

Developing compassionate communities in Australia through collective caregiving: a qualitative study exploring network-centred care and the role of the end of life sector

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Background: The new public health palliative care movement calls for a move away from an individualised model of caregiving to a whole of community approach which will increase expectations on community carers. In order to avoid carer isolation, exploitation and potential burnout there is then a very real need to understand environments and relationships which support collective community caregiving. In this research we explored in-home caring networks to understand if and how network centred care supports carers of the dying while developing a whole of community approach.

Methods: Over a 6-year period the research team spoke to 301 caregivers, service providers and community members via interviews and focus groups in regional, rural and urban Australia.

Results: People are already caring for their dying at home and doing it well provided they are comprehensively supported by networks of care. Being part of a caring network provided people with a sense of achievement and developed their death literacy which flowed into a myriad of other community activities. While caring networks are essential they are not widely supported by service providers. At worst, services are obstructive of peoples stated preferences for place of death and caring and often adopt a paternalistic approach. Place of care, in this case the home, was supportive of maintaining networks and peoples' wellbeing.

Conclusions: Operationalising public health approaches to palliative care requires moving to a place-based network centred model of care comprising formal and informal carers. Service systems need re-orienting to place caring networks as central to the caregiving process. This can be achieved by putting systems in place which initiate and maintain such networks and enable service providers to work with informal networks as equal and respectful partners.

Keywords: Informal networks; end of life care; public health; palliative care; social networks; caring at home; social capital; community development

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Introduction

Caring and support and community can be difficult to bring together at times of need. The services in our community and extended support networks are essential so that both the person being cared for and the carers are supported (ON 12).

New public health approaches to end of life (EOL) care are encapsulated in the compassionate communities

and cities movement (1) where caring for one another at times of need, loss and/or crisis becomes the task and responsibility of everyone (2). Such a move towards social and collective responsibility requires a recalibration of health and social services and communities. For health and social services, the challenge is to work with people in respectful partnerships which promote collective wellbeing;

for community members it means taking responsibility to care for each other in times of need.

Most of the research in EOL care focusses on non-professional caring as a burden (3-6). Such research tends to have a narrow focus on the primary carer, usually a family member, with the emotional, physical and psychological costs of such care being well documented (7-10). This reflects a medicalised and individualized orientation where the carer is at risk of harm, needing to be relieved of the burdens associated with such care (11), as such it is problematic to expect community members to take on this burden as informal carers. However, caring at EOL can also be rewarding providing meaning, purpose and a sense of belonging, thus having a positive impact on carers wellbeing, quality of life and social relations (12-14). Furthermore, carers do not always want to be relieved of their caring role preferring to be supported to continue caring in non-institutionalised environments (15).

Understanding these complex lived experiences is becoming increasingly urgent as policy developments towards deinstitutionalising dying and death (16) will increase the role of community EOL care. Adequate support is required to develop a whole of community approach to avoid potential exploitation of informal carers, often women who dominate the unpaid caring field (17-21). A caring network approach can be protective of primary carers wellbeing in addition to developing compassionate communities by building a network's death literacy (22,23). A care network is a functional subset (24) of a person's social support network which emerges to provide specific help because of a particular need—in this case dying. They comprise a complex web of supportive relationships which surround the dying person and their primary carer (24-28). There is increasing evidence that carers with active networks experience decreased social isolation and fatigue, improved social support and increased confidence in asking for help with the result that a successful home death is achieved (28-30).

If dying, caring and death are to be understood and responded to as social events (22) where isolation, anxiety and fear are seen as social problems which can only be fully addressed by a whole of community approach (2,31) then we need to understand the communities experience of caring together from their point of view. In the present research a networked approach to care was explored with new public health perspectives of palliative care and social capital (32,33) the main conceptual frameworks particularly the micro position of social capital, which focusses on social

networks and relationships (34).

