

Compassionate community structure and function: a standardised micro-model for end-of-life doulas and community members supporting those who wish to die at home

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Abstract

Background: End-of-life doulas are an emerging, non-medical support and advocacy role for the dying and their caregivers. As more and more people are dying at home, research shows end-of-life doulas are increasingly in demand as non-medical advocates and companions for the dying, and their friends and families. Compassionate communities are essential to those who wish to die at home by helping to avoid carer stress and burnout associated with physical and emotional labour when a person is at end of life. However, compassionate community models are top-down in nature as they focus on public policy, missing a domestic-scale, standardised design applicable when someone wishes to die at home. This gap affects care networks and communications and arguably hinders the work of end-of-life doulas.

Aim: Findings from original qualitative research with end-of-life doulas in four countries demonstrated the importance of compassionate communities for death literacy and support for a person at end of life and their networks and that all practitioners were using ad hoc, variable approaches to compassionate community formation and maintenance. A micro-level standardised and replicable model for organising and maintaining compassionate communities for end-of-life doulas which completes the established compassionate community model was developed to fill this gap and provide a vital tool for end-of-life doulas and training programmes internationally.

Methods: Thematic analysis of research data from qualitative semi-structured interviews with end-of-life doulas in four countries was undertaken and considered as a cohort as well as by country.

Conclusions: A model was developed that addresses a gap in international approaches to practice, offering a standardised way to discuss, teach, and implement compassionate communities for end-of-life doulas in a variety of countries and languages. This article discusses the research and model in detail.

Keywords: compassionate communities, dying at home, end of life, end-of-life doulas, model of care

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Background

The role of end-of-life doulas is a relatively new one, experiencing a surge of interest and uptake in many western nations, and research is in the early stages of the field and those who chose this occupation.^{1–3} End-of-life doulas work as supports and

advocates for the dying and those close to them, although the approaches to practice and interaction will vary according to a person's training/s and the customs developing in each country where doulas are working. While some doulas work as volunteers, others are paid in this role – either as

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Table 1. Years participants have been working as end-of-life doulas.

Country of participant	Number of participants	1–3 years	4–6 years	7–9 years	10+ years
Australia	8	1	2	2	3
Canada	1		1		
The United Kingdom	9		2		7
The United States	10	2	4	2	2
Total	28	3	9	4	12

Table 2. Number of end-of-life doula training courses undertaken by participants.

Country of participant	Number of participants	1	2	3	4
Australia	8	3	2	2	1
Canada	1	1			
The United Kingdom	9	8	1		
The United States	10	5	4	1	
Total	28	17	7	3	1

part of a team on a salary, or as a private arrangement with individuals and/or families. End-of-life doulas do not usually live in as end-of-life companions, and although this may occur, it is a rarity as most doulas travel from their homes to be with clients (either in private homes, in medicalised environments or aged care facilities) or work remotely via phone and video call in times of COVID lockdown.

As with any emerging field, approaches to practice are still in the process of discovery and standardisation is ongoing – universals include holding a non-medical role, compassion and listening. At the time of writing, the field is overwhelmingly populated by female practitioners, as males and non-binary persons are still in the minority of students and identified practitioners. Original research conducted with end-of-life doulas (26 female, 2 male) from four countries (Australia, Canada, the United Kingdom, and United States) examined the intersection of end-of-life doula work and compassionate community formation – including barriers and facilitators to compassionate community formation with clients (Tables 1 and 2).

The data from research participants confirmed that there is a gap in terms of a straightforward,

well-understood, replicable micro-model for compassionate community coordination and structure, and that end-of-life doulas frequently help to build and foster micro-level compassionate communities for clients and their networks. However, approaches to practice that would arguably streamline individual practice as well as helping to consolidate professional identity are still in formation; compassionate community formation on a small/domestic scale is one area that would benefit from standardisation and help to bolster professional identity internationally. One aspect of dying at home that is well researched is the number of people required to have someone die at home with no carer burnout and minimal stress: 16, according to Horsfall *et al.*,⁴ which the model can readily accommodate.

Compassionate communities as a social model offering support to those at end of life are well-documented, and there are many pilots, trials, and successful examples to date in several countries around the world.^{5–7} In addition to the compassionate community model at neighbourhood and community levels, there are also projected compassionate cities underway.^{8,9} However, discussions and models of compassionate communities are macro- and meso-scale, aimed at public and social policy writers and community framework

designers to enable top-down rollouts.¹⁰ To date, there is no formalised, replicable micro-level model for a compassionate community designed to work specifically in a domestic setting when someone wishes to die at home; end-of-life doulas, palliative care teams, and other support workers have been creating ad hoc systems to date. The compassionate community general overview model developed by Abel¹¹ alongside discussions of the dying person is a six-tier structure reaching up to macro policy level but does not address or facilitate small-scale, everyday domestic networks which end-of-life workers and family members alike can both understand and readily implement and/or replicate.

