son	3
Wife/female partner	12
Daughter	8
Other	1
Language other than English spoken at home	
Yes	6
No	22
Highest level of education completed	
Year ≤10	9
Year 12	1
TAFE Cert/dip, bus college	7
University degree	5
Higher degree	4
Other	2
*Employment status	
Full-time employed	6
Part-time employed	3
Retired	12
Unemployed	1
Religious/spiritual beliefs	
Christian	22
Atheist/none	3
Agnostic/unsure	2
Buddhist	1

SD, standard deviation.

*Missing data does not add up to 100%.

3.1. The achievements of a home death

Care at home was experienced as positive by many participants bringing a sense of purpose and achievement:

“Death at home ‘wonderful, you know, wonderful way to go.’ Home death was dad’s wish, ’ that kept me going’ (his gratefulness), “broke my heart” . . . “it was full on but it was wonderful, you know, wonderful way to go.” “. . . we brought him home he was always very grateful that we did it and yeah, I suppose that kept me going.” (Daughter, P24)

Home care provided a chance to be with the person who was dying to ensure they were well-cared for, not alone, and also signified a sense of maintaining control. Care at home was seen to allow the family member to “live until they died” and for many, a way of honoring the patient’s wishes.

“I never wanted him in the hospital because I thought no matter how good the hospital is and no matter how good the care is there is never going to be somebody sitting with him that whole time, and he may die in a hospital with nobody around him and I couldn’t let that happen” I said, “While he is under this roof he is under my care”. (Wife P13)

3.2. Taking on the mantle of care

Although caregivers wanted to take on this role and were proud of their achievements, the caring was not without challenges. There was a sense of the role being “massive” and “overwhelming” and having “no boundaries” in what was required of them to provide care. A particular concern for caregivers was managing medication with the fear that administering medication may have brought on the death, as this quote illustrates:

“I question this now when I think about it: with mum, like, how much medicine I was giving and what was I actually doing? At that time, you sort of think you just do what you’re told, and I thought...“have they increased the dose?” And, I have a question that does it – does that hurry it up? . . . What am I actually doing to my parents? What am I doing to my dad with the medicine? I would’ve liked . . . a bit more information about it. (Daughter, P7)

The costs of taking on this mantle of care at home for caregivers also brought uncertainty about doing the “right thing” and for some, the risk of physical injury.

“Most of the time I could do it by myself’ (but with loss of mobility, shift from oral to injectable medications), ‘got harder’ // ‘She was ok up until the last, I suppose month and then it got very scary as the carer, just, you know, making sure you’re doing the right thing.’ (Husband, P5)

“What was really difficult was needing to lift {husband} and do things and my back has really caved in’. // ‘He was incontinent and I had quite a lot of cleaning to do.’ (Wife, P81)

Caregivers considered themselves to be the repository of reassurance, ongoing comfort, and presence and highlighted the importance of care provided by a family member rather than a health professional:

“I.. just sat beside him and when he wanted to get up because they didn’t like him to get up, you know, I would just stand and hold him beside the bed or just try and calm him down by talking to him, you know, just sitting beside him and that did help a bit. And it’s the sort of thing you can do I suppose when it’s, you know, your own loved one, you can’t expect a nurse to do it. (Wife, P13)

For some caregivers, even though they had planned for a home death, the care needs were too great or symptom management was not optimal and the family member was admitted to hospital:

“He didn’t want to go to [name hospital] . . . he really wanted to come home but then he couldn’t breathe without the oxygen and there was no choice really.” “They {the staff} said it would be too hard I think. It would have been too hard for me to nurse him even though I am a nurse.” //, couldn’t get him up the stairs” (Wife, P41)

3.3. The burden of witnessing the dying process

Several caregivers spoke of the psychological trauma of care at home, this included difficulties in witnessing the physical deterioration of the patient, their perceived loss of dignity and the unavailability of assisted dying to ease suffering which is currently not legal in New South Wales, Australia.

“It was degrading and disgusting for a person to go through when somebody has to clean you up and put nappies on and it’s just – they are not unconscious they are aware of what’s going on.” // “No, that was cruel. It should have not been allowed. If that had been a dog we would have had to take it to the vet.” (Wife, P32)

“She was really struggling to breathe, it was pretty awful I hadn’t prepared for that, I didn’t know how people passed away.” (Husband, P5)

3.4. Home as our space/their space

Impacts of death at home were both positive and negative. Bereaved caregivers provided accounts of their interactions with health care providers depicting a complex relationship with the care system. Some families struggled to manage boundaries of home and private space as the dying person’s needs escalated.

