‘The more you give, the better it is for you.
You know the reward is greater than the effort’: the Compassionate Communities Connectors’ experience

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Abstract
Background: The Compassionate Communities Connectors programme is a volunteer-led initiative designed to enhance the social networks of families living with chronic or life-limiting illnesses. Specially trained volunteers supported existing members of the families’ social networks and also enlisted the support of community members, Caring Helpers, to address the social and practical needs of these families. The programme is an initiative of The South West Compassionate Communities Network in Western Australia, in partnership with the health service.

Objective: To explore the experiences and views of Connectors implementing this model of care with a particular focus on its feasibility and acceptability from their perspective.

Methods: Semi-structured telephone interviews were undertaken with 11 Connectors covering their experience with 37 patients/family carers (March 2021 to April 2022). A deductive content analysis was used in analysing interview transcripts.

Results: Six themes captured the Connectors’ view of their role and its impact on their clients and themselves: Mutual benefits from connection and reciprocity; It is ok to ask for and receive help; Sense of community as being ‘part of a village’; Making a difference in social connectedness; Frustrations when not achieving everything you want to; Reflecting on the difference with traditional volunteering. These themes are complemented by a social network mapping example and a vignette demonstrating the increase both in connections and interaction between these connections and the process by which such changes took place.

Conclusion: Volunteering as a Connector has been a positive and feasible experience for fostering a sense of community among participants, developing relationships with other community members, seeing the difference that the Connector role makes in the lives of those involved in the enhanced network and fostering growth in Connectors’ emotional capacity and compassion. The work is challenging but rewarding and differs in several respects from traditional volunteering, particularly in the agency Connectors can bring to their role. A public health approach based on a close partnership between health services and communities/civic institutions is the optimal practice model.

Keywords: compassionate communities, Connectors, public health palliative care, social capital, volunteers

Introduction
Volunteers play a significant role in the palliative care workforce in support of the allied health and medical care provided by hospices and palliative care services. Their contributions include a variety of tasks such as providing transport, respite...
for carers, housework and cleaning, and emotional support and counselling.\textsuperscript{1–3} Palliative care volunteer research frequently focuses on the outcomes of these physical and practical caring tasks on patient care and caregivers. There is, however, a growing number of studies providing deeper insights into other aspects of the volunteer experience. Increasingly palliative care volunteers are involved in psychosocial care such as bereavement support, emotional support, spiritual care, and arts programmes such as biographical programmes.\textsuperscript{4,5} When community members volunteer in end-of-life services, they report feeling greater life satisfaction\textsuperscript{6,7} and have increased death competency and decreased death anxiety following training programmes.\textsuperscript{8}

A recent systematic review of the emotional experiences of volunteers identified personal challenges (both intrinsic and extrinsic) and personal gains such as the development of relationships.\textsuperscript{9} Volunteers reported feeling ‘useful and appreciated by patients, feeling inspired and rewarded, giving back to others, learning from patients and self-growth’.\textsuperscript{9} In one study, volunteers reported they were personally changed because of the volunteering experience,\textsuperscript{6} and in another, volunteers reported feeling stronger and more resilient because of the conversations and interactions they have with people who are at the end of life.\textsuperscript{10} In considering the intrinsic challenges, volunteers reported fears about taking personal leave or time away from their duties;\textsuperscript{6} they also worried if their interactions with patients were helpful and expressed fears that they may not know what to do or say despite their experience and training.\textsuperscript{11}

Researchers have also found that participating in traditional service models do not always provide the most satisfactory personal experience for community volunteers.\textsuperscript{12} One reason for this is that the role of palliative care volunteers has been professionalised in the sense that the service expects them to function as an extension of clinical teams.\textsuperscript{13} This professionalisation of end-of-life services has had an impact on the way volunteers interact with patients, families and even the palliative care service itself.\textsuperscript{14} Morris \textit{et al.}\textsuperscript{14} reported that palliative care services provided an example of ‘volunteering caught between the informality of their roots and the increasing formalisation of the current climate’ (p. 1710). Other researchers have argued for models of volunteering that make better use of the existing skills and capacities of community members who want to be involved in end-of-life and bereavement care.\textsuperscript{15–19} When volunteers have reasonable autonomy to utilise their emotional, intellectual, and practical skills, the volunteer role can be especially fulfilling.\textsuperscript{20}

