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FEATURE ARTICLE

Exploring the role of palliative care occupational therapists in supporting compassionate communities in end-of-life care

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Abstract

Introduction: The compassionate communities' movement is a public health approach to end-of-life care that emphasises the integral role of communities in supporting and caring for dying persons and their informal carers. Although occupational therapists have well-established roles in palliative care teams, little is known about their potential in assisting in the formation and maintenance of compassionate communities.

Method: Data were gathered via semi-structured interviews with nine Australian occupational therapists with experience in specialist palliative care. Interview questions were based around the British Columbia Compassionate Community Ideal framework. Key themes were derived through qualitative descriptive analysis, blending deductive, and inductive reasoning.

Findings: Interviewees indicated that occupational therapists have a role in supporting compassionate communities that centres on the facilitation of networks and connections between palliative care professionals and in the promotion of informal care networks. The importance of education and awareness raising were also discussed as valuable to the development of community capacity. It was also suggested that occupational therapists have important skills to support dying persons and their caregivers to remain engaged and safe in their homes and communities, in a meaningful and sustainable way. However, many interviewees maintained a profession-centric view on control within compassionate communities, as opposed to approaches that are community led.

Conclusion: Findings offer early insights into the promise and potential of occupational therapists in supporting the compassionate communities' movement. However, education regarding the ethos of the compassionate communities' movement so as to facilitate a shift away from professionally oriented modes of practice may be needed to maximise success.

KEYWORDS
compassionate communities, end-of-life care, occupational therapy, palliative care, public health approach

1 | INTRODUCTION

Palliative and end-of-life care aim to enhance the quality of life for people with life-limiting illness and their caregivers through symptom management, care, and support (Palliative Care Australia, 2018). In recent years, challenges associated with the provision of quality palliative and end-of-life care have become increasingly recognised, particularly in relation to the growing number of people seeking access to this care. World Health Organisation (2020) data indicate that, internationally, approximately 40 million people require palliative care services yearly. In Australia, it is expected that the demand for palliative and end-of-life services will increase substantially over the coming years, highlighting the need for the development of sustainable models of end-of-life care (Palliative Care Australia, 2018).

Since the initiation of the modern hospice movement in the 1960s, there has been a shift in the recognition and management of death and dying within society (Remington & Wakim, 2012). Service provision has typically been provided by multi-professional teams, including, but not limited to, doctors, specialists, nurses, social workers, physiotherapists, occupational therapists, speech pathologists, psychologists, and counsellors (Abel & Kellehear, 2016; Australian Government Department of Health, 2019; Remington & Wakim, 2012). However, despite this model yielding some positive outcomes, there remains a concern that overreliance on specialist professionals as the primary form of end-of-life care is unsustainable and produces inequalities in service availability (Abbey et al., 2020; Horsfall, 2018; Kellehear, 2013; Paul & Sallnow, 2013). Empirical evidence suggests that palliative care services are unavailable for many dying persons and are not initiated until much later in the progression of the terminal condition than desired (Meredith, 2010; Mitchell, 2011; Paul & Sallnow, 2013; Sarradon-Eck et al., 2019).

Additionally, some argue that the professional management of death and dying has resulted in the disenfranchisement of communities from the dying process (Kellehear, 2013; Sallnow et al., 2022). Recent evidence, for example, suggests that many health professionals have a self-identified role within palliative care, and these roles tend to align with the professionals' traditional discipline-specific paradigms, rather than an expanded community-centric stance (Abbey et al., 2020; Kellehear, 2020; Paul & Sallnow, 2013; Pesut et al., 2017). These concerns have contributed to growing calls for approaches to care of dying persons that draw on public health principles by empowering communities to take increased ownership of end-of-life care. Palliative care approaches that do not solely rely on professional input, therefore, are becoming increasingly recognised as a necessary component for end-of-life care (Aoun et al., 2020; Rawlings et al., 2021).

Key Points for Occupational Therapy

- Occupational therapists have a potentially important role in supporting compassionate communities in end-of-life care.
- Targeted education will be valuable in improving the contributions of occupational therapists to compassionate communities.
- A reorientation from profession-centric models of care to community-oriented approaches is needed for best outcomes.

