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Palliative and End-of-Life Care in the Home in Regional/Rural Victoria, Australia: The Role and Lived Experience of Primary Carers

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Abstract

Introduction: Palliative support services (generalist or specialist) can provide much-needed assistance to carers who are providing palliative and end-of-life care in their homes, but access to such services in regional and rural areas of Australia is poorly understood.

Objectives: This study aimed to explore the role and lived experience of primary carers who are providing palliative and end-of-life care in the home in regional/rural Victoria, Australia.

Methods: Nine female participants, of whom six were bereaved between 7 and 20 months were interviewed using a semi-structured interview technique. Each interview was audio-recorded, transcribed verbatim, and analyzed thematically.

Results: Two themes emerged: “*Negotiating healthcare systems*” which described the needs for multidisciplinary supports and “*The caring experience*” which discussed daily tasks, relationships, mental and physical exhaustion, respite, isolation, medication management, and grief and loss. Findings show that regional/rural carers have an added burden of travel stress as well as feeling overwhelmed, isolated, and physically and emotionally exhausted. Carers would benefit from greater flexibility for short-term respite care. The engagement of specialist palliative care services assisted the participants to navigate the health care system.

Some participants did not understand the value of palliative care, highlighting the need for general practitioners to conduct early conversations about this with their patients. Education is needed to build capacity within the primary palliative care workforce, confirming the importance of timely referrals to a specialist palliative care practitioner if pain or symptom control is not effectively managed.

Conclusion: Providing palliative and end-of-life care in the home is an exhausting and emotionally draining role for unpaid, primary carers. Multiple supports are needed to sustain primary carers, as they play an essential role in the primary health care system.

Keywords

palliative care, death/dying, family, support, respite

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Introduction

Providing palliative and end-of-life care for someone at home may span months to years depending on the recipient of care’s illness trajectory (Kenny et al., 2010). In their role, unpaid primary carers may provide physical, emotional, psychosocial, financial, and spiritual care to the recipient of care (Keesing et al., 2011), an essential service to primary health care delivery while saving the health budget billions of dollars (Stajduhar et al., 2010). Family members, friends,

and neighbors may undertake this role for various reasons and with a varying set of life skills, experiences, and philosophical outlooks (Burns et al., 2011; Wong & Ussher, 2009).

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Balancing the roles between caring for the recipient of care and one's other responsibilities, such as attending to the needs of one's household, work requirements, their co-morbidities or frailty, adds to the carer's burden (Lee et al., 2009). Therefore, carers need to be cared for themselves to avoid emotional overload, physical exhaustion, and sleep deprivation (Aoun et al., 2010; Lee et al., 2009; McConigley et al., 2010; McNamara & Rosenwax, 2010; O'Connor et al., 2009). Being unprepared or overloaded with information too early can also add to carers feeling overwhelmed (McConigley et al., 2010).

In Australia, specialist palliative care services operate at Levels 2 and 3 within the workforce capability framework to provide advanced palliative care and support in community and in-patient public or private settings for those patients with complex needs, as well as consultation and education to primary palliative care providers within Level 1 (Broom et al., 2013; Palliative Care Australia [PCA], 2018a). Level 1 palliative care includes services provided by the primary (generalist or nonspecialist) health care workforce, such as the patient's general practitioner (GP), and may include conversations about prognostication, goals of care, advanced care planning, and the management of basic symptoms and pain (Forbat et al., 2020; PCA, 2018a; Wiencek & Coyne, 2014). Referrals to other multidisciplinary health professionals may provide additional support to the patient in personal care, medication administration, aids and equipment, financial and social support, counseling, bereavement, and referrals to formal respite care within the three levels depending on need. Regardless of whether these services (or a form of them) may be available, cultural norms, nonacceptance of the life-limiting diagnosis, or the perception that palliative care services are for the end-of-life only are all barriers to engaging them (Heidenreich et al., 2014; Lee et al., 2009; Mason & Hodgkin, 2019; McConigley et al., 2010; O'Connor et al., 2009; Sekelja et al., 2010).