Community participation has the potential to increase social connection\textsuperscript{21,22} create a sense of empowerment,\textsuperscript{23,24} and reduce hospitalisations.\textsuperscript{25} Compassionate community volunteering has the potential to build on the existing capacities of community members.\textsuperscript{12,17,26–30} Understanding how these new volunteering models are experienced by volunteers is important for nurturing the growth of compassionate communities.

The Compassionate Communities Connectors programme presents a distinct form of volunteering without the professionalisation mentioned above.\textsuperscript{31,32} The programme is an initiative of The South West Compassionate Communities Network (SWCCN) in Western Australia (WA) in partnership with the WA Country Health Service (WACHS).\textsuperscript{31,33} The Connectors’ role is to mobilise existing community assets (civic organisations, informal support groups, individuals) and encourage them to contribute to the practical and social support needed by people with terminal illnesses in their community. The evaluation of the programme showed significant improvements in social connectedness of supported families, reflected in reduced social isolation, better coping with daily activities and a two-fold increase in supportive networks of people with terminal illnesses.\textsuperscript{33}

This article reports qualitative findings from interviews with Connectors about their experience of and satisfaction with the intervention.

\textbf{Objective}

The objective of this study was to explore the experiences and views of Connectors implementing the model of care of the Compassionate Communities Connectors programme. A particular focus was the feasibility and acceptability of the intervention from the Connectors’ perspective.

\textbf{Methods}

Ethics approval (RGS3419) was obtained from WACHS Human Research Ethics Committee and La Trobe University Ethics Committee. All Connector participants signed a consent form to participate.
**Description of the Connectors’ programme**

The Compassionate Communities Connectors programme is a volunteer-led initiative designed to enhance the social networks of families living with chronic or life limiting illnesses. Specially trained volunteers supported existing members of the families’ social networks and also enlisted the support of community members, Caring Helpers, to address the social and practical needs of these families. The programme is an initiative of The South West Compassionate Communities Network in Western Australia, in partnership with the health service. Palliative care and chronic disease health service teams referred families to the programme, and the project coordinator matched the families with the connectors. The development, implementation, and evaluation of the programme were extensively described in our previous article.33

**Participants**

The Connectors who were invited to participate were drawn from the database of those who had attended the SWCCN educational programmes, anticipating that these people would have a moderate level of death literacy because of their prior involvement. Connector selection involved an interview process with members of the project team, which enabled the interviewers to determine the person’s understanding of the role and the project. Connectors underwent reference checks and a National Criminal History Record Check according to the volunteer policies of the health service.

Twenty Connectors undertook a training programme developed for this study, and their feedback was positive in terms of the perceived improvement in their confidence to take on such a role.33 The training programme was just the foundation as the learning and support continued through the fortnightly zoom meetings Connectors had with the project team. Only 13 Connectors were able to participate for various reasons related to changes in their personal circumstances, or not wanting to be vaccinated for COVID-19, as stipulated by the health service, and out of those, nine stayed on for the duration of the data collection period (15 months). The median age of Connectors was 62.5 years (28–74) and 92% were female.

Forty-three families participated in the trial. The average number of families supported by each Connector during the study period was 3, with a range between 1 and 9 families. Families were followed up by Connectors for a median of 18 weeks, ranging from 3 to 52 weeks. Connectors had 1,055 contacts with families and Caring Helpers and 402 contact hours with the two groups, this being an underestimate due to a shortfall in reporting.33

**Procedure and data analysis**

There were 27 semi-structured interviews, conducted by phone, with 11 Connectors, covering their experience with 37 patients/carers (March 2021 to April 2022). Interviews took place at the conclusion of the trial, which timing varied for each family according to the needed follow-up period by their assigned Connector. Interviews were audio recorded and transcribed verbatim. On average, interviews lasted 11.04 minutes ranging from 4.17 to 29.08 minutes. All identifying information was removed.