Compassionate communities are an important example of a public health approach to palliative care. As a model of end-of-life care, compassionate communities centre around the idea that health is everyone's responsibility, not solely the domain of health professionals (Kellehear, 2013). The movement advocates for the community to take on many responsibilities associated with caring for the dying person, while also providing support to the caregivers of these individuals (Abel, 2018; Kellehear, 2013). This approach positions formal service providers as being 'essential but not central' to the everyday care of the dying person (Horsfall, 2018, p. 45). It recognises that most dying persons have an existing (but small) inner network of informal carers who complete most of the physical care needs, typically a spouse, adult child, or close relative/friend. Beyond this, however, an outer network of informal care exists that has the potential to fulfil other needs such as yard maintenance, cooking, walking dogs, and cleaning (Abel, 2018). By building these circles of care, communities can be effective in addressing many of the practical, physical, social, psychological, and spiritual needs of the dying persons and their primary caregivers that might otherwise remain unmet because of the stretched capacity of formal health-care services (Abel, 2018; Kellehear, 2013).

A number of frameworks have been developed to support compassionate communities for end-of-life care. One such framework is the Compassionate Community Ideal (BC Centre for Palliative Care, 2020). The Compassionate Community Ideal is composed of five domains, these being: Awareness & Advocacy; Attitude & Commitment; Leadership & Capacity; Networks & Connections; and Opportunities & Recognition. These five domains can be implemented strategically to nurture community readiness and commitment towards the growth and maintenance of sustainable compassionate communities.

Palliative care health professionals have the potential to serve an important function in promoting and assisting the development of compassionate communities as a means of expanding the range and quality of the avenues of support available to dying persons and their caregivers (Abel et al., 2011). However, despite a growth in literature pertaining to the benefits of a public health approach to end-of-life care, there is still confusion and misperceptions among health professionals who work in palliative care regarding this concept (Paul & Sallnow, 2013; Sarradon-Eck et al., 2019). This is of concern because best outcomes can be achieved when health professionals work in genuine partnerships with community members to provide holistic care and support for the dying persons and their caregivers (Horsfall, 2018; Kellehear, 2020; Paul & Sallnow, 2013; Pesut et al., 2017; Rawlings et al., 2021).

Occupational therapists often work with the dying persons and their families within their homes and provide a wide array of practical and informational supports to enable comfort, safety, occupational participation, quality of life, and end-of-life preparations (Hammill et al., 2019; Mills & Payne, 2015; Talbot-Coulombe et al., 2022). Given this scope of practice, palliative care occupational therapists may be well placed to offer support in the development and maintenance of compassionate communities. Currently, however, there is a lack of published literature examining the role and capacity of occupational therapists in supporting compassionate communities in palliative care. Hence, this study aims to address this knowledge gap, by examining the perspectives of occupational therapists concerning their role in supporting the compassionate communities' movement.

2 | METHODS

2.1 | Methodological approach

A qualitative descriptive study design guided data collection and analysis in this research (Sandelowski, 2000). This research design allowed the exploration of the occupational therapist role in supporting the compassionate communities' movement by capturing the views and experiences of occupational therapists working in the field of palliative care. Qualitative descriptive research aligns with a relativist ontological and interpretivist epistemological stance, thereby positioning the individual experience of reality as relative and subjective rather than fixed (Nayar & Stanley, 2014; Nayar & Stanley, 2015). This position acknowledges the role of researchers in interpreting participants' narratives, meaning that the research findings are not intended to be universalisable, but rather a synthesis of participant experiences.

2.2 | Participant recruitment

Participants were sampled purposively, targeting Australian occupational therapists with experience in the field of palliative care (Creswell, 2007). A participant information sheet was uploaded to the Research4OT and Palliative Rehabilitation Facebook pages with permission from the page moderators. The participant information sheet was also distributed via the Australian and New Zealand Council for Occupational Therapy Education (ANZCOTE) network. Snowball sampling was also used, whereby interview participants were encouraged to pass the study details on to other occupational therapists who might be eligible for, and interested in, the study. Recruitment was conducted across a 5-month period from January 2022 until the end of May 2022.