Methods

The Caring at End of Life research project, comprised a pilot [2009–2011] in New South Wales (NSW) Australia, and the main project [2012–2015] in NSW and the Australian Capital Territory (ACT). Both were partnership research primarily between Western Sydney University (WSU) and the Cancer Council of NSW (CCNSW). The pilot was jointly funded by CCNSW and WSU and the main project funded by the Australian Research Council (ARC) and CCNSW. Project partners included WSU, CCNSW, the Commonwealth Scientific and Industrial Research Organisation (CSIRO), Australian Catholic University/Calvary Health Care ACT, and Queensland University of Technology. Institutional ethics approvals were obtained prior to commencement.

Specifically, the aims were to understand:

- ❖ The lived experiences of people who successfully provided in-home care for someone who was dying;
- ❖ How caring networks are initiated and maintained and what enables and supports these networks;
- ❖ The nature, function and effects of in-home caring networks;
- ❖ The relationship, if any, between formal and informal caring networks;
- ❖ Differences in regional, rural and urban locations.

The research was qualitative, in-depth and strengths based comprising interviews and focus groups with carers, caring networks, community members and service providers involving 301 participants in urban, regional and rural areas. Providing robust opportunities for carers and community members to tell us about their lived experiences (11) of successful in-home caring was central. In this move away from a problem centred approach the design was informed by Appreciative Inquiry which seeks to uncover, analyse and document what works in a given situation, with a view to sharing this knowledge to effect systems change (35-37).

Photo voice was chosen as the main method with informal carers to respectfully and sensitively elicit their experiences of caring, not dying and death. This was a significant challenge as narratives of dying and death are powerful and usually accompanied by feelings of loss and grief. In such situations photo voice enables participants to tell visual stories providing a form of detachment that facilitates critical reflection on lived experience (38-40). Additionally, third generation network mapping (41) was

used. The network mapping method, which places peoples lived experiences as central, was used to reveal the extent and dynamics of networks, the relationships within them, and to capture how these changed, or not, over the course of the caring journey (27).

Carers and caring networks focus groups and interviews

Participants were recruited, through an opt in approach, by CCNSW network communications, and regional and state-based newspaper and radio interviews with the researchers, advertisements and editorials. Respondents were invited to participate if they, as a primary carer, had cared for a person with a terminal illness in their home. At this point they also self-selected either a focus group comprising their own caring network or a 1:1 interview approach. Carers choosing the focus group were supported by a research assistant (RA) to recruit their self-identified caring network for focus group participation. Subsequently a third group of opt in participants, an outer network (e.g., teacher, friends of friends, local shop keepers), were interviewed 1:1 via phone having been identified from the previous focus groups and interviews. Only people who self-identified as having successfully cared for someone at home participated, people who had predominantly negative home-caring experiences may have chosen not to take part.

All participants, with the exception of the outer network, were given a disposable camera 2 weeks prior to their focus group or interview to take photographs of significant people, activities or events from their time of caring. Cameras were returned to the RA and the processed photos were informally displayed at the interviews or focus groups where participants discussed the visual data (their own photos) guided by a series of questions. In the second half of the interview or focus group participants were invited to collectively draw two network maps showing the size and density of their caring network before they began caring for a dying person at home (map 1) and in the second map to draw their networks at time of interview of focus group (map 2) (27). Participants then discussed any perceived changes in the two network maps. Focus groups and interviews were semi-structured, held in a place of the primary carer's choosing, usually the home, audio-recorded and transcribed. Focus groups took approximately 3 hours and interviews approximately 1 hour. Outer network participants were interviewed 1:1 about their experience of the caring situation, the role they played and the effects if any this network made to their knowledge about death and

dying with participants drawing their network maps at the end of the interview.