Australia is a vast country divided into classes of remoteness, including major cities, inner and outer regional, remote, and very remote areas according to the Australian Statistical Geographical Standard Remoteness Structure (Australian Bureau of Statistics, n.d.). For this research, regional and rural refers to all areas outside of the major cities. Literature highlights a reduction in available services proportionate to the distance required to travel from a major city (Tham & Ward, 2016 cited by Mason and Hodgkin, 2019; Weinhold and Gurtner, 2014). This is due to many factors, including greater demand for services due to an aging population, exacerbated by a structural shortage of G.P.s, supporting specialists, an experienced workforce, and the cost of service provision (Holloway et al., 2020; Weinhold & Gurtner, 2014). For those patients and carers living in regional and rural areas requiring palliative care for complex needs, a shortage of specialist palliative care practitioners requires travel to a major city, adding to caregiver burden and hardships (Miller & Porter, 2021). Poor

coordination between services also disrupts the smooth transition between in-patient and community services within regional and rural areas (Department of Health [DOH], 2018; National Health & Medical Research Council, 2011).

While urban studies have explored the needs of carers providing palliative and end-of-life care in their homes, little has been published about the role and experiences of carers in regional/rural areas of Australia, specifically West and Central Gippsland in Victoria, in the last ten years. It is important to understand current and bereaved carers' experiences in all regions of Australia to inform policy development, service provision, and access amidst a growing demand from an aging population and funding challenges (DOH, 2018; Miller & Porter, 2021). Therefore, the study aimed to explore the role and lived experience of primary carers providing palliative and end-of-life care in the home in regional/rural Victoria, the supports they utilized, and what the carers believed were their current and future needs. Research into understanding service use and carer experience aligns with the Palliative care 2030 vision (PCA, 2018b), so both current and bereaved carers were included in the study in order to answer the research question.

Methods

The study used an exploratory qualitative methodology underpinned by a phenomenological approach to understand the participants' thoughts, feelings, and perspectives (Whitehead et al., 2016).

Geographic Location and Services

Participants lived in West and Central Gippsland, 125–160 km east of Victoria's state capital city, Melbourne. Within this regional/rural area, there is a small city with a large regional public hospital with four funded palliative care beds, and a cancer center. The hospital does not have a dedicated palliative care unit, but the in-patient specialist palliative care team can review patients upon referral. Two funded in-patient palliative care beds are available at a smaller regional hospital, 55 km east of the larger hospital. The area has two funded specialist palliative care services within community health services, coordinating and providing specialist palliative care to patients and families through home visits from specialist palliative nurses and other multidisciplinary health professionals. Within this service model, the patient's G.P. maintains contact with the patient and provides the necessary medication prescriptions. For more complex needs, a referral can be made to a palliative specialist.

Sample Population

Primary, unpaid carers meeting the following criteria were invited to participate, specifically, carers currently

providing end-of-life care to a person in their home who had been diagnosed with a life-limiting illness, OR provided end-of-life care in the home but bereaved within the last 24 months; aged between 18 and 80 years; English speaking; able to attend an interview in the absence of the person they were caring for; and living in the regional/rural Gippsland area of Victoria, Australia.

Participant Recruitment

A regional community health service that provided specialist palliative nursing care agreed to recruit participants for this project from their database. A recruitment flyer was provided for dissemination to potential participants, but only one participant agreed to participate. It is unknown how many potential participants were contacted. After the first interview, the participant contacted another bereaved carer and invited them to participate in the study, thus beginning a snowball recruiting method between carers who had contact with each other via informal carer or bereavement groups or other social links and became a convenience sample. One current male carer was invited to participate in the study but declined due to being too busy. Participants interested in participating in the study contacted the research team to arrange an interview date and time and were emailed the plain language information statement.