Participants were eligible for the study if they (1) were occupational therapists currently practicing within Australia, (2) worked at least 50% FTE in a specialist palliative care role, and (3) had worked in a specialist palliative care role for a minimum of 12 months. For the purposes of this study, specialist palliative care roles were defined as practice roles designated specifically to the provision of occupational therapy services to a palliative care caseload. The decision to focus eligibility for this study on specialist palliative care roles was made because of a belief among the research team that specialist palliative care occupational therapists were more likely to be familiar with the recent development of the compassionate communities' movement in end-of-life care in comparison with therapists in generalist or non-palliative care specialist roles.

Participant recruitment continued until the research team believed that data saturation had been achieved, this being the point at which no new beliefs and ideas were presented in participant narratives (Creswell, 2007; Fusch & Ness, 2015). Efforts to ensure maximum variation among the participant sample were made by distributing the details of the study widely via multiple platforms and sources (Creswell, 2007).

Through the processes detailed above, nine participants were recruited for participation in this study. Eight participants identified as female and one as male. Years of experience in palliative care practice varied widely ranging from less than 5 years to more than 20 years. Four participants worked in the State of Victoria, two in New South Wales, and one each in Queensland, South Australia, and the Northern Territory. Three participants reported working in regional areas, two in metropolitan areas, one in a rural area, and three as a combination of metropolitan and regional or rural. Six participants described their practice settings as being a mixture of acute and community, two as acute only, and one with a sole focus on community. A summary of the participants' demographic data is outlined in Table B1. Some data have been presented in ranges so as to protect participants' anonymity.

2.3 | Data collection

Participants were emailed a participant information sheet, consent form, and three handouts explaining compassionate communities approximately a week prior to their interview. An interview guide (Appendix A) was used flexibly to steer the interview process and allow participants to discuss thoughts and ideas that were of importance to them (Kallio et al., 2016). A number of the interview questions were of a structured format, based around the five domains of the Compassionate Community Ideal, an internationally recognised framework constructed to support the development and maintenance of compassionate communities (BC Centre for Palliative Care, 2020). The remaining interview questions encouraged reflections on practice and consideration of factors such as enablers and barriers to the realisation of compassionate communities and were, therefore, of a semi-structured design. Prior to commencing data collection, the interview questions were piloted among the research team to ensure they were fit for purpose.

The principal researcher conducted all interviews using the video-conferencing program, Zoom. The interview times ranged from 33 to 80 minutes, averaging 50 minutes. All interviews were digitally audio recorded, with participant consent, and transcribed verbatim.

2.4 | Data analysis

NVivo 12 software was used throughout the data analysis process to assist in organising the data. Interview transcripts were read in their entirety by SS prior to commencing initial coding, to allow immersion within the data. Subsequently, SS and her co-researchers (DL and ND) completed initial line-by-line coding on the first two transcripts with SS then completing line-by-line coding on the remaining transcripts. Initial codes were discussed and refined through a series of meetings among the research team. Thematic analysis was then undertaken, beginning with deductive reasoning using the domains from the Compassionate Community Ideal framework followed by inductive analysis to capture ideas within the data that were not directly aligned with the framework. In order to promote transparency and rigour, memoing was also completed alongside the coding process to allow a record of key analytical insights and decisions that shaped the research findings (Saldana, 2013).

3 | FINDINGS

3.1 | Overview

Three key themes were identified within participant interviews: (i) 'facilitating end-of-life care networks and connections'; (ii) 'awareness raising and education for compassionate communities and end-of-life care'; and (iii) 'supporting engagement and wellbeing in home and community'.

3.2 | Facilitating end-of-life care networks and connections

The majority of participants expressed a belief that occupational therapists' ability to form and maintain networks and connections is a key skill they can utilise to support successful compassionate communities. Interestingly, the networks and connections that occupational therapists form with other health professionals and teams were given particular attention by participants.

> We're constantly trying to network with all of those teams, so everyone knows who we are and we know who they are … [P1]

> I think allied health more broadly is also in an excellent space and I think that network that runs alongside the medical model, which is allied health, I think just being connected to allied health colleagues is a great strength as well. And knowing what our colleagues do and how they might be able to help your client. [P2]

Although formalised networks of support such as health or social care services can constitute an important part of end-of-life care delivery, they are not community led and, therefore, do not directly align with the Compassionate Community Ideal. Most participants did, however, speak about the potential role of occupational therapists in developing and promoting informal networks of care. Although they noted that the accessibility of informal networks varies with each individual, they believed that occupational therapists can, at times, assist in identifying existing networks and in suggesting ways in which these networks can support dying persons and their caregivers during the end-of-life process.