From both the pilot and main projects there were 23 focus groups, 34 primary carer interviews and 17 outer network interviews representing 56 caring networks. Detailed demographic data was only collected for the main project: 9 primary carers were men and 30 were women; women cared as spouses/partners, sisters, daughters and friends and men were primary carers only for their spouse. Age range of primary carers was 42–80 s, with most being in their 60 s, with other focus group participants in the main project comprising 50 women, 21 men, 1 girl, and 4 boys, from 9–80 years of age. The period of in-home care ranged from 4 weeks to 25 years with the majority being between 3 months and 1 year with 33 people dying at home and 6 in hospital.

Service provider focus groups

For focus groups with EOL sector service providers the research team worked closely with the research partners, particularly Cancer Council NSW and Calvary Centre for Palliative Care Research, to recruit participants. Letters and emails were distributed widely to health services, community organizations, peak bodies, and volunteers with participants opting in via an online booking site. Eighty-eight participants (82 women and 6 men) took part in one of 10 focus groups held across NSW and the ACT. They were asked to discuss their experience with informal care networks, their perception of the nature, role and benefits of such networks, and their current and/or potential role in assisting carers to establish and/or maintain care networks. Focus groups lasted 2 hours, were held in central community locations, were audio recorded and transcribed. Participants came from a range of EOL services including palliative care nursing/medical (n=32), volunteers (n=15), volunteer coordinators (n=8), disease-specific organizations (n=12), pastoral care (n=6), carer services (n=8), social workers (n=4), support groups, and other (n=3).

Data analysis

Transcripts were thematically analysed using both an inductive and deductive method (42,43) and NVivo10™ software was used to manage the large dataset and facilitate an interpretive and data-driven analysis. Transcripts were firstly collectively coded by the research team to identify elements key to effective EOL caring at home. Each

researcher then worked with core concepts independently. At the end of this stage each individual's analysis was correlated between researchers, searching for rigour, validity and meaning. Emergent findings were further tested at national and international conferences in the palliative care sector over the final analysis period.

For the network maps the first level of analysis took place in the focus groups and interviews to understand and determine the important aspects for participants. The second level of analysis was a qualitative analysis of the discussions, as detailed above, and the quantitative analysis of the maps where the hand drawn network maps were transcribed into an adjacency matrix. UCInet and NetDraw software were used to analyse the extent and density of the network and any significant changes over time (27).

In the results and discussion below, people's names have been changed, verbatim data is included in italics with (FG 9) indicating data from a caring network focus group; (CI 2) indicating data from a carer interview and (ON3) indicating data from an outer network interview. PS indicates data from the pilot study and SP indicates data from a service provider focus group.

Results

The importance of networks of care

I'd do it again for Mum. It improved my relationship with my brother. It gave me insight into Alzheimer's. It allowed me to come in contact with people I would never have come in contact with. I feel very blessed in that I've had that opportunity (CI 10).

The caring networks in this research were competent, capable and essential. They undertook a variety of caring tasks from bringing food, walking the dog, modifying the home environment, and mowing the lawn to assisting with personal and medical care and helping the carer navigate the complexities of the health system. This support was specific to each situation and was what was needed, not what was assumed: *she didn't need massage or meditation she needed firewood (CI 3 PS)*. The size of the caring networks varied considerably with the smallest having 3 people and the median being 15 with a common feature of containing at least one person who had prior experience of death, usually a hospital death. Service providers when mentioned, were seen as essential, but not central, to the everyday caring of someone at home.

Carers did speak about challenges and struggles and the sheer hard work of sustaining their caring role, often over

years. The main struggles included access to information and advice; the costs of caring at home often compounded by a reduced income; the emotional impact of their own and others' expectations; anxiety; and the physical demands of caring. Significantly, some of the greatest challenges carers reported were with hospitals, GPs, and other formal medical services (44): *the pain we had in having to fight for these things along the line... its ten times worse because you're into the bureaucracy type stuff (CI 9)*.