Table 1. Semistructured Interview Questions.

1. Can you tell me who are you caring for, their name, and their age?
2. What is the medical diagnosis of [Keith]?
3. How long has [Keith] had this condition?
4. What does being a carer mean to you?
5. When [Keith] was first diagnosed as being unwell, were you given any written material or attended an education session that helped to explain what being a carer was about?
6. Do you feel the support you have received empowers you in your role as a carer?
7. Please share with me how [Keith's] illness has affected the family's ability to live and function day today
8. Tell me about the daily activities (toileting, showering, dressing, feeding, and medication administration) for [Keith]—does someone else assist you with any of these things. How is this for you?
9. Please describe any other support services that you use to help with caring for [Keith] and are they helpful?
10. Does [Keith] need to travel to appointments, if so, how often?
11. Have you discussed care with [Keith], and if so, what supports do you think you will require?
12. Please share what you believe are your greatest needs now and in the future?

Data Collection

Data was collected using a semi-structured interview technique audio-recorded and transcribed verbatim. The interview questions (Table 1) were prepared during the study's design by the first and second researchers and were not changed during the data collection process. The semi-structured interview questions allowed the first researcher to prompt the participant for further details and encourage them to expand their story. Field notes were written during and post each interview by the first researcher and were helpful for reflection and context to participant responses. Participants were provided with a plain language statement describing the study and a consent form before the interview, with written consent obtained prior to commencement. Eight of the nine interviews were conducted in the participant's homes; the other at the participant's workplace, at a time that was convenient to them in the absence of the recipient of care, with interviews lasting on average between 30 and 60 min. The researchers agreed that data saturation occurred after nine interviews as there were no new developing concepts or themes arising.

Data Analysis

The final data set was analyzed and coded into themes using Braun & Clarke's 6 step process for thematic analysis, which included becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining and naming the themes, and producing the report (Braun & Clarke, 2006). The first author read transcripts several times throughout the data collection process and discussed emerging themes with the second author. During the analysis process, the three authors coded together and reached a consensus on the themes. The participants and those they mentioned during the interviews were de-identified with pseudonyms to protect their identity.

Trustworthiness and Reflexivity

The Consolidated Criteria for Reporting Qualitative Research was adopted to improve the rigor, comprehensiveness, and credibility of reporting this qualitative study (Tong et al., 2007). In addition, trustworthiness was assessed, incorporating the concepts of credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985). A systematic review of the literature examining the needs of Australian carers (Miller & Porter, 2021) was undertaken which validated and supported the outcomes of this study proving credibility and consistency of data. Dependability was achieved in the form of field notes forming an audit trail. The second author helped the first author to maintain objectivity by debriefing and allowing the first author to maintain a professional distance at the end of each interview.

Confirmability was achieved by checking the audio-recordings against the transcripts.

The first author had no prior relationship with the participants but quickly developed a rapport enabling the participants to respond to questions in an open, honest and detailed manner. As palliative care is a sensitive topic, it was important for participants to feel comfortable and trust the researcher with their story (McGarry, 2007). The first author had minimal personal experience with grief and therefore believed she did not influence the participants.

Ethics Approval

Ethical approval to undertake this study was obtained from the University Human Research Ethics Committee in September 2018 (A18-099).

Results

The results section of this paper will be divided into two sections. The first will be a summary of the demographics, including the details of the participants and recipients of care, and secondly, the thematic analysis of the nine transcribed semi-structured interviews.

Table 2. Summary of Demographics.