> I've definitely seen through family members who have strong connections with sporting clubs step in … I think there's lots of different avenues. I think it's giving people the ideas and the empowerment to ask for help, to use the people around them … [P6]

> I know with a client recently; we sat down with the family. We did a timetable, an online Google Calendar, where people could log in when they were going to do meals and having that support … it doesn't tend to be a traditional OT role, but simply as an OT, we have those skill sets. We could absolutely do it, and if we are the one that had that therapeutic relationship, we are the one at the door. [P8]

However, some participants indicated a limitation in their ability to assist in mobilising informal networks of support for dying persons and their caregivers due to a lack of knowledge of where these supports might come from. To overcome this, these individuals stated that they work in close partnership with other members of the palliative care team in arranging informal supports.

> … we've got a volunteer coordinator … she helps organise our volunteers … otherwise, I don't know any linked up to the hospital per se, because I think they all usually tend to be NGOs [non-government organisations] or other service providers that we don't really have – like we have connection, but we don't have a direct connection to it. [P4]

Furthermore, despite their perceived potential roles in facilitating informal care networks, many participants expressed concerns relating to the capacity of communities in relation to their ability to provide reliable and quality end-of-life care.

> People would be very happy to go and do some shopping for you, but it's really hard to get them to come in and shower someone, or help change a dirty pad, when it's needed, which is often in the middle of the night. Yes, I think that's the thing, people are very compassionate and willing to help, but people are often scared and not sure how to help. [P3]

3.3 | Awareness raising and education for compassionate communities and end-of-life care

Participants frequently discussed the roles of occupational therapists in education and awareness raising with the dying persons and their caregivers. Their responses shed light on both helpful forms of awareness raising and education as well as areas in which gaps and limitations in existing practice were apparent. In some cases, the education and awareness raising discussed was practice-oriented, centring on issues such as safe manual handling and the use of assistive technology. Three participants indicated that occupational therapists are well-placed to offer education of this type to caregivers, not only because of their specific skill set but also because of their ability to empower and support everyday people.

> … showing that everyday people with their everyday skills can do it. You don't have to be a dynamo. You just need to relate to people well … [P9]

It could be argued that the practice-oriented education provided by occupational therapists simply constitutes a normal part of their professional role. However, education of this nature also aligns with the Compassionate Community Ideal because it can assist in supporting the effectiveness and sustainability of informal circles of care.

At a more macro level, participants suggested that occupational therapists may play a role in nurturing community knowledge in relation to the needs of the dying persons and their caregivers, as well as issues that can arise during the dying process. As part of this, participants highlighted an important role in encouraging and normalising conversations about death and dying as a means of increasing and readying the availability of informal supports. For instance, reflecting on the process of dying, one participant commented:

> I think occupational therapists can be good at really talking about the realities of situations and potential futures of situations as well, without creating fear. [P3]

Two participants also spoke about the limitations of current practice models, suggesting that the medicalisation and professionalisation of end-of-life care act as a barrier against the natural occurrence of compassionate communities. Importantly, one participant suggested that there is a lack of cohesion and connectedness between medically oriented services and the informal avenues of care through which compassionate communities arise.

> … the medical model and our hospital, [are] not great at preparing people and creating awareness … I would say our local area is probably quite disjointed. There's not a collective focus on doing it all together as a community. [P2]

A professionally oriented emphasis in relation to awareness raising and education was also present in the discussion among some participants concerning community education priorities. Although these education sessions were likely to have been of value, they reflect a degree of professional control rather than community-oriented partnerships.

> … education wise … we had education sessions, so I hold general ones, like when we do the grief and loss, when we've had those palliative care weeks, they find out what OTs do, but I can also get into the specific nitty gritty and do a presentation of what I do for palliative care. [P1]

Shortfalls concerning education and awareness raising resulting from a lack of knowledge regarding the specific needs of non-Western cultural groups were also discussed by three participants. These individuals emphasised that this is an area in which occupational therapists will need to improve on to be successful in promoting compassionate communities through education.