The brief interview consisted of five broad questions: (1) What was your experience of being a Compassionate Connector? (2) What has been difficult about being a Compassionate Connector? (3) What would you share with others who are thinking about becoming a Compassionate Connector? (4) What would you share with others who are unsure about accessing support from a Compassionate Connector? (5) Is there anything else you would like to share?

A deductive content analysis, beneficial for testing concepts, categories, theories or any conceptual structure in a new context was used in analysing transcripts.34 Qualitative data were analysed by reviewing transcripts and audio-recording of interviews and applying codes that were developed from concepts drawn from the literature.17,35 The interviewer, who is one of the authors, participated in the analysis so that consideration of the non-verbal context could improve the credibility of the findings.

The interviews were brief and geared towards evaluating the Connectors’ overall perception of their contribution to the programme and satisfaction with their role. They were not intended to provide data for an in-depth study of the Connectors’ personal insights.

**Results**

The analysis provided six themes describing how Connectors viewed their role and its impact on their clients and themselves.
Mutual benefits from connection and reciprocity

Connectors felt that everyone involved in the programme – the clients, their families, their networks, and other community organisations can all potentially benefit from the emphasis the programme has on mutual support and community development. There were clear benefits observed for people who are dying and their families, and Connectors also experienced their own benefits:

- it is a fantastic opportunity to get out of your comfort zone, to get to know other people and in a roundabout way get to know a little bit about yourself and different emotions and reactions in different circumstances. (C40)

Further reflecting on the mutual support, Connectors were very positive and encouraging in their advice to people considering the Compassionate Connector role. They described it as ‘A very worthwhile experience’ (C07) ‘I think it’s wonderful’ (C24) and how personally rewarding and fulfilling for them:

- Growth for me in my emotion and compassion (C26); ‘I have found it very rewarding; it’s a fabulous program and yeah, I would thoroughly recommend it and it’s something that I would like to see developed in each town. I think it would become stronger as time goes on’. (C07)

An important feature of their responses was the personal satisfaction in the bonds that formed between the Connectors and their clients. Many of these relationships were described as continuing social connections, as per these comments:

- ‘we’ve sort of become mates . . . we’re sending photos, we’re sending text messages, we chat about books’ (C40). I would not have missed the opportunity because I feel like, I’ve definitely connected with [couple] and they’ve very much adopted me as a person that’s in their circle and that’s lovely too” (C29).

It is ok to ask for and receive help

Connectors encouraged community members to consider having a Connector – ‘give it a try’ (C41), ‘be bold’ (C05) and ‘do it because every little bit helps when you’re in a tough situation any support you can get helps’ (C11).

The reciprocity of benefits was noted by Connectors, ‘I’ve said you might feel that everyone is doing you a favour, but it actually helps them too. Don’t feel embarrassed or humbled just let people help. People genuinely want to help’. (C29) Connectors reported that clients ‘wanted the company and to talk to me about things that were bothering them . . . ’ (C23).

Community Connectors drew upon their own experiences when they needed help to encourage their clients do the same, and explained how they can do the asking for help on their behalf:

- I’ve been very ill a couple of times in my life and it is really hard to ask and even to ask your own family when you know they’re really busy and that’s what the Connector will do and that’s usually the first thing I say to people: You tell me who your family and friends are and I’ll do the asking. And everybody without a doubt has always said to me ‘oh that’s wonderful. I knew they wouldn’t ask me. I’m so glad you’ve asked. And that’s how I always present myself as the link between the two. You tell me who they are and I’ll do the asking and it works every time. (C32)

Sense of community as being ‘part of a village’

A key aspect of being a Connector is network enhancement. This is described as both fulfilling and at times a challenging part of the role. Connectors have a strong desire to help their clients build supportive relationships in their neighbourhoods and communities. In particular, clients who wanted to create new care networks or build on their existing social networks, were viewed as benefitting most from the programme. Connectors noted that:

- ‘once people find out it’s community helping community, there’s an untapped resource out there’. (C31) and ‘It’s beneficial for everyone really, it’s bringing back that sense of community and village that we’ve lost in society’ (C29).