	Bereaved carers	Current carers
Participants	6 women aged 47–64 years Bereaved between 7 and 20 months	3 women aged 37–69 years NA
Cared for	4 husbands, 1 mother, 1 father	2 husbands, 1 mother
Age of recipient of care	53–100 years at death	62–70 years at interview
Diagnosis	Cancers x3 (brain x2, oesophageal x1), type 2 diabetes mellitus x1, strokes x2	3 cancers (pancreatic, ovarian, prostate) including chronic obstructive pulmonary disease x2
Length of diagnosis	11 months–4.5 years to death	2.5, 2.5, 13 years, respectively at time of interview
Specialist palliative care engaged	Yes—4 (1 in final 3 months) No—2	Yes—1 No—2
Place of death	3 at home (by choice) 3 in hospital (2 choices to stay, 1 not)	1 at home, 2 not discussed

Demographics

Nine females were interviewed over 5 months; six had been bereaved between 7 and 20 months prior to an interview and were aged between 47 and 64 years. Of this cohort, the majority had adult children and grandchildren; one had teenagers. Four participants had cared for their husbands, one her mother and one her elderly father. Half of them died at home, and the diagnosis to the time of death ranged from 11 months to 4.5 years. Two husbands diagnosed with brain cancer received immediate treatment and were linked to specialist palliative supports upon diagnosis. Their decline varied—one died at 14 months and the other just over 3 years. A husband with esophageal cancer died within 11 months of diagnosis, but specialist palliative supports were not engaged until 3 months prior to death, due to efforts to find options from alternative medicine. Two of the three current women carers were grandmothers caring for their husbands (in their palliative phase), and the other cared for primary school children and her mother (in the end-of-life phase) in her home (Table 2).

Thematic Analysis

The data was analyzed thematically into two major and 11 minor themes as set out in Table 3. The thematic analysis of the findings section of this paper will be presented under the two major theme headings, “*Negotiating healthcare systems*” and “*The caring experience*.”

Negotiating Health Care Systems. The participants described the value and difficulties they faced engaging and communicating with the health care system within three minor themes.

Shared Decision Making. Communicating with health professionals caused angst for some of the participants at times as they could not comprehend who was in charge of the whole treatment process, felt they were not being listened to or involved in decision making:

[The Doctors] wanted to try all these things and we were saying, “We’ve already done all that stuff, it’s not

Table 3. Major and Minor Themes.

Major themes	Minor themes
Negotiating health care systems	1. Shared decision making 2. Specialist palliative care services 3. The value of bereavement care
The caring experience	1. Understanding the caring role 2. Reality sets in 3. A change to relationships 4. Mental and physical exhaustion 5. Needing time-out 6. Geographical isolation 7. Medication management 8. The rollercoaster of grief

working” ... We weren’t being heard. They had their processes they wanted to follow (Elissa).

On the other hand, despite Elissa’s desire for her husband to be involved in hospital decision making and to be part of conversations with the medical team, he eventually could not mentally cope. She firmly believed it was better for her husband’s mental health if the pertinent conversations were to occur outside of the room. She continued by explaining, “In the visitor’s area, where we could talk it all through. We could cry ... That was really good. But yes, there was a lot of things around that time that were handled incredibly well, and things that were handled incredibly badly [by the medical team]” (Elissa).

Specialist Palliative Care Services. The specialist palliative care services were viewed as essential by the participants who had engaged them, and they commented on the efficiency of linkages and referrals. Initially, Jasmine was not aware of the help a social worker could provide and attempted to complete the paperwork to receive welfare payments through Centrelink (Australian government welfare agency) herself:

It took me six weeks to fill those forms in and find all the documents. It was just so overwhelming, that when I finally did it, they told me I’d taken too long, and I had to start again. And it was like; I’m not going to do it. It was too hard. Lo and behold, along comes this social worker who just fixed it (Jasmine).

Of the three participants currently providing palliative care, only one had contacted a specialist palliative care service. The other two believed this service was only for the very end-of-life: “They probably stay away until someone really enters those final, final stages” (Nora). “They offered [palliative services] at the hospital [during chemotherapy] but we said ‘no we’re not ready for that yet’” (Irene). Of the six bereaved carers, four had engaged a specialist palliative care service, with two engaging at the time of diagnosis. The participants’ views of their specialist palliative care services were almost all positive, commenting that they phoned the service regularly for advice, no question was too trivial, and felt fully supported by the staff.