“They took away that sense of her own space and the whole point of course of dying at home is to keep you in your own spacehaving all these other people coming in and taking over three or four times a day may have contributed to the fact that she somewhat changed in personality. She was much more irritable. And to suddenly, for the last three weeks of your life, have this endless procession of strangers and relatives all kind of sitting around the bed, not really particularly engaging with you but just sort of being there, I mean it was quite unnatural really to have all these people in her space, in our space after not for 10 years” “I was too tired all the time to really control the situation. I didn’t get any sleep for the last three or four weeks. I was completely at the end of my tether all the time.” (Daughter, P72)

For other recipients of the SPCP, privacy was not an issue as this quote illustrates:

“I think we had about – there were three of them all together, so once we got to know – you didn’t feel like you were having to explain the situation to new people coming all the time. They knew where everything was and I’d come home and find – they’d done all sorts of stuff that I hadn’t even asked them to do. They were just absolutely wonderful, angels.” (Wife, P70)

There were difficulties with navigating different care service providers, with implications for established relationships.

“When the palliative care gets involved ‘you have to drop your Department of Veteran Affairs Services [...] so all these people dad had built up a rapport with over the years weren’t allowed - I was told couldn’t come anymore, it had to be just the Palliative Care team Look I get that there’s rules but it was really traumatic and that’s even me in a nursing capacity.” . . . - ‘I think it (death at home) is a wonderful idea, you know, wonderful to do it but it’s just sort of people negotiating the path.” (Daughter, P24)

At the same time a number of caregivers whose relatives had received the package were ambivalent about or unhappy with the care provided, feeling that it was not the care that was needed. Direct care for the patient was valued over ancillary tasks such as cleaning or hanging out the washing, “*I don’t know if I could have managed – well I couldn’t – I needed them now in hindsight.*

I didn’t need them to do anything for me or in the house which I thought was a waste.” (Wife, P13)

For others, the provision of the home care package provided the essential services that allowed them to care such as having a phone number to contact the palliative care services, and having support that was “compassionate,” “helpful,” “reliable,” and helped feel that they were not “*doing it alone.*”

“Then the palliative care people just did everything else and they were just fabulous. The care people who came – the nurse said to me, “He must have the 48 hour package,” So we said okay and we arranged for various – and these people who came were just absolute angels. They were so lovely and just said, “You go out and have a walk or go and have a coffee or have a meal or whatever. We’re here. Just give me your phone number and I promise I’ll call you if anything” They did washing and they would say, “Have you got any ironing?” There was one lady who was just lovely. She sat with him for ages and she just massaged his hands and his feet. They were, the whole palliative care thing was as good as anything could have been.” (Wife, P70)

A lack of continuity of carers who were part of the SPCP was problematic with some participants reporting that the community carer was disruptive and not helpful in ways that were wanted.

“I think I suggested I needed it (SPCP) at some stage and I don’t know if they realized that maybe [Name] was in that last stage, and I didn’t get anybody come until probably the last 12 hours or 24 hours. He’d already had a bed bath and I really didn’t know what she was to do. So I found – yes and they were talking about staying the night. I didn’t need anybody staying. And I wasn’t scared of [Name] dying or being here on my own. . . . I mean the woman that came was lovely but she didn’t know what to do and I didn’t know what to do with her.” (Wife P82)

3.5. Resistance or submission to the ideals of best place of care

Ideals about where the best care could be provided sometimes conflicted without easy consensus, between patient, family, and service providers. For example, family members wanted to fulfill the patient’s wishes to provide care at home but were told by other family members or health professionals that the task was too great. Conversely, other caregivers believed they could not manage at home and after a trial period the patient was transferred to hospital. There was a sense that their own personal capacity such as knowledge, advocacy skills, and personal resources and support could not always protect them from gaps in the system.