> … I think awareness is a lot of work … particularly on the occupational therapy spectrum – on how do we create a compassionate community that is inclusive? I don't think we do that well at the moment. We don't raise awareness in non-Western communities, and we don't know how to advocate very well for them. [P3]

3.4 | Supporting engagement and wellbeing in home and community

A number of participants spoke about the skill sets that occupational therapists have to support dying persons and caregivers to remain meaningfully and sustainably engaged in their homes and communities. Perhaps unsurprisingly, many participants alluded to occupational therapists' knowledge and skills in supporting dying persons and caregivers in remaining safe and, where possible, independent at home, even as the dying persons' support needs increase.

> I think, certainly the enablers around, from an OT perspective, is the ability that we can get some equipment to make life a little bit easier in there. I think being able to change the environment … to actually, just reassure that they're doing the right thing, to give them the right training around that manual handling … and for them to feel safe, that they can phone us if there is a symptom change or anything else. [P8]

One participant [P8] emphasised that the occupational therapist role in relation to support at home encompassed both the physical and psychological wellbeing of dying persons and caregivers.

> I would focus on our breadth that we have within OT, around the ability that we are not only able to look at the physical environment, but also the psychological environment that we're working within, and the carer being part of that as well, that we don't just see the patient as an individual, but really it comes as a package for the carer being part … or the family, and the community, being part of what we're looking at. [P8]

Participant P4 discussed the way in which planning for sustainable end-of-life care at home often involved logistical considerations and compromise through analysis of the capacity and needs of existing care networks.

> So a lot of family members go; 'We want to look after mum or dad … right until the end.' So working towards it involves … What's realistic, what's not realistic, what's going to be easiest. Coming to a compromise about the ideal situation [if] you had all your carers verse there's only one carer, what can we do in the middle? So I guess it's kind of a stepping it up and stepping it down and rating what you've got at home, what resources you've got … empowering the family members. But they can manage if you give some confidence, training and time… [P4]

Participants also spoke about the potential role of occupational therapists in supporting the continued engagement of dying persons and their caregivers within communities. As part of this, they touched on the importance of community engagement in bringing normality, meaning, and purpose in individual's lives.

> So, I suppose just to open up the scope that OTs are not just there to put in grab rails. It's really important that OTs go into this with an understanding that to do something like encourage community involvement, it's all of those skills that we need about engagement, and motivation, and purpose and meaning, and that side of it. Not just the practical side. [P5]

As was the case with strategies aimed at enabling dying persons to remain at home, facilitating engagement in the community was also recognised as requiring both mitigation against and acceptance of a certain degree of risk.

> But I also believe that when you're talking about people within community that occupational therapy is very key at looking at what is important to individuals and to their significant others with regards to maintaining those community connections … I know occupational therapists who are very based around evidence-based practice. However, I find occupational therapists that work in palliative care are a little bit freer with that, and they say, 'Hey, what works?' It doesn't have to be perfect. It doesn't have to always be what we would consider safe. The question is always, 'What works?' [P3]

The needs of caregivers in maintaining their own community connections were also highlighted as being important by the therapists interviewed. Doing so was seen as being critical to addressing the social isolation that can often be experienced by primary caregivers of dying persons.

> … that they haven't been socially isolated at home and just done the nursing care… Recognizing that the carer is still a person that needs occupation … that they need to be looking after themselves and still be a person … that they're not then just lost in the carer role. That they've still got a part of who they are, and that they're still engaged in their community and their support network. [P8]

4 | DISCUSSION

This study explored the potential role of palliative care occupational therapists in supporting compassionate communities in end-of-life care. Three key themes were identified from the data: (i) 'facilitating end-of-life care networks and connections'; (ii) 'awareness raising and education for compassionate communities and end-of-life care'; and (iii) 'supporting engagement and wellbeing in home and community'. Taken collectively, the findings point to a number of potentially important functions that occupational therapists could serve in supporting compassionate communities. However, they also suggest that shifts in the way in which occupational therapists in palliative care conceptualise their practice roles may be needed if they are to be successful in doing so.

This study's findings highlighted the value that palliative care occupational therapists place in supporting occupational engagement and wellbeing for dying persons and their caregivers within both their home and community. This finding reflects core aspects of occupational therapy practice that seem well aligned with compassionate community development, even though these elements of practice are not explicit in the Compassionate Community Ideal framework. Furthermore, the findings of this study also indicate that occupational therapists perceive themselves as serving an important function in facilitating both formal and informal networks and connections within community-based end-of-life care. If approached effectively, this role could be of particular importance in nurturing effective and sustainable compassionate communities, because occupational therapists often work with dying persons and their caregivers both in acute settings and their homes, thereby serving as an interface between the two. Hence, occupational therapists can come equipped with knowledge of a dying person's individualised care needs but may also find themselves closely connected to potential informal and formal networks of care that can otherwise go unnoticed within the confines of acute care settings (Mills & Payne, 2015).