Aim

Given that Abel's model is established and functions well at the macro and meso levels, the Mallon model is designed to dovetail with the compassionate community layers already in place. Tailored for the domestic environment with three 'roles' for the network participants to move between, the simple and effective Mallon micro-model of compassionate community function described here will facilitate an effective support network when someone wishes to die at home,^{4,12,13} and – in essence – completes Abel's model. The Mallon model is designed to work in any domestic setting, and to encompass multi-layered, variable, and flexible sets of individuals who interact with the home of a person who is at end of life. While the roles are nuanced and flexible in terms of movement between and across roles for compassionate community members, given the inherent simplicity of the model itself, replication and implementation of the model for end-of-life workers is straightforward and lends itself to translation into multiple languages with relative ease. As the model consists of three roles and each role has a single word title, the model is not only flexible and adaptable, but easy to remember which is a boon for people who would like to focus their time and energy on a person at end of life, rather than on a complicated model with multiple or confusing titles.¹⁴

Methods

The original research undertaken by the author (University of Western Sydney HRE clearance number H12662), consisted of qualitative, hour-long semi-structured interviews of seven questions; with one face-to-face interview exception

the interviews were conducted via Zoom video call.¹⁵ The interview questions asked participants to consider and discuss their role of end-of-life doula in terms of compassionate communities, continuity of care, death literacy and how clients respond to working with end-of-life doula. Criteria for participation included some considerations of professional identity; therefore, only those who had undertaken a minimum of 5-day training explicitly labelled as 'end-of-life doula' were included; some applicants with considerable experience in death support were excluded as a result; however, the focus on end-of-life doula practitioner perspectives was a central focus of this research.

Recruitment took place online, and all participant names were changed to pseudonyms to protect participant anonymity. Participants responded to calls for participants via Facebook, Twitter, and email addresses used with permission from Inelda¹⁶ from a publicly available state-by-state list of registered practitioners – and via word of mouth where the research call for participants had been passed along to potentially interested parties, as with End of Life Doula UK.¹⁷ With the training criteria in place, those who were present at end of life and/or death by way of other training and medical-focused employment (nurses, palliative care workers and the like) were excluded so that the non-medical aspects of end-of-life doula work remained a constant. Those participants with medical training and backgrounds were quite careful to describe the differences of what they talked about and awareness of the difference of a medical role to that of the non-medical end-of-life doula. *Alex* (UK) encapsulated his significant tangible difference in status and perception thusly:

... how angry and upset I got when I thought, as a retired doctor, I would be able to form alliances with community palliative care services in my locality ... they gave me a brush off. I was really distressed by that. It was part of the journey that was about my retirement, no longer having an identity as a doctor and realising that this kind of work is really different, is really different. And, what it calls for, is something very different.

While Canada has a high number of end-of-life doulas and high-profile training options for end-of-life doulas, due to legal proceedings taking place over the use of 'death midwife' as an identifier which affected peak body and individual

business branding, identity, email addresses and other communication interactions, only one participant from Canada was able to be included in this study.¹⁸ Emails were returned as website domains were changed to reflect an initial court finding against a well-established practitioner and trainer who had used the term ‘death midwife’ her entire career; while this finding was later overturned, the timing of the initial court case and the research project’s recruitment phase overlapped. Multiple attempts to connect with practitioners were made; however, higher numbers of Canadian practitioners were not possible for this research.

Enacting feminist research praxis, a verbatim transcription of the audio-recorded interviews by a transcription service followed by a full-transcription review by the author, the initial transcripts were returned to individual participants for editing and approval, thus empowering participants by ensuring their statements and perspectives on practice are represented as authentically as possible.^{19–21} The returned, approved transcripts comprise the project data set, and thematic analysis was conducted on each of the 28 data sets individually, then collectively.²² Findings overwhelmingly demonstrate that compassionate community structure and function are a high priority for practitioners, and that each practitioner – regardless of whether or not participating in a peer or regional group to exchange ideas or working as an individual with no team or group for support – has their own approach to creating and building a compassionate community at the micro-level for clients. No participant used a specific, identified and replicable system for compassionate community formation and function that was not unique to their own practice approach.

The research shows that not all participants were entirely familiar with how compassionate communities may relate to their own work with individuals and families, and how vital a standardised, generally understood lexicon and approach to compassionate community aspects of end-of-life doula work is. For *Arcadina* (UK), compassionate community dynamics are present, but not articulated or clear:

Well, it’s with the family, and the family are always involved because you know family dynamics can be complex things and people’s approach to end of life can vary enormously, depending on the family dynamic. But I haven’t thought of it in terms of compassionate communities at all.