“I guess somehow society has to accept that people want to die at home, that they have terminal illnesses, they want to die at home and be able to go through that process with the least amount of trauma, because what I’ve gone through, what I’ve experienced and I had all the support, I had all the knowledge... and yet I still had to go through with it...work out how do I move on from such a horrific thing.” (Daughter, P14)

Thus one of the overarching findings in the interviews was family members’ awareness of and reaction to these perceived ideals from some health professionals, and society in general, positioning home care and death at home as ideal and others who

considered in-patient hospital care as ideal. The bereaved caregivers we interviewed who had a home death, reported that they had to negotiate the path to attain or sometimes resist professionals' ideals of hospital providing the best care. Some carers had to actively advocate to ensure the person was not admitted to hospital:

"I think for lay people it would be very difficult . . . one of my sisters did ask the RN from (Service) well what usually happens and they said well, that's when people go to hospital. But yeah, like you know the director of nursing where I work said you know the government wants people to stay at home and I thought well they'd better start making it a bit easier for people. . . . I think it is a wonderful idea, you know, wonderful to do it but it's just sort of people negotiating the path . . . If it wasn't for me speaking up saying no . . ."

(Daughter, P24)

4. Discussion

Many people with life-limiting illnesses prefer to be cared for and die at home rather than in the hospital.^[3] Overall, care and death at home are considered preferable, although still not achievable for many,^[27] and this has led to the establishment of new services, such as the PCHSP. However, for both patients and caregivers, preference for place of care is not necessarily synonymous with preference for place of death.^[28] The experiences of caregivers may be complex with a high level of expectation of care and death at home, but to achieve this they find themselves required to take on increasing amounts of complex care which was once provided by nurses.^[3,29,30]

Enabling people to choose a home death underpins Australian national palliative care policies.^[3] However, our findings suggest that caring for a person to enable a home death is not always wanted either practically or emotionally. Although home is seen as a valued space for both care and death, bereaved family caregivers reported difficulty in navigating this path. They reported that they were often overwhelmed by the complexity of the tasks involved especially managing medications and the physical and emotional work of caring. In keeping with findings from other studies,^[5,15] many did not know what to expect of the dying process and reported being traumatized by witnessing the physical deterioration of their family member and being unprepared for the last hours and moments before death.

Those interviewed highlighted the need for preparatory information and knowledge before the patient being discharged from hospital for a home death and ongoing information to enable the patient to stay at home. This supports earlier findings and highlights that family caregivers need practical and psychosocial support as well as education on symptom management to continue caring at home.^[6,12] The findings from our study, particularly the distress in caregivers witnessing the dying process at home suggests that preparation for the visual aspects of dying such as altered breathing and physical changes is warranted. These findings are supported by a recent study which describes the bereavement issues caused by poor communication and lack of understanding or awareness of the dying process.^[15]

A number of suggestions from caregivers and health professionals for improving communication and support for families at the end of life are provided. For example,

"carers expressed wishes for bedside updates on what was happening and what they could be doing to help their loved ones at that time." [Harrop, P3]

Carers and health professionals also described the need for better information on the signs of death and what to expect to facilitate their preparedness for the death. Some called for post death consultations so that families' questions could be answered by the health professionals who were directly involved at the end of life. It was felt that this would alleviate some of the confusion and concerns of bereaved family members and provide an opportunity to improve future care.

Our data suggest a targeted approach including information for caregivers on administering medications, particularly opioids, and systemic and structural supports including financial assistance.

Caregiving is shown in this study, like others, to be gendered^[31] with the majority, female partners and daughters. Policy makers and funding bodies need to address the way care is delivered in the home including, the quantity of resources provided. Assumptions about appropriateness of care/death at home, and the pursuit of this as "ideal" by caregivers and society in general need to be challenged. It could be argued that a home death transfers the burden of best palliative care practice to, often female members of, the family, and turns the safe space of home into something different with lack of privacy, anxiety about the ability to cope, physical exhaustion, and in some cases injury.

Bereaved caregivers who received SPCPs valued personalized care but also reported they were confused and stressed by the steady stream of "strangers" in their home in a space that was considered "private" and during a time that was "sacred." For many, these short-term new relationships with health professionals and personal care workers, even when they were valued, added to their stress. The timeframe of the Packages (48 hours — although a 2nd package could be requested) may have contributed to these short-term relationships as some palliative care patients can be connected to specialist community palliative care services for weeks, months, or even years where more established relationships are formed. The packages are structured to support families in the last days of life when caring may be more intense.