One of the participants regretted not contacting the specialist palliative care service early in her husband’s disease trajectory by saying:

We only found out about things like district nurses and palliative care and all that stuff ... when [we were] in the throes of really needing it. I feel like if I’d had things a little more mapped out [ahead of time explaining] ... “This is what it will look like, and this is how it will support you if you want to keep Phillip at home ...” I was finding out on the

go ... and being bombarded with information when my brain was struggling (Elissa).

Participants who had not engaged in a specialist palliative care service found the health care system more challenging to navigate. At times, frustration and delays were experienced when seeking medical care. Beth complained about repeating her mother’s story to her G.P.’s receptionists at every phone call, while Elissa and Nora faced admission delays at the local hospital. “The hospital thing that I was frustrated with ... is you have to go through [the] emergency [department]. There’s no route for people who are palliative ... I feel very strongly that there needs to be something” (Elissa). For Elissa, this occurred despite the G.P. organizing a bed in advance.

The Value of Bereavement Care. Both specialist palliative care services that the participants utilized provided bereavement care. This was highly regarded by the participants as expressed by Ruth who said:

Thankfully the books aren’t closed the day the patient dies. They’re left open for a year ... I know it’s only a few phone calls and things, but it’s very generous of the organization to have that as an end process of wellbeing ... It’s really, really important for the year (Ruth).

Although services were available, Ruth added that the nurses were very busy, “I do know the nurses don’t like to play the part in the bereavement process, understandably, because they’re too busy with the active dying” (Ruth). When asked about future needs, Ruth said that it was important that the bereavement service had an end date, forcing her to begin to move on. “You’ve got to move on in your life, you can’t be attached to palliative care and the nurses and the whole thing anymore. But it is something that is closure too, and everyone has different times where closure is” (Ruth).

The Caring Experience. The second overarching theme brought together the day-to-day tasks and experiences the carers faced as reality set in, including understanding the caring role, changing relationships, mental and physical exhaustion, needing time-out, geographical isolation, medication management, and the rollercoaster of grief.

Understanding the Caring Role. When asked about understanding their new role as a carer, participants stated they received concise information about the life-limiting illness at diagnosis, “but [not] the nitty-gritty of what’s ahead of you ... what complications are we likely to strike” (Elissa). For all participants, this began an extensive online search for further information. “We did the research ourselves more about what it is and how people have gone through the treatment themselves and how they’ve managed”

(Ruth). Eventually, two of the participants attended a 6-week carers' course at their community health care service.

Reality Sets In. The magnitude of caring for a family member with a life-limiting illness occurred gradually for some of the participants and for others this occurred immediately upon the receipt of an unexpected life-limiting diagnosis and surgery: "My husband's going to die and I've got to look after him for this time, straight away, day one" (Ruth), and felt the multidisciplinary team had taken over her home. "It means a rather large intrusion of strangers coming in, it means a change in your lifestyle at home" (Ruth). Elissa's response was similar, "It didn't feel like home. It felt like huge pressure on us to be doctors and nurses" (Elissa).

A Change to Relationships

Relationships changed during the caring role:

The change in being a wife to being a carer was just phenomenal, in how you communicated with each other and how I had to take on so much so quickly and make decisions (Ruth).

Well, it really put my relationship with my daughter on the back burner as well ... She felt she couldn't come to me with anything, for anything, because I was so worn out looking after him, she didn't want to put any more pressure on me (Dawn).

One of the participants was managing her young family as well as caring for her mother in her own home: "I'm a little bit stressed with [the University] workload and the hospitalizations where [mum's] really deteriorated—it probably has impacted on me and the kids a bit, and my husband" (Zoe). Whereas Irene, a current carer stated her family was only impacted regarding future planning ... "because we can't plan ahead because we've got to be around for treatments" [chemotherapy] (Irene).