For *Athena* (Australia) the genuine risk of carer burnout is evident from personal as well as professional experience:

... for me working with clients and communities it’s about, I’m going to say plugging the gaps. Because I found, personally when I was caring for my parents through their deaths, some of the things that I needed support with were weird, little things.

For others, compassionate community formation was included, but not necessarily standardised: *Amber* (Australia)

Well, one of the first things I do is in the initial interview process of when I’m sort of establishing where families are at, where an individual is at. Where a group is at, that I’m identifying who is in their circle, or circles around them. ... I’m looking at all the medical professionals and or nursing, or hospitals, or units, or departments. I’m really looking to identify pretty much anyone. And so as they’re talking, I invite people to tell me the whole story.

And from *Sheila* in the United Kingdom, we have a glimpse of where a standardised, straightforward model can also help families and friends who want to help but are not sure how or in what way:

People want to help but are scared to ask or are waiting for the client & family to tell them what they want and on the other hand the family don’t like to ask so you can end up with a bit of a vicious circle.

Strategies for forming compassionate communities range from the general and for information dissemination: *Geoff* (Canada) ‘Right now I’m very subtle with everything I do. ... putting stuff out there on social media’, *Alex* (UK)

I spend quite a lot of time, probably around 80 or 90 percent of my time, when I’m involved in this kind of work, doing things like death cafes and other types of community events that just bring people together and start the conversations. Then, from that, every now and again, somebody gets in touch with me and I see them one to one.

and *Lydia* (Australia) ‘Having open, transparent conversations, talking about what I do. Doing education sessions ... and that can be formal or informal or with large or small groups or even

individuals' to the quite detailed for information collection described by *Jane* (Australia): 'I think it starts with listening on a one-on-one basis. ... the most important thing for me is to build the picture of where they're at and what they want from it [compassionate community]'. *Helen* (USA) offers a pragmatic and personal view:

The community surrounding an individual in the time leading up to their death is important in bringing about non-judgemental, compassionate care. By making myself available, not only to the patient but to their family and care team helps establish trust. Being present and giving of my time, strengthens that foundation of trust and encourages a dialogue among the patient and the family and allows them to be vulnerable and open to what they feel they need during this time.

Therefore, in terms of community of practice development, having a standard, readily replicable micro-model of home-based compassionate community will assist in strengthening the professional aspects of the field and support the work of end-of-life doulas considerably.²³

The first of the interview questions concerned the creation and building of compassionate communities as a part of the end-of-life doula role, and most participants had very clear ideas of how this was achieved in their work. As end-of-life doulas act in a non-medical, advocacy and support role – rather in the manner of birth doulas who act as emotional coaches during labour and sometimes post-partum^{24,25} – the networking aspect can take place whether or not someone is in hospice, hospital, or home for end of life and palliative care stages, as a personal life continues even when someone is 'dying'. Pets need to be cared for, information needs to be transferred among support network members regarding household tasks, such as laundry, shopping or transport for appointments, and administrative tasks including bills and personal correspondence still need to be attended to. Pets are a very important part of the family for most owners, and end-of-life doulas are aware of this fact.^{26,27} *Gilda* (USA) works with a team that includes pet specialist services: '... sometimes we have volunteers that only work with the pets, go over and walk the dog or take it to the vet, or things like that'.

Furthermore, updates regarding the health status of the person at end of life often need to be given,

both in person or as part of a 21st-century social media presence.^{28,29} Most participants emphasise being client-centred in the course of their work, focussing on bringing extant skill sets to the role. For example: *Keisha* (Australia) notes 'My professional background is in community', which enables her to bring a broad-based compassionate community structure together effectively for clients, as she routinely links to local events and community-based resources as a part of her work. *Myra* (USA) discussed the need for a re-embracing of being cared for by a community in a way that is familiar:

A compassionate community is flying in some ways, against the culture, and at the same time, if you dig down a little bit, almost everybody understands what it's like to be cared for by community. Whether from their childhood or from their work people, or, you know, there's some place in their life that they've felt the power of the collective that comes together to help somebody. So, expanding on that ... that is that the place that I'm seeing that is when people realise that they don't know how to do that and they don't have it set up – and: how do I do that?

The model here allows for very clear delegation of communication and information transfer responsibilities, helping everyone in an end-of-life compassionate community to function more effectively and appropriately when it comes to discussing personal information or being accountable for ensuring changes to schedules are communicated in a timely manner.

Results

Often people at end of life are unaware of how a compassionate community can be a powerful network of support and comfort, especially when a client is spending a good deal of time in hospitals and forgetting about domestic life as a centre of identity and care.^{4,30} As *Hayley* (USA) sees it, her role as an end-of-life doula is to help people overcome the reliance on doctors and the medical system in terms of families being disempowered and struggling to come together when someone is at end of life:

The medicalisation [of life] has also then left a crevice, a huge crack, in the system that people fall into. If someone in the medical field doesn't come and fill that, or bridge that, space families are ill-prepared for how to walk or bridge that themselves.