The importance of caregivers having a "secure base" and "safe space" in which to provide care has been highlighted.^[4,32,33] This includes

"the importance of feeling secure that health care services will be provided by competent professionals, timely access to needed care, services, and information and feeling secure in their own identity and self-worth as a caregiver." [Funk, P435]

A critical theory lens prompts consideration of who possesses and exercises agency and power in interactions about place of death, care arrangements, and in accessing necessary supports.^[24,25] This is more than achieving patient-centered and family-centered care. It provokes reflection on the context and impact of "dominant" or upheld positions and recognizes that these can be used in ways that can negate the patient or family's lived experience. Our data highlighted that caregivers contended with implied/imposed "rules and expectations about care in the typically private domain of home. It is evident from the themes elucidated for example resisting or submitting to ideals of care, and home as a "private" space that caregiver and service provider goals/priorities are not necessarily congruent. A critical perspective considers the extent to which caregivers exercise agency and resist or submit to dominant "ideals" or "truths" about care, alongside their own conceptualizations of the meanings of care and the associated costs. The agency of some

carers appeared to be enhanced by the available personal and interpersonal resources, which therefore shaped their experience. A critical analysis of these findings urges the palliative care service providers to interrogate paternalistic approaches to service provision and interventions in the context of care and death at home, and to attend carefully to the relational aspects of their work with caregivers.^[34]

5. Conclusion

Support provided by professional palliative care services and community care workers through the SPCPs was valued by family caregivers for enabling choice, if it was their preference to realize end-of-life care in the home, and provided practical assistance, emotional support, and reassurance.

Death may be natural but best practice palliative care requires skilled assessment and care, even for an “uncomplicated” death. Understanding the complexities of end-of-life care and the support needs of family caregivers in the home setting could improve services. Relationships where families and patients are partnered with, mentored, empowered, and feel comfortable with clinicians and volunteer caregivers are valued. Flexible practical assistance is valued highly and care arrangements that are not flexible may be more harmful than helpful for some families.

Finally, models of care that are based on the assumption that home death is straightforwardly beneficial may cause unintended consequences. Thus, providing care in the private space of the home requires close attention to family concerns, resources and outcomes. A deeper understanding of the costs and benefits of families’ caregiving in the context of palliative care bereavement will contribute to the development of models of community palliative care.

6. Conflicts of interest statement

The authors declare that they have no financial conflict of interest with regard to the content of this report.

7. Acknowledgements

The authors thank the participants who shared their experiences with us in the interviews. The Mapping Grief study was funded by the Commonwealth Department of Health as part of a University of Notre Dame Australia Collaborative Research Network grant. Additional research funds were provided by HammondCare.