Mental and Physical Exhaustion. The participants described feeling emotionally exhausted by "losing themselves in the care" (Dawn) and forgetting to shower, and Dawn added, "Mentally and emotionally, it's really taxing" (Dawn), and Elissa said: "There's chaos in your household, in your mind, in your heart" (Elissa). For Jasmine, managing urinary and fecal incontinence was exhausting:

Sometimes I was changing him six times a day ... in the bed. Doing all that washing and cleaning and keeping the house germ-free ... It was an exhausting process ... Sometimes I had to get my son to come and put him in the commode and hose him off (Jasmine).

Despite living in the community and having people coming into the home some of the participants recognized their isolation and reached out to form lasting friendships with the personal carers or nurses: "[the personal carer] still calls in ... we've just become very good friends" (Judith).

Two of the participants who had not engaged palliative services struggled with the added burden created by the lack of emotional and physical support. Dawn said, "I think [what] would have been really good is someone to talk to about your emotional and mental state and maybe some skills around looking after yourself" (Dawn). Many of the participants described online support groups as a mechanism to share grief and learn from one another with the benefit of remaining anonymous if needed. "It's a safe place [Facebook carers group] and we all get it. It's been fantastic" (Elissa).

Needing Time-Out. All the bereaved participants described the necessity of having a break whether it being through family or formal respite services yet only one of the nine participants received overnight respite from the extended family. Beth described the lack of support from her adult siblings saying:

Wow ... That's all you see me as, kind of the hired nurse ... and I don't get paid for it. The hired person who's just there to take care of all things to do with mum, even when you're there (Beth).

Dawn was able to negotiate one week of formal respite every three months and eventually, her husband was placed in an aged care facility in the last 3 months prior to death. On the other hand, Jasmine found that formal respite services did not meet her needs:

Unfortunately, all the aged care homes only do respite for two weeks. You're lucky if you can find one that will do it for a week. That's not what I wanted. I tried to explain to them that I don't know what's going to happen in two hours' time, let alone a week. I would just like him to go for two days so I can sleep. No one would do it for me (Jasmine).

Jasmine went on to suggest an in-home respite would suit many carers' needs better by saying, "That was one of the things that really needs to be looked at for people that are caring for the partner in the home, that need in-home respite because ... you just don't know what's going to happen and when it's going to happen" (Jasmine).

Geographical Isolation. The participants lived in regional/rural Victoria and often needed to travel in and out of the major city for cancer diagnosis, treatments, and other specialist appointments which they described as a tiring and expensive exercise. At other times, some of the recipients of care received treatment at the cancer center in the regional city.

It was always a really long day. Not just because of the travel, but the actual getting him from the house to the car, getting there, parking, getting into the doctor, fixing him up if he needed a drink, some lunch. All that, it was like almost

trying to take someone on holiday all in one day and bring them home again (Dawn).

Usually, the appointments were quite early in the morning, so we'd stay in a hotel the night before just so it was only 10 min away (Zoe).

Medication Management. Beth had medical experience and was able to liaise with her G.P. regarding the necessary medications, but for other bereaved participants and the G.P.s, managing uncontrolled pain or medication side effects was a challenging experience. Elissa explained: "We were ... going to the G.P. trying to manage the fentanyl patches ... We weren't getting it right. Either he was ... 'la la' or he was in pain" (Elissa). A referral was made for assistance from a specialist palliative medicine practitioner, but Elissa's husband died before this service had been implemented. Ruth's G.P. was also not comfortable or experienced in palliative care, so a specialist palliative nurse practitioner from the city provided much-needed expertise. Ruth said: "There are seven or eight drugs and integration of them all on how they all worked was the nurse practitioner's role, it was beyond our G.P., totally beyond our G.P." (Ruth).