In terms of helping people see the compassionate community as a genuine asset, *Cynthia* (USA) succinctly states: ‘... identifying resources that people have that they may not realise are resources’. *Sheila* (UK) works with clients to identify everyone in their circle can contribute: ‘I find out what capabilities all of them have either by talking to them or listening to what they have done so far for my client and build from there’.

The main themes discovered in the research are: clarity of the end-of-life doula role boundary as non-medical; confidence that end-of-life doula work is needed in both domestic and medicalised environments and systems for end-of-life support and advocacy; understanding that networks of support are essential for the dying but no formalised approach was identified.

As identified in the themes, even with all the skills and ideas that end-of-life doulas bring to compassionate community work as a part of their role, there is no consistency of verbiage, approach or structure to the compassionate community network, meaning that death literacy advocacy is arguably hampered,³¹ and the emerging end-of-life doula field is missing out on community and consumer understanding of the potential benefits they can offer to someone at end of life.^{12,32–35} For *Kitty Swelligant* (USA), in-home work is different to hospice work: ‘... referral, people’s experience, then wanting other people to have that experience and the rippling out’, so private practice clients often arrive via word of mouth at this point in the development of her end-of-life doula work.

Fundamentally, for an emergent, grassroots, community-based field, like end-of-life doulas, having a replicable, known framework like a micro-model for compassionate community formation for someone who wishes to die at home can go a long way in establishing consistency and confidence in clients and in general community awareness.¹⁴ Simultaneously, additional death literacy efforts can gain traction^{31,36,37} due to a firm and replicable lexicon from the micro-level compassionate community model and the three roles identified in the [Mallon] model. Based on the findings of the research project, and bearing in mind the structure of the Abel model earlier, the model will now be examined at length.

The Mallon model – three roles

Given the stresses and uncertainties of end of life, the model has three roles. These roles support effective function of a small-scale compassionate community network and facilitate ease of reproduction in action, making this an ideal model for end-of-life doulas. Ideally, each role would contain multiple members of the compassionate community network at any given time – although there may also be circumstances when some cross-over between roles for individual members will be a natural part of a network’s mechanism. As *Florence* (Australia) identifies, the relationships are essential for end-of-life compassionate communities: ‘Ultimately, it’s about relationships. And that’s not necessarily about the relationship I have with the person I’m working with. It’s about the relationship that the person who is requiring support at end-of-life has with their community’. With a community aim and flexibility of capacity and availability of individuals in mind, the three roles are: Intimate, Gatekeeper and Peripheral. It is important to note that all three roles together are essential for the overall compassionate community to function effectively and well (see Figure 1, below); proximity to the dying person per se does not therefore dictate ‘importance’ in terms of the role undertaken in a compassionate community network.^{38,39}

Vitality, while the roles are useful in terms of delineating work and supporting both the members of the compassionate community and the person at end of life, the roles are not fixed or permanent. Specifically, one person may at differing times occupy all three roles during the course of caring for someone at end of life. As each of the roles has a particular focus of work and purview, shifting between roles may help to effectively support people who require space in order to process anticipatory grief⁴⁰ or attend to matters in their own lives,⁴¹ as well as people who are comfortable with, and look forward to, spending time being close to the person who is dying. While the roles are designed for adults, tasks within each of the roles – and spaces within the household of the person at end of life – will be a good fit for children and pets also. It is quite important when someone is dying that children and pets be included in routines and task participation for all three roles as modelling compassionate community work is often best transferred through action.^{27,42} Depending on need and numbers of people in a compassionate community at any point in time, it may be appropriate for an

end-of-life doula to act in any of the roles, or all of them at times, depending upon need. While this model has been devised with the idea of flexibility in mind, ultimately all decisions regarding roles must be guided by the needs and wishes of the person at end of life, as well as their close network of support.

The roles will be discussed at length here below, but may be summarised as follows:

- **Intimate** – aspects of this role involve personal care and extensive periods of time spent with the dying person. Ideally suited to people who are personally close to the dying person and for personalities who like to ‘be’ in times of heightened emotion for themselves and/or others. Over an arc of extended time for end of life, this role will specifically suit those with the capacity for holding space with a person at end of life and/or actively dying for long periods of time while listening and being in silence when needed.
- **Gatekeeper**¹ – this role is concerned with information dissemination/withholding and maintaining boundaries regarding access to both information and the home itself on behalf of (and in consultation with) the dying person. Ideally suited to people who thrive on being an organiser, those who are comfortable both saying ‘no’ to hold a firm boundary, being flexible while negotiating, and those whose personalities like to be ‘organising’ in times of stress.
- **Peripheral** – this role is concerned with tasks and routine aspects of running the household of the dying person but does not entail contact with the person who is dying (although there may be minimal contact if both the person at end of life and the person in this role are comfortable with that level of contact). Ideally suited to people who like to be ‘doing’, are not necessarily personally close to the dying person and who wish to contribute to the compassionate community, and for personality types who may feel emotionally overwhelmed at times of stress but who flourish when their focus is directed to being task-oriented and of service without taking on a mantle of directive authority.⁴³ This role also functions as a community-connected respite space when the *Intimate* or *Gatekeeper* roles have been onerous for an individual.^{44,45}