Having a functioning caring network mitigated feelings of burden as the networks assisted in negotiating the health system and identifying relevant services and in-home help. There was evidence that having a supportive network alleviated feelings of anxiety: *I was kind of scared that I wouldn't be up to the task, and I thought 'well everybody thinks I am, so perhaps I am' (FG 7)* in addition to being available to help at all times of the night and day: *I gave Mary a call at six o'clock in the morning and said, 'Mary! You know you said you might be able to help with Ray...' they came round in five minutes (FG 9)*. Networks also helped financially giving gift cards (FG 8) fundraising (SPFG 5) or collectively giving money: *for Bernie's funeral quite a few of them turned up and they gave me a card and inside the card—they had a collection—was \$350 cheque (CI 4)*. The data showed numerous other examples of problem solving by the networks in addition to people just showing up at the end of the day for happy hour around the bed with a glass of champagne or a cup of tea.

Collective caring at EOL also had a communal effect. All of the networks increased in size with relationships, or ties, between members strengthening over the period of caring (27,30). For example, Jane, who cared for her husband for 2 years had a self-identified caring network of five people when caring commenced. At the time of the focus group this had grown to 17. As carers developed knowledge about network members trust and reciprocity increased changing the nature and quality of the relationships. For members of the network, other than primary carers, relationships transformed demonstrating increased cohesion: *these sorts of things do broaden your community and your support (FG 1 PS)*. These changes built a sense of community and feelings of trust and reciprocity as people felt they could rely on their community in times of need: *I suppose the main thing is that it's obviously the building blocks of community. That people pull together when they need to... it made me think I want to stay (CI 15)* demonstrating that collective caring at EOL can contribute to, and build, social capital. Furthermore, when these caring networks worked well they were enduring: *this network has been maintained even a year later. So in fact this is*

an enduring network (CI 17).

In all of the networks it was the primary carer who was the bridge between members of the network and professional EOL services. This is significant as while caring networks work against social isolation and potential carer burnout, as the network increases in size the burden of coordinating can increase. While there were examples of other people taking up bridging activities as the network grew it was still the primary carer who did the majority of this work.

There were no discernible differences in the data between caring networks in rural, regional or urban areas despite the data being re-interrogated in search of differences. Another surprise was that while the primary carer was usually, but not always, a close relative it was friends of the primary carer or dying person (or both) who were central and consistent. In terms of how networks arise there were no discernible patterns with each network being born of local and relationship specificities. For example, in one location (FG 1) the corner shop owners learnt that a community member was being cared for at home so they put a notice up in the shop to inform people and devised a roster of support. In another example the dying person was a member of a local spiritual group and it was this group which primarily rallied around the carer supplemented by family members (FG 5).

Both primary carers and members of caring networks spoke about their caring journeys as ones of collective achievement expressing their experiences triumphantly: *I tell everyone because I just had no idea that that's what went on at home. So I'd never seen anything like this before and I tell everyone. Just amazes me (FG 3).* This differs from much of the burden focussed literature and can partially be explained by the collective nature of the caring effort. People collectively learnt what they needed during the caring process, supported each other to overcome their fears and felt proud of their achievement in addition to finding meaning in the death of the person they cared for: *it wasn't just a death. It was a good death. It was a loving death, surrounded by love and kindness and gratitude for this wonderful man (FG 8).*

As a result, people increased their death literacy (23) rippling out into the community as they became advocates within the health system or supporting others to provide in-home care. In one of the few examples where a palliative nurse was included as a core network member (FG 5) the experience changed his perception of the benefits of caring at home and the competency of informal caring networks.

As a result, he is now actively supportive of a caring networks approach.

The importance of place

Place, in this case the home, facilitated the maintenance of caring networks. Home, like community, is contested in the literature (45-48) with good reason as home can be a place of abuse and exclusion, people can be isolated at home and when people are dying the home may be full of the paraphernalia of care (18), rendering them less home-like. The findings do not present home as an idealised or romantic ideal, they do however show how home facilitated the coming together and maintenance of caring networks.