Towards the end of the caring process, Jasmine struggled to have enough morphine ampoules to provide sufficient pain relief. Just as she had enough for the weekend, her husband died, and she explained the story this way,

I spent three or four days stressing out about how the hell am I going to get these scripts. I finally managed to get a bulk lot so don't have to stress, and now I don't need them. One hundred and sixty dollars' worth of script that I can't do anything with (Jasmine).

The Rollercoaster of Grief. The physical process of death was important for the participants to describe in detail and reflected their position in the grieving process. Three recipients of care died at home as desired, and three died in hospital; admitted due to pain management and symptom control issues in the final days/weeks of their lives. Two participants explained: "It was his wish to die in the hospital. He didn't want to leave me with the memories that he'd died here" (Ruth), and: "My son actually said, 'I would prefer Dad stays here [in the hospital] because our house was starting to smell like death'" (Elissa). Ruth also commented that it would be too strange to sleep in the same bed that her husband had died in.

One of the participants described grief as a "roller coaster" due to a perceived inability to maintain control of her emotions which began from diagnosis and continued throughout the bereavement period. Jasmine said: "You never know when it's going to hit, or for why or when or where or for how long. It just does" (Jasmine). Dawn described feeling relief:

I did go through grief and loss and all that sort of thing, and then once he had died, it wasn't so much shock as a relief for him. Relief for me, relief for my daughter even, because she got her mum back (Dawn). Whereas, Beth struggled with feelings of guilt: "My big thing is I have guilt ... I feel guilty that I'm glad she's gone, and I miss her terribly, but I was over it. So, I feel guilty that I feel free" (Beth).

Discussion

The findings from this study add to the body of knowledge on the topic of providing palliative and end-of-life care in regional/rural Australia and align with the need for research in this area as set out in the Palliative care 2030 vision (PCA, 2018b).

The participants in this study described their role as a primary carer as overwhelming and all-consuming, evidenced by a lack of self-care and physical and emotional exhaustion which is consistent with the literature (Aoun et al., 2010; Hatcher et al., 2014; Keesing et al., 2011; Lee et al., 2009; Mason & Hodgkin, 2019; McConigley et al., 2010; McNamara & Rosenwax, 2010; O'Connor et al., 2009). An inability to obtain sufficient time-out from formal respite or family support may have contributed to this and is needed to sustain the carer's own physical and mental health. The findings showed the negative impact the caring role had on some relationships and the importance of social connectedness, which some participants gained through online support groups and restored relationships when the caring period ended.

Participants described the benefits of engaging specialist palliative care services early receiving links to bereavement care and other multi-disciplinary health professionals, especially with a sudden diagnosis, immediate surgery, and a limited life expectancy as vital, and findings were supported in the literature (Aoun et al., 2010; Mason & Hodgkin, 2019; McConigley et al., 2010). The participants continued with bereavement services for 12 months post-death, maintaining established relationships important to them (O'Connor et al., 2009). Commencing bereavement counseling early in the caring process is also recommended to assist carers in moving through the grief process (Aoun et al., 2010; Sekelja et al., 2010).

The participants reported almost complete satisfaction with both specialist palliative care services that were utilized. Participants who did not engage in such services faced additional challenges negotiating the health care system and managing their caring role. Non-engagement or referral may be due to stigma around the meaning of palliative care and a lack of understanding of the supports that can be provided early in the illness trajectory, as was implied by some of the participants and echoed in the literature (McNamara & Rosenwax, 2010; O'Connor et al., 2009; Sekelja et al., 2010; Spelten et al., 2019). The experience of gaining

hospital admission for symptom control described in this study may not represent the local population but highlights the importance of smooth transitions and communication between services (Hatcher et al., 2014).

Shared decision-making and clear and straightforward information sharing were essential to the participants as information overload is common and needs to be given in increments to allow absorption (McConigley et al., 2010). All participants stated they received some information regarding the diagnosis but had to rely on internet searching, carer support groups, and the specialist palliative care service (once engaged) for information about the carer role.