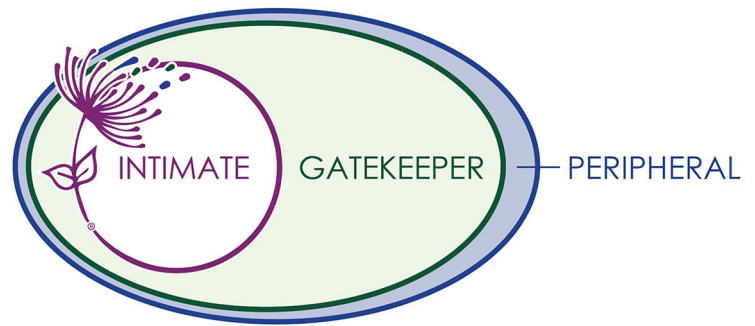


Figure 1. The three roles of the {name} micro-model.

The Intimate role

Aspects of this role include sitting with, reading to, talking with, sleeping near, entertaining, and holding a space for presence around the dying person. Notably, a good deal of active presence and listening in silence may be required in this role, especially as active dying occurs.⁴⁶ The paradox of having one’s end of life and death at home is that we are – ideally – socially supported at a time when we are withdrawing into ourselves,^{47,48} but a compassionate community does involve people being present with them – or available to be present, depending on the wishes of the dying person (Figure 2). As *Amber* (Australia) describes, the person at end of life may not desire many people around them: ‘they [clients] may only want to have a couple of people [close around them], their primary person. Maybe some of their family, but we can have an extended network outside that ...’.

The person/s engaged in this role may or may not consider that regular respite from this work, which may have gradually evolved over time to be more all-consuming than the carer may realise, is essential to avoid carer burnout. Therefore, at least a few people comfortable with acting in this role in a compassionate community would be ideal.⁴¹ If there is a primary carer – and often this is the spouse or partner of the dying person – then a break at a minimum frequency of twice a week needs to be scheduled for personal time and personal errands; having more than one person acting in the Intimate role helps facilitate this respite. Often an end-of-life doula is one of the people working in this role, particularly when the client may not have many people around them at all in a social network, or is at a physical distance from friends or family members.

The intimate role can be quite intense, especially at times when the person/s in this role are

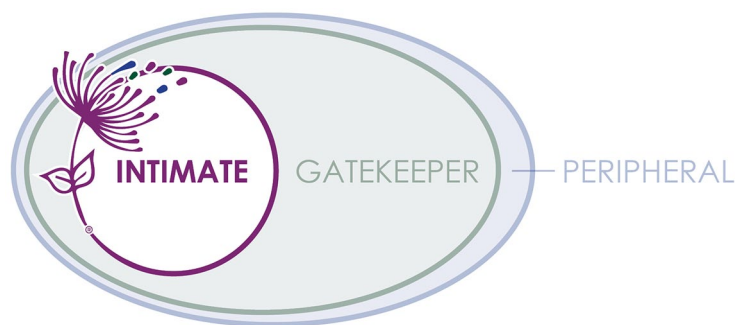


Figure 2. Intimate role in context.

experiencing strong levels of emotional feeling or are pushing through their own physical tiredness and ignoring their own bodily and psychological needs.^{44,45,49} Members of the compassionate community who are functioning in other roles can play a key part in helping maintain a healthy equilibrium for those in the intimate role by offering pre-agreed forms of practical support. Good communication, as ever, is essential; sometimes, an end-of-life doula will step in to initiate conversations about rest and healthy self-care for those in the intimate role, smoothing the path for the rest of the compassionate community to step into the supportive routines and spaces needed to ensure all members of the network avoid burnout and remain as positively connected as possible. As *Victoria* (USA) states: ‘So, in terms of ... slipping in and out of various roles ... it’s really patient driven, and I’d much rather it be that way in the first place ... it’s really about the care that they [clients] need at that moment’.

N.B: The work of dressing and undressing, washing, and toileting sometimes sits within the intimate role, but these tasks may also be shared with, or taken over by, professional personal care staff. Sometimes engaging health and care support workers from outside the initial compassionate community helps to strengthen the connection between those in the Intimate role and the person at end of life because time and energy can be concentrated solely on the personal connections, rather than on care tasks. As a bonus, care support workers may become welcome members of a compassionate community and offer new communication and support opportunities for the person at end of life.⁵⁰ An end-of-life doula can help to support ongoing conversations around the delivery of personal care needs – for both the dignity of the person at end of life, as well as for the health and physical safety of the carer/s in this role.