Interestingly, however, participants in this study also declared that they are often unaware of potential sources of support, relying on other professionals, such as volunteer coordinators to identify informal care options. It is also noteworthy that many participants expressed concern regarding the capacity of compassionate communities to provide reliable and effective end-of-life care. This differs from the perspective of Abel (2018) who describes communities as being the 'backbone' of formal health services (p. 7). Future research specifically examining the concerns held by occupational therapists regarding the capacity of compassionate communities may, therefore, be of value to better understand barriers against professional engagement with the compassionate communities' movement. This research could also be used to guide priority areas that need to be addressed to achieve genuinely connected end-of-life care delivery encompassing both formal and informal networks of care.

The palliative care occupational therapists interviewed in this study also recognised their function in community awareness raising and education concerning particular topics relating to end-of-life care. Often, however, the emphasis tended to focus on education around the occupational therapy role rather than education and awareness raising to empower and strengthen compassionate communities, reflecting the maintenance of a profession-centric perspective. This professionally oriented focus is not atypical for health professions in relation to compassionate communities and has been noted in research for other professions such as social workers, nurses, and medical professionals (Remington & Wakim, 2012). It is clear from this that more work needs to be done to reorientate health professionals, including occupational therapists, to the community-led ethos of public health palliative care, and indeed, compassionate communities. As such, consideration is needed as to how occupational therapists could adopt a broader, more flexible, and community-led focus on development and education to assist communities in the support and care of dying persons.

It is possible that organisational influences play a greater role than professional philosophy in dictating occupational therapists' perspectives concerning their role (or potential role) with compassionate community networks. Occupational therapists within formal health services are typically governed by a variety of legislative and policy requirements that can limit their ability to genuinely partner with these informal networks. For example, uncertainty in relation to the knowledge and capacity of communities in managing the care of the dying, coupled with concerns about medico-legal consequences should things go wrong, may contribute to a reticence among therapists to form authentic practice partnerships. It is perhaps, unreasonable, therefore, to expect occupational therapists to take a lead in embracing compassionate community initiatives in the absence of legislative and policy frameworks that support and protect them in doing so. Evidence suggests that these structural challenges are not peculiar to palliative care occupational therapists. In their recent review of the literature, Rumbold and Aoun (2021) identified that examples of authentic co-design between formal and informal end-of-life care networks remain rare, in part due to the complexities of governance arrangements associated with these partnerships.

Although the legislative and policy landscape presents some challenges for occupational therapists in working alongside compassionate communities, the findings of this study suggest that therapists do have a desire to assist in the formation and maintenance of these communities where possible. To be successful in achieving this, palliative care occupational therapists may need to turn their attention to other elements of the Compassionate Community Ideal framework in order to reconceptualise and develop their practice potentials (BC Centre for Palliative Care, 2020). For example, much could be done in relation to the role of the profession in nurturing leadership and capacity, supporting attitude and commitment, and harnessing opportunities and recognition, so as to grow and empower compassionate communities within their local area. This shift in focus should be within the reach of occupational therapists because occupational therapy theory recognises community development approaches and development of partnerships as key forms of practice (Whiteford et al., 2017). For example, occupational therapists have useful skill sets in rapport building, development of connections, and shared problem solving that can serve as a catalyst to encourage community cooperation. Occupational therapists are also well positioned to assist their local communities in identifying and addressing occupational needs among community members (Pollard et al., 2010). Approaches such as these will need to be given increased attention over and above clinically oriented emphases for the capacity of occupational therapists in supporting compassionate communities to be realised.

To achieve this, work needs to be undertaken to assist occupational therapists in better understanding public health approaches to end-of-life care. Meredith (2010) has previously argued that the uniqueness of the occupational therapy role within end-of-life care necessitates the development and delivery of undergraduate and postgraduate palliative care-specific content. The findings of this study support this assertion but point to the importance of the inclusion of education that brings to light compassionate communities as a key aspect of end-of-life care provision. Critically, however, emphasis must be placed within this education in ensuring that any future professional efforts to engage with compassionate communities are undertaken in a manner that ensures professional control does not inadvertently override the strength of communities (Paul & Sallnow, 2013; Sarradon-Eck et al., 2019).