Living outside major cities posed access and service issues for some participants in this study, demonstrated by one participant's need to stockpile morphine ampules for end-of-life pain relief over the weekend. The reason for this is unclear but may be due to the shorter opening hours of the pharmacy in her small town. Some participants and recipients of care had lengthy and costly travel episodes to appointments in the major capital city, which travel stress often added to physical and emotional burdens, which findings were confirmed in the literature (Hatcher et al., 2014; Lee et al., 2009; Rainsford et al., 2017; Spelten et al., 2019).

In Australia, primary health care providers (G.P.s, district nurses, aged care staff, hospital staff) are expected to have at least a basic understanding of palliative care (DOH, 2018; Nevin et al., 2019) in order to support people where they live, and should provide the majority of palliative care (Forbat et al., 2020). As was highlighted in this study, when end-of-life care becomes more complex, G.P.s need to be aware of what assistance is available and where and how to refer to specialist teams without delay (Broom et al., 2013). One of the goals of the National Palliative Care Strategy is to upskill and build capability within the primary health care workforce to keep abreast of the growing need for quality palliative care in line with the rise of the aging and chronically ill population (DOH, 2018; Johnson et al., 2020). To this end, specialists in palliative care have an important role in education and developing expertise within primary health care providers (DOH, 2018).

Implications of the Findings

This study demonstrates the importance of building capacity and knowledge within the primary health care workforce to improve understanding of language use and definitions of palliative care, including an agreed protocol and timeline for referring patients to specialist palliative care (DOH, 2017; Forbat et al., 2020) and advertising what services are available through local directories (AIHW, 2019). The findings from this study confirm the need for support and guidance to be provided to carers to help them understand their role as per the National Palliative Care Standards (PCA, 2018c) and should be initiated by the primary palliative care workforce.

G.P.s are well-positioned to initiate conversations about the role and benefit of palliative support services early in the disease trajectory to their patients, to de-stigmatize palliative care so patients may be more receptive to referrals when needed, and to encourage patients to engage in family conversations (Johnson et al., 2020).

Carers would benefit from more flexible short-term respite services, whether provided by formal facilities or health professionals who can stay in the home. Future research could be undertaken to examine the motivations and volume of referrals to the major city palliative care specialists to build a picture of the services and facilities that could be improved or expanded when providing palliative and end-of-life care to people in regional/rural areas.

Limitations

Only women aged between 37 and 69 years agreed to participate in this study, creating a gender bias and possibly a more active caring role than older women may have managed which may have affected the findings. A broader sample including a culturally and linguistically diverse population may have also altered the findings regarding the uptake of specialist palliative services and family expectations (Heidenreich et al., 2014). While the sample may not be an accurate representation of all carers in the region, data saturation was reached, and findings were consistent with other studies on carer experiences (Aoun et al., 2010; Hatcher et al., 2014; Keesing et al., 2011; Lee et al., 2009; Mason & Hodgkin, 2019; McConigley et al., 2010; McNamara & Rosenwax, 2010; O'Connor et al., 2009; Sekelja et al., 2010; Spelten et al., 2019). A snowball method in which some bereaved carers knew each other from their carer support group may have produced similar beliefs on some topics. The bereaved participants in the study had come to terms with their loss, whereas participants with unmet needs and in the final phase of providing end-of-life care did not agree to participate. Further research is needed to strengthen these findings in this and other geographical regions.

Conclusion

This qualitative study examined the role and lived experiences of primary carers providing palliative and end-of-life care in their homes in regional/rural Victoria, Australia. Important findings from this study include engaging specialist palliative care and other support services early if needed, more flexible respite care services, and improved communication and collaboration between health care services and carers. Implementing these recommendations will help to mitigate the physical and emotional exhaustion felt by carers and inform future policy and practice guidelines in palliative care.

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