The Gatekeeper role

Gatekeepers are quite active in terms of holding boundaries and transferring information between the dying person and their household, between the household and the outside world, and arranging the schedule for the person at end of life. Gatekeepers may spend a good deal of time on the phone or online liaising with medical and allied health staff, negotiating appointments for the dying person – personal and professional – and ensuring that the wishes of the dying person are enacted insofar as this is possible. Gatekeepers often actively update social media and scheduling platforms, thus interacting with and updating friends, colleagues, and acquaintances of the dying person, so this is also a role that requires a good deal of sensitivity and a capacity for nuanced communication skills at times (Figure 3).⁵¹

In addition to communicating with the world outside of the compassionate community, Gatekeepers also work to liaise and update members of the compassionate community itself, so there is a good deal of communication and administrative work that goes into this role. End-of-life doulas are particularly suited to performing in this role, as they are both *internal* and *external* to a compassionate community network – a position which facilitates effective and rapid information transfer as noted in Tushman and Scanlan.⁵²

There are digital options to support coordination of activities, for example, online-only organising platforms and social media apps do offer many avenues of support for calendar planning, status updates, and communication between members for those networks who are all comfortable with having digital interactions. Of course, some households prefer to use non-digital means of communication, and a large calendar or whiteboard on the fridge, or at another central point in the home, works quite effectively to let everyone know what is happening in terms of appointments and the weekly ‘to do’ list, as noted by both *Adrienne* (USA) and *Keisha* (Australia). Kitchen areas – refrigerators in particular – frequently become the space for the schedule to be displayed as members of the compassionate community will usually be in the kitchen at some point of the day, and kitchens are traditionally gathering points for home-based communication historically.^{53,54}

One of the challenging aspects of the Gatekeeper role – and a good reason not everyone will be comfortable in *all* parts of this role – is that of

holding firm to boundaries set by the client.⁵⁵ Boundaries may relate to relatively innocuous aspects of life, such as styles of music not to be played in the house, but some boundaries specifically relate to which people the dying person wishes to see or to whom information will be communicated regarding the end-of-life journey of an individual. A boundary around access of this kind may mean that not everyone in the compassionate community may be comfortable with holding firm to the dying person's wishes, or even find themselves in accord with the decision taken to exclude someone. End-of-life doulas may be called upon to mediate and support dynamics of communication and dialogue regarding responses from members of the compassionate community in instances of this kind, helping to foster understanding and empathy when the realities of personal choice also layer over the reality of end of life and immanent death.^{56,57} This is where the Gatekeeper role in this model is especially useful for reminding everyone in the network, regardless of the role/s they occupy, that the compassionate community in this instance is focused supporting someone to die at home; the wishes or ideas of other people in the network around the dying person are not the priority.

There are times when a decision to exclude a person, or to withhold information from someone, has been taken with an eye to safety – and it is important to recognise that the history may not be known to anyone. From this position, end-of-life doulas model the Gatekeeper role for the other members of the compassionate community, so the social model of activism, action and information transfer is in evidence,^{38,58} which also offers a place for questions and dialogues from everyone in the compassionate community as needed. Holding a boundary with compassion and empathy simultaneously acts to reinforce trust, nurture communication and permit discussions of doubt, fear and vulnerability; often these discussions relate to the reality of imminent death from members of the compassionate community. As *Florence* (Australia) states: 'As a Doula, I will be 100% supportive around anything safe and anything legal that someone wants to do at end of life'.

In the end, therefore, the Gatekeeper's actions are always informed by the dying person's wishes, and the Gatekeeper's underlying function is to hold boundaries well; there may well be times when the end-of-life doula is the person best equipped to function in this role simply due to the

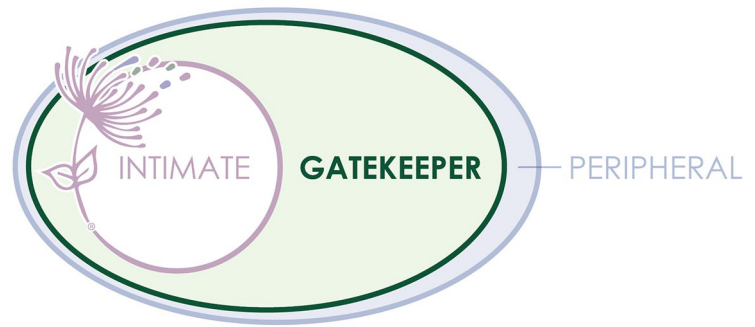


Figure 3. Gatekeeper role in context.

separation from the personal history which led to a boundary being formed in the first place. End-of-life doulas are also well positioned to mediate and negotiate shifting and/or softening in a boundary regarding people – again, due to emotional detachment from prior history of interactions – and are well positioned to support and facilitate opportunities for a person at end of life to resolve past hurts.¹²