Network members developed and strengthened their relationships with each other through renovating, gardening, cooking and eating together, celebrating important occasions and collaboratively planning to meet the dying person's and carers needs: *it was just kind of a hub for me (FG 7).* People spoke of sitting with friends and/or family, having a cup of tea or a chat under the window (CI 12) or around the kitchen table. This gathering together meant they could also identify and take care of everyone's practical and wellbeing needs. While the focus was on the dying person and the carer the network also sustained itself and this was enabled by sharing space, tasks and rituals such as meals and celebrations. Additionally, the home accommodated intergenerational caring networks: *it was the ability to just have the little ones and they could just wander up and down (CI 18).* With no visiting hours and flexible, familiar and comfortable spaces caring at home made it possible for visits to be organised around member's responsibilities. Routines could be accommodated, created and negotiated as a set of social and familial relations: *everybody knew that if they wanted to visit...they could just come in...so everybody could do what they wanted, when they wanted (FG1).* Home as a place of care enabled the complex needs of the dying person to be met while connections with family and friends were maintained.

The importance of nature and pets

Social isolation is well-documented in the literature (49) with in-home carers being especially susceptible. However, an effective caring network works against this, indeed, it is possible that people's networks can grow during the caring journey. The data in this research also enlarges understandings of connections that are important

to people challenging who and what are considered essential components of a caring network. While social connectedness is known to be essential for emotional and psychological wellbeing (50,51) nature and the non-human may be as vital to our wellbeing (52-54). This was reflected in the data where participants spoke at length of the importance of nature and the non-human with carers taking solace in a view from the window or walking in the local bushlands: *being able to go outside where it feels peaceful and calm—it's just about being able to have spaces that feel really nurturing outside (CI 6)*. Being at home provided easy access to these supportive places which also provided respite from caring: *I had a courtyard...It was a great outlet for me because it was just straight outside the door at the back...it was wonderful (CI 26)*.

Animals were also important members of the caring network providing comfort and support to the dying person and the caring network: *I felt the experience at home here was a lot better because...the dog was involved (FG 5)*. If the pet was with the dying person then the primary carer could get on with other tasks knowing that the dying person was in good company: *I'd say Sophie was Phil's best friend I think regardless of all the humans around the place (FG 11)*. Pets also welcomed network members to the home and provided a way of easing into the caring environment. Carers spoke strongly about these members of the caring network with many animals attending focus groups and interviews.

The relationship between formal and informal networks

Service provider participants had extensive knowledge of informal networks and the multiple benefits they provided, however, overall they did not believe it was their role to help establish or maintain caring networks despite them recognising their complementary relationship: *if we're told that the church group is helping with meals and transport we don't ever talk to the church group (FG 3 PS)*. These participants spoke at length about barriers to working with informal networks with the most persistent being complex institutional rules and regulations which worked against strengthening relationships (28,44). These regulatory systems included risk management, privacy, and confidentiality which constrained service providers from working directly with informal networks:

We'll get people on the periphery who contact us and say, 'Joe Bloggs at number 6 Smart Street really needs some help. Can you please do something and we're stuck in a situation where we have

to say, 'I'm terribly sorry. If Joe Bloggs hasn't committed to this referral and he hasn't consented to this referral, we're not able to do anything' (SPFG. 8).

Service providers were also concerned about the lack of caring skills in informal networks, believing this could be addressed by screening and training. They also questioned community capacity believing that dispersed families and work demands meant people were unavailable to care. These combined concerns meant services are not inclined to support peoples' choice to die at home. While these are very real concerns, and demonstrate a lack of trust in non-professional support, they were not borne out in the data [or other research (55)] from the carers and the networks where there were numerous examples of family temporarily moving back to help, of networks providing financial assistance and of employers providing flexible work arrangements including extended leave, for example.