5 | LIMITATIONS AND IMPLICATIONS FOR FUTURE RESEARCH

A number of limitations are present within this research. Firstly, only three out of the nine participants had heard of the compassionate communities' movement prior to their involvement in this study. Although this highlights the importance of better education concerning compassionate communities, it does limit the overall strength of the findings concerning the potential occupational therapy role.

Secondly, all three researchers involved in data analysis in this study are from Westernised cultural backgrounds, which may have influenced the lens through which findings were constructed. Similarly, the scope of this study was limited to Australian palliative care occupational therapists and a large percentage of participants worked in rural and regional areas. It is possible, therefore, that particular beliefs and or practices associated with these locations may have shaped the study findings. Further research exploring occupational therapy perspectives from countries outside of Australia and/or with a greater emphasis on metropolitan practitioners may offer further insights into this evolving aspect of practice. In addition to this, although the decision to focus recruitment upon specialist palliative care occupational therapists was beneficial in highlighting the viewpoints of professionals with particular expertise and experience in end-of-life care, the decision to do so may have obscured potentially interesting perspectives from occupational therapists practicing within a wider range of fields.

Finally, the research team acknowledges that the sole focus of this study on perceptions of occupational therapists concerning their professional role, rather than the perspectives of community members, may, itself, run counter to the ethos of empowerment underpinning the compassionate communities' movement. This limited focus was a pragmatic decision based on an assumed current limited public knowledge regarding palliative care occupational therapy practice and theory. Regardless, future research examining the viewpoints of communities regarding the potential contributions of occupational therapy would likely offer important new insights.

6 | CONCLUSION

This research was undertaken to explore the potential role of palliative care occupational therapists in supporting compassionate communities within end-of-life care. Results from nine semi-structured interviews revealed three prominent themes: 'Facilitating end-of-life care networks and connections'; 'Awareness raising and education for compassionate communities and end-of-life care'; and 'Supporting engagement and wellbeing in home and community'. The findings shed light on a number of potentially valuable aspects of occupational therapy practice that could be utilised to support the compassionate communities' movement. Importantly, however, reorientation away from profession-centric modes of practice towards community-led approaches will be needed to maximise these contributions.

AUTHOR CONTRIBUTIONS

We, the authors, declare that the contents of this research paper are original and have been developed and written by the authorship team. Samantha Smith contributed to the methodology, collected all research data, analysed the data and constructed themes, and completed the original draft of the manuscript. Daniel Lowrie and Nathan Dawes advised on the research methodology, contributed to the data analysis and construction of themes, and edited the manuscript in advance of journal submission. All three authors are accountable for the authenticity, accuracy, and integrity of the study.

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CONFLICT OF INTEREST STATEMENT

None of the authors of this paper have a conflict of interest to declare.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

ETHICS STATEMENT

The James Cook University Human Research Ethics Committee granted ethical approval for this study (approval number: H8620).

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APPENDIX A: INTERVIEW GUIDE

Introduction

a. Introduce myself (4th year OT research honours student)
b. Consent—reiterate purpose of research and obtain verbal consent to participate

Part 1

Demographic questions:

a. Age
b. Gender
c. How many years ago did you graduate as an OT?
d. How long have you worked in palliative care?
e. What state is/was the palliative care role in?
f. Is your palliative care experience within a metropolitan area or a rural & remote context?

Part 2: Main Interview

1. Can you tell me what you knew about the compassionate communities' movement in end-of-life care, prior to hearing about this study?
2. What are your general thoughts regarding the current or potential OT role within the compassionate communities' movement?

I am now going to ask you some questions about the current or potential OT role in relation to 5 key domains of the Compassionate Communities Index created by the British Columbian Centre for Palliative Care in Canada. Please note, that it does not matter whether or not you know about this index, I am just interested in hearing your thoughts about its different elements. I would also add that, it might be that you have not given a lot of thought to some of these elements or, perhaps, do not see them as being part of the OT role. If that is the case, it is okay. We are just looking to explore palliative care OTs' current thoughts on compassionate communities and strategies for their enablement.