If any member of the compassionate community does not feel comfortable with the boundary-holding aspect of the Gatekeeper role, then open and frank discussions about limits and alternative people to attend to boundary-related work within this role will need to take place and be negotiated. End-of-life doulas who have a team of colleagues to call upon to cover shifts when vigiling can ensure that this role is fulfilled at all times, but when working alone, people whom the dying person trusts will be occupying this role and maintaining good communication will therefore be especially important to ensure no lingering stress or distress is unduly affecting the Gatekeeper.^{45,59} End-of-life doulas in this role will need to ensure good professional practice by regularly scheduling peer or professional supervision and regular debriefing.^{60,61}

The Peripheral role

The Peripheral role is one that is focused on facilitating the practical running of the household around the dying person, and undertaking the tasks that make the routine of daily life possible without requiring the direct input of the primary carer/s (Figure 4). Laundry, pet minding and care, cleaning the house, collecting the post, gardening, school-runs and childcare, grocery/household shopping and general errands are some of the more common tasks that this role covers.^{30,62} People

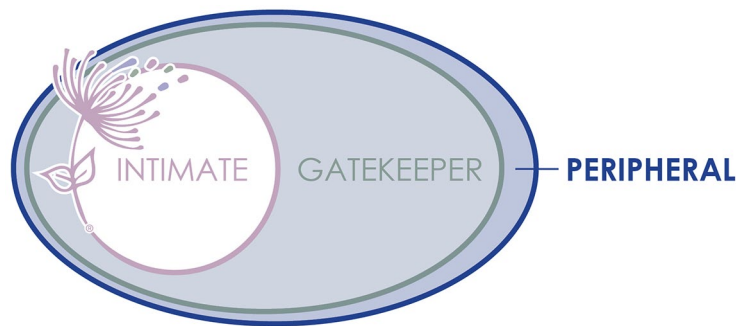


Figure 4. Peripheral role in context.

who prefer this role may be more loosely connected to the dying person than those in Intimate or Gatekeeper roles – neighbours or work colleagues, for example – but would like to be included in the support system.⁶³ Alternatively, people in this role could be close to the dying person and may genuinely struggle with the knowledge and reality of immanent death.^{40,64,65} Sometimes, it is a matter of personal or cultural boundaries around entering the intimate personal space of someone they do not know well.^{66,67} Regardless of the motivation, this role is an important one, and for the compassionate community to truly work effectively, this role needs to be recognised and valued as much as the Gatekeeper and the Intimate roles.

As mentioned above in the Intimate role discussion, those close to a dying person may not recognise their need for additional support, and this is one area where those in a Peripheral role can be particularly helpful in offering a range of support options to help ease the stress and burdens experienced by a person in the Intimate role.^{68,69} An example of support options might include being in company with someone in the Intimate role when they take meal break. It is especially important for older primary carers to retain social contact around food and meals,⁷⁰ or stopping for a cuppa and a chat when the person in the Intimate role takes a bathroom break, or gets ready to leave the dying person's space to go to their own home.⁴⁵ Regularly scheduled, as well as impromptu, breaks can be offered and negotiated by a Peripheral person, although a different compassionate community member may end up accompanying the carer for outings. For example: a Peripheral person may recognise that physical movement has not been a priority for an Intimate person, and an end-of-life doula, Gatekeeper or another Peripheral person may go for a walk with them.⁵⁴

Alternatively, when an Intimate person has not had much contact with people other than the dying person, a Peripheral person may arrange for the Intimate person to come with them to a café for a break, or – if there is a dog in the house – to take the dog out to the park for some playtime.^{26,71} As *Alex* (UK) notes on the importance of including pets at end of life: '... So, animals, pets and all sorts of other critters ... are really integral to this part of what actually is going on here'. Arranging for time out of doors, or at least out of the home, is often a good opportunity to bring both children and pets into the orbit and routine of someone in the Intimate role; however, sometimes silence may be needed so an adult companion may be a better choice. Checking in with the carer in the Intimate role may not have been possible, so an end-of-life doula is often a good point of information contact to ensure the appropriate support can be offered to the person in the Intimate role. In addition, when a micro-level compassionate community is working well, an end-of-life doula may be best suited to this role, maintaining contact with the general family system but not immediately involved in communications or direct care. This would be appropriate when the client is friends and family rather than the dying person, and the network is running effectively and well with minimal facilitation required.