The role in this sense, lives up to the name ‘Connector’ because they function as facilitators and champions of network building. For example,

- it’s a much easier way of asking your friends, that I will ask your friends . . . I can do for you what you often won’t ask yourself. So your friends and family are waiting to be asked and I can do the asking. And often the clients won’t ask. My role is to ask on your behalf. (C32)
Connectors reported a strong sense of the role they played in network enhancement activities, and there were times they needed to manage multiple roles moving between being part of the network as a caregiver, a social and emotional support person, a driver, a network organiser, and a resource/service finder. Connectors described a number of practical and emotional experiences involved in being a volunteer for network enhancement. The majority of families either initially embraced the network enhancement activities immediately, or over time with the support from the Connector developed their social and care networks. When clients were unsure however, it was more difficult. One Connector reflected that their client was really cautious about using their friends as a network because they wanted them to remain friends and were a bit reluctant at times to share their inner private life with a friend. So I don’t know how you get around that, as forming a network. (C11)

Another reflected

‘people often don’t have their own network, that’s why they get referred to us’ (C41) and ‘it’s battling to get the involvement of both the recipients and the ones that want to do the caring, connecting. It’s a bit to do with our society... we’re a very independent society, that’s the main problem’. (C20)

These quotes highlight the importance of supporting the development of a network of family and community-based carers and why this is a key task for the community Connector role.

Figure 1 is an example of the increase in one family’s social networks due to the intervention, showing the increase both in connections and interaction between these connections, particularly in the community sector. The process by which such changes take place is illustrated by the vignette in theme “Making a difference in social connectedness”.

**Making a difference in social connectedness**

Connectors expressed positive support for the idea that the programme provided an important community service noting the positive transformations that occurred in families and with clients and felt that their role ‘made a difference’, for example:

I thought, I don’t think I can really do anything for this guy. He was obviously desperately isolated but everything I suggested was right up against a brick wall. Loved me going there. You know, never got away under 2 hours and was quite animated. And was improving socially himself but still didn’t want to go out and then slowly over a period of time he became more and more positive. You could see him growing, it was like watching a little kid grow. (C24)

Connectors felt rewarded as the effect of their help was tangible when they were ticking the boxes and improving the quality of life:
My experience was really positive . . . so I am very much a Connector anyway by nature and having been in [area] for so long, it was great to get the people that I was given. Do you know what I mean, like you can connect in the street and stuff but to be given someone specifically that you knew what their needs were and then be able to fill that, tick those boxes for them. It was really good. I really enjoyed it. I just felt it was really worthwhile, it wasn’t a matter of meeting someone and walking away. You knew that it was helping someone on going. (C04)

Through the families in their care, they experienced the gaps of the formal services and how they were able to fill those gaps:

We look at the social side of things and I think that’s really valuable. I spoke to one of my fellows the other day and he said yes the palliative care come in and they might just put their head in, poke their head in or if they say they’ll do something they will but it’s in a very physical manner; you know you need a wheel chair, you need this, you need that. We come down to the social and I really think that even going and talking to these people even though you might not solve any of their problems that we’re going in and we’re listening. (C02)

The vignette in Box 1 gives an idea of a Connector in action making a difference.

Frustrations when not achieving everything you want to

While participation in the programme was reported to be a positive experience overall, community Connectors also reported some challenging experiences. A main concern was with attempting network building in cases where network enhancement wasn’t always accepted: for example, ‘Oh it can be a bit frustrating, because you know you’ve got all of these ideas but if you come up against ‘no we’re doing that ourselves’ (C13).

Connectors found it difficult when clients did not want to extend their networks. In these situations, Connectors talked about their need to be self-aware and thoughtful. For example, one Connector said:

I might think – I could do this for you, that would make your life better or whatever, but if that’s not what they want, you really got to listen to what they want which sometimes I guess tests your motive. (C04)

Connectors’ advice to themselves in these situations was to recall their key purpose:

And