References

- [1] Gomes B, Calanzani N, Koffman J, Higginson IJ. Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study. *BMC Med* 2015;13:235.
- [2] Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers’ mental health. *J Clin Oncol* 2010;28:4457–4464.
- [3] Swerissen H, Duckett S. *Dying Well*. Grattan Institute; 2014. ISBN: 978-1-925015-61-4.
- [4] Wright AA, Ray A, Mack JW, Trice E, Balboni T, Mitchell SL, et al. Associations between end-of-life discussions, patients’ mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2998;300:1665–1673.
- [5] Rainsford S, Phillips CB, Glasgow NJ, MacLeod RD, Wiles R. The ‘safe death’: an ethnographic study exploring the perspectives of rural palliative care patients and their families. *Palliat Med* 2018;32:1575–1583.
- [6] Garrido MM, Prigerson HG. The end of life experience—modifiable predictors of caregivers’ bereavement adjustment. *Cancer* 2014;120:918–925.
- [7] Sanderson C, Lobb EA, Butow PN, McGowan N, Price MA. Signs of post-traumatic stress disorder in caregivers following an expected death: a qualitative study. *Palliat Med* 2013;27:625–631.
- [8] Funk L, Stajduhar KI, Toye C, Aoun S, Grange G, Todd CJ. Part II: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998–2008). *Palliat Med* 2010;24:594–607.
- [9] Burke LA, Neimeyer RA. Prospective risk factors for complicated grief: a review of the empirical literature. In: Stroebe M, Schut H, van den Bout J. (Eds.), *Complicated Grief: Scientific Foundations for Health Care Professionals*. New York, NY, US: Routledge/Taylor & Francis Group; 2013; pp. 145–161.
- [10] Wong WKT, Ussher J, Perz J. Strength through adversity: Bereaved cancer carers’ accounts of rewards and personal growth from caring. *Palliat and Support Care* 2009;7:187–196.
- [11] Hughes ME. A strengths perspective on caregiving at the End-of-Life. *Aust Soc Work* 2015;68:156–168.
- [12] Stajduhar K, Funk L, Toye C, Grande GE, Aoun S, Todd CJ. Part 1: Home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998–2008). *Palliat Med* 2010;24:573–593.
- [13] Jack BA, O’Brien MR, Scrutton J, Baldry CR, Groves KE. Supporting family carers providing end-of-life home care: a qualitative study on the impact of a hospice at home service. *J Clin Nurs* 2015;24:131–140.
- [14] National Palliative Care Standards. 5th edn. Canberra: Palliative Care Australia; 2018.
- [15] Harrop E, Morgan F, Byrne A, Nelson A. It still haunts me whether we did the right thing”: a qualitative analysis of free text survey data on the bereavement experiences and support needs of family caregivers. *BMC Palliat Care* 2016;15–92.
- [16] Kramer BJ, Kavanaugh M, Trentham-Dietz A, Walsh M, Yonker JA. Complicated grief in caregivers of persons with lung cancer: the role of family conflict, intra-psychic strains and hospice utilization. *OMEGA J Death and Dying* 2011;62:201–220.
- [17] Eagar K, Clapham SP, Allingham SF. Palliative Care is effective: but hospital symptom outcomes superior. *BMJ Support Pall Care* 2018;0:1–5. doi: bmjSPACE-2018-001534.
- [18] MacLeod R, Johnson C, Yule S. Making it easier for people to die at home—an innovative programme in New South Wales, Australia. *Eur J Pall Care* 2015;22:26–29.
- [19] Poulos RG, Harkin D, Poulos CJ, Cole A, MacLeod R. Can specially trained community care workers effectively support patients and their families in the home setting in the end of life? *Health Soc Care Comm* 2018;26:e270–e279.
- [20] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–357.
- [21] Constantinou CS, Georgiou M, Perdikiogianni MA. A comparative method for themes saturation (CoMeTS). *Qual Res* 2017;17: 571–588.
- [22] Michalski MJ, Vanderwerker LC, Prigerson HG. Assessing grief and bereavement: observations from the field. *Omega* 2006;54:91.
- [23] Riessman CK. *Narrative Methods for the Human Sciences*. CA, USA: SAGE Publications; 2008; 244 pages, ISBN: 978-0-7619-2998-7.
- [24] Kincheloe JK, McLaren P. Chapter 10: Rethinking critical theory and qualitative research. In: Denzin NK, Lincoln YS, (Eds.). *The landscape of qualitative research: theories and Issues*. 2nd ed. Thousand Oaks, CA: Sage; 2003; pp. 433–488.
- [25] Harris D. Oppression of the bereaved: a critical analysis of grief in western society. *OMEGA* 2010;60:241–253.
- [26] Attride Stirling J. Thematic networks: an analytic tool for qualitative research. *Qual Res* 2001;1:385–405.
- [27] Higginson I, Sen-Gupta . Place of care in advanced cancer. A qualitative systematic review of patient preferences. *J Palliat Med* 2000;3:287–300.
- [28] Agar M, Currow DC, Shelby-James TM, Plummer J, Sanderson C, Abernathy AP. Preferences for place of death and place of care in palliative care: are these different questions? *Palliat Med* 2008;28:787–795.
- [29] Mohammed S, Swami N, Pope A, Rodin G, Hannon B, Nissim R, et al. I didn’t want to be in charge and yet I was’: Bereaved caregivers’ accounts of providing home care for family members with advanced cancer. *Psychonc* 2018;27:1229–1236.

- [30] Ward-Griffin C, McKeever P. Relationship between nurses and family caregivers: partners in care? *Adv Nurs Sci* 2000;22:89–103.
- [31] Sutherland N, Ward-Griffin C, McWilliam C, Stajduhar K. Structural impact on gendered expectations and exemptions for family caregivers in hospice palliative home care. *Nurs Inq* 2017;24. doi: 10.1111/nin.12157.
- [32] Funk LM, Allan DE, Stajduhar KI. Palliative family caregivers' accounts of health care experiences: the importance of "security". *Palliat Support Care* 2009;7:435–447.
- [33] Milberg A, Wahlberg R, Jakobsson M, Olsson E-C, Olsson M, Friedrichsen M. What is a "secure base" when death is approaching? A study applying attachment theory to adult patients' and family members' experience of palliative home care. *Psycho-onc* 2012;21:8886–8895.
- [34] Rosenberg JP, Horsfall D, Leonard R, Noonan K. Informal care networks' views of palliative care services: Help or hindrance? *Death Studies* 2018;42:362–370.