3. Awareness and Advocacy:
    a. What is your understanding of and thoughts on awareness raising and advocacy as a means of highlighting community knowledge concerning the needs of dying persons and their caregivers?
    b. Are you aware of any local or national initiatives that support this awareness raising and advocacy?
    c. What role (if any) do you think OTs might play in awareness raising and advocacy as a means of promoting community knowledge concerning the needs of dying persons and their caregivers?
    d. Can you think of any examples from your own practice, or practice that you have observed, where this occurred? Can you tell me a little bit about this?
4. Attitude and Commitment:
    a. In what way, if any, do you think that the general community in the area where you work demonstrates a commitment and willingness to provide support and assistance to dying persons and their caregivers?
    b. Based on your observations, what form does this assistance usually take?
    c. What do you see as the enablers and barriers to the provision of this support?
    d. What role (if any) do you see OTs playing in trying to mobilise community-based supports for dying persons?
    e. Can you think of any examples from your own practice, or practice that you have observed, where this occurred? Can you tell me a little bit about this?
5. Leadership and Capacity building:
    a. Are you aware of individuals or groups in your local area who undertake leadership roles in promoting the involvement of communities in the support of dying persons and their caregivers? Can you tell me a little bit about the sorts of things that these individuals do in fulfilling these roles?
    b. What role (if any) do you see OTs as having in leading on the development of the confidence

    and capacity among lay community members in providing care and support to dying persons and their caregivers?
    c. Can you think of any examples from your own practice, or practice that you have observed, where this occurred? Can you tell me a little bit about this?

6. Networks and Connections:
    a. Are you aware of any informal (voluntary) support organisations available to dying persons and their caregivers in your local area?
    b. What role (if any) could OTs play in linking people with informal support organisations to assist in the care and support of dying persons?
    c. What role, if any could OTs play in linking dying persons and their caregivers with other forms of informal support, such as families and friendship circles?
    d. Can you think of any examples from your own practice, or practice that you have observed, where this occurred? Can you tell me a little bit about this?
7. Opportunities and Recognition:
    a. Are there any groups/organisations/initiatives that you think would be helpful partners to link in with to promote the compassionate communities' movement? And, if so, how might you go about doing this?
    b. In what way (if any) do you think OTs might be able to recognise, support, and celebrate the work of others within the compassionate communities' movement?
    c. What might be the role of the palliative care OTs or the OT profession in promoting compassionate communities' success stories?
    d. Can you think of any examples from your own practice, or practice that you have observed, where this occurred? Can you tell me a little bit about this?
8. Thinking about everything we have discussed so far. What (if any) enablers do OTs have at their disposal to be successful advocates for the compassionate communities' movement?
9. Can you think of any barriers that might exist to preventing OTs from supporting the success of the compassionate communities' movement?
    a. How might these be overcome?
10. Thinking about your own practice, what key steps could you take to assist in better supporting the development and success of compassionate communities within your local area?
11. Are there any other ways palliative care OTs might contribute to the development and success of compassionate communities that we have not discussed so far?
12. Hypothetical question: Imagine you are in a forum, in which you have been asked to impart your thoughts about compassionate communities to a palliative care OT audience, what are the three key crucial components you think you would discuss that would allow our profession to successfully work within this initiative?

Close interview (revisit verbal consent)

APPENDIX B

TABLE B1 Participant demographic data.

Participant	Age (years)	Gender	Number of years as a graduated OT	Number of years in a palliative care role	State/territory of palliative care role	Context	Practice setting (acute/community/mixed)
1	51–55	Female	6–10	5–10	NSW	Regional	Mixed
2	46–50	Male	6–10	<5	VIC	Regional	Mixed
3	46–50	Female	21–25	5–10	VIC	Regional & metro	Mixed–mainly acute
4	36–40	Female	11–15	5–10	NSW	Metro	Acute
5	56–60	Female	16–20	11–15	VIC	Rural	Community
6	41–45	Female	21–25	5–10	VIC	Regional & metro	Mixed–mainly community
7	36–40	Female	16–20	<5	QLD	Regional	Acute
8	41–45	Female	21–25	11–15	SA	Metro	Mixed
9	61–65	Female	41–45	>20	NT	Rural & metro	Mixed–mainly community