From the informal networks point of view health services and systems, including palliative care, were often experienced as cumbersome, paternalistic and depersonalizing bureaucracies. While carers reported that their negotiations with such systems were often when they experienced the greatest sense of struggle they also showed insight into why this might be so:

The social worker told me that it was 85% don't make it back home and I said, 'Watch me'. John and I were both in tears. She said, 'No. It's not going to happen'. I said, 'Well what would you like to see happen to him?' She said, 'Well, we'll put him in. If he takes too long to die in the hospice, we'll put him in a home'. I think they're trying to save you. I understand where they're coming from. They know it's difficult and it is, it is (FG 8).

The data from carers, caring networks, service providers and community members demonstrated that when the network works well the outcomes were transformational for all concerned. However, successfully integrated networks were rare (44) often due to differing cultures and expectations. Competent, appropriate and timely professional support was welcomed by informal carers. However, when formal network members showed they cared through listening, acting with integrity and dedication, providing equipment that worked and demonstrating warmth through a smile or a kind word these were highly valued: *he was very gentle and loving and caring and very professional (CI 15)*. Such people were seen as going above and beyond their duty. As one palliative care specialist said, this is not rocket science (SPFG 7), however, the seemingly simple requires a re-negotiation of the usual relations of power present in such encounters and this is never an easy

task requiring the sharing of power and authority.

When services recognised the value and competency of the caring networks and facilitated communication between informal and formal carers, they were seen as helpful, and central to the tasks of caring: the nurse in charge—arranged with the chemist she'd ring up the chemist and say '*we've got to have this*' (CI 23). In doing so service providers reoriented their values and behaviours to see themselves as part of a team of carers who were equal, who each had an important part to play.

Discussion

Perhaps one of the distinguishing features of caring for the dying at home is that it involves complex and demanding care tasks (56) within an atmosphere of heightened emotions and lack of knowledge as a result of institutionalisation (23,56,57). As such what is required are competent and compassionate care networks comprising both formal and informal carers to share the caring work. Much of the work are tasks of everyday living: dropping children off to school; making sure there is enough food for visitors who flow in and out of the home and having the right medications at hand when needed, for example. Such tasks require life experience and the ability and willingness to help (2). This stance towards caring recognises the multiple interdependencies we have on each other where caring about and caring for one another is underpinned by a set of ethical moral practices (58,59) which improve the wellbeing of us all. In the research reported here it was clear that when a caring network functioned well and carers were comprehensively supported everybody benefited and the effects flowed into the community.

However, in order to provide people who are dying, their carers and caring networks with the right support at the right time and in the right place the systemic paternalism inherent in many of the interactions between dying people, their caring networks, and systems of professional support require recognition, challenge and change. Services need to re-orient their systems to closing the gap between the two cultures currently embedded in formal and informal caring networks. This can be achieved by: a re-evaluation of organizational values; a recognition of the primacy of caring networks; and, finally removing the inherent paternalism in health care provision, including palliative care (44). The realisation of these three principles is located firmly in the new public health framework (60) and is a civics approach (61) where we are all responsible for each other in

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a networked ethic of care.

The findings also show that place matters and can be actively supportive of caring networks. While home can be problematic for some this is not an excuse to dismiss the stated preferences of dying people and their carers (20,62) or to ignore the potentiality of in-home caring to facilitate caring networks and carer wellbeing (12). In operationalising new public health approaches to EOL care a central concern has to be promoting and sustaining the wellbeing of informal carers of the dying and place is part of that.

Conclusions

This network centred place based approach requires a reconceptualization of caring away from individuals to networks and activities of collective caring. This means that the EOL sector must develop communication pathways with informal caring networks and provide resources to develop and implement strategies for working with them, not instead of them (44). An obvious starting point is to relieve the primary carer of the potential burden of initiating and coordinating the network of care. It also means treating seriously peoples stated preferences for places of dying and of providing care. It means moving from a predominantly individualised care model to a network, community centric, model of care which when done well can indeed be good for everyone.

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Footnote

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