The Peripheral role space may be one that a close friend or family member occupies for some, or all, of the end-of-life timespan – while for people who are coming to terms with the reality of death, particularly if this is the first end-of-life process someone has been witness to, the Peripheral space permits an individual to contribute to the compassionate community network in tangible and practical ways without being in overwhelm.⁴¹ When a person acting in the Peripheral role is personally close to the dying person, the Peripheral role itself can support an acceptance of the inevitability of death, which then often sees a person's capacity to sit comfortably in the space of the dying person increase.¹² Sometimes a Peripheral person moves into the Intimate role, and this shift may be permanent or occasional depending on the network needs and the emotional and psychological resilience of the individual Peripheral person.⁷² An end-of-life doula is often a neutral contact point for checking in and confirming comfort levels and discussing responses to increased time spent with the person at end of life, helping to ensure no member of the compassionate community over-stretches their boundaries and comfort levels.^{44,61}

Conversely too, a person who is very comfortable being in a Gatekeeper or Intimate role for the majority of their time may elect to occupy a Peripheral role on an occasional, or regular, basis due to the stresses and strains of their usual role.⁴¹ Arguably, this is one of the strongest arguments in favour of well-planned and –organised end of life compassionate communities: flexibility offered to network members in moving around within the roles to maintain good mental and physical health. This is in addition to offering spaces that can be tailored to best include personality types, while respecting an individual's personal boundaries and the relationship any individual person has with the person at end of life. The Peripheral space fosters community and contact with both the person at end of life, as well as the overall network, and there are times in the end-of-life space where practical, mundane tasks and chores may be soothing and calming. Although this particular aspect of micro-model compassionate community function is straightforward, the absence of a formalised system in the past has meant that end-of-life doulas have not considered functionality from this perspective. For example, when asked to think about compassionate community formation in a systemised way *Arcadina* (UK) offered: 'You know, I haven't even thought about that ...'.

Some compassionate communities may have a check-in point for shifting into Peripheral roles for those in Intimate or Gatekeeper roles either on a whiteboard kitchen schedule or as part of an online calendar arrangement. Alternatively, an end-of-life doula may be the contact point for moving between roles – each compassionate community will have its own dynamics and particular preferences for communicating and negotiating. Ultimately, one of the best benefits of a well-planned compassionate community wherein all the roles are understood and respected is that all members are offered judgement-free options and choice within and between roles.

Conclusion

...for a lot of people it's task-driven. Here are the things that you can do.)people don't really know what to do, they say they want to, but they don't really know what to do until we give them something to do. *Cynthia* (USA)

As Cynthia notes here, community benefits of the compassionate community micro-model include

helping people to both feel and be useful in contributing in tangible and relevant ways to the quality of life for the person they know who is at end of life.^{4,38} The role of end-of-life doula is projected to continue growing as our ageing populations return to dying at home as a normal site of end of life and death. End-of-life doulas can offer a specific set of skills, particularly advocacy and personal time to listen and support clients and families, that the medical roles are not capable of offering. Given that compassionate communities can be nurtured and facilitated at the micro-level in private homes, and end-of-life doulas are already often working in private homes, a standardised micro-model of compassionate community function that is straightforward and readily understood by both families and end-of-life doulas is a sensible and timely tool for supporting clients. The Mallon model will arguably bring consistency of death literacy in terms of network function to end-of-life practices in many countries, contributing to end-of-life doula professional identity and facilitating individual contributions to a support network for someone at end of life.

Furthermore, while palliative care does offer a good deal to someone at end of life, there are known issues and gaps in medical palliative care delivery,^{73,74} several of which can be filled when an effective micro-model of compassionate community is in place and an end-of-life doula is engaged as part of the overall end-of-life support network. The Mallon model is responsive to the needs of network members, flexible, easily tailored to suit personal needs, and can be coordinated to suit a network's member numbers and schedules (pp. 4–5).⁷⁴ In addition, the recognised benefits and advantages of palliative care – reliable medication delivery, input from medical professionals on a regular basis, and regular contact with compassionate nurses⁶ – can be facilitated when the standardised home-based micro-model of compassionate community is in place. Participant *Kitty Swelligant* (USA) identified the need for a consistent micro-level framework thusly: 'So, no one is really addressing the whole community of the dying and their families'. Clearly, issues pertaining to a gap in end-of-life systems for families and friends are well-known in the end-of-life doula field, and the micro-model of compassionate community can help address this gap. In addition, friends and family of the person at end of life are offered a variety of roles, with flexibility for moving between roles, helping to be inclusive of personal community while safeguarding against burnout due to an overburden of care. All compassionate community members are able to move, or not move, between micro-model roles as

appropriate to their own personal needs, thus ensuring the person at end of life is supported by people who are consciously present and who are empowered with agency throughout the end-of-life journey.

Author contributions

Dr Annetta Mallon is the sole designer, researcher, data collector, data analyst, writer, editor/revisor and also responsible for Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; Drafting the work or revising it critically for important intellectual content; Final approval of the version to be published and Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved and also the approver of this article.

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Notes

1. I have known some colleagues seriously, and accurately, refer to this aspect of compassionate community work as being just like the bouncer to a VIP section in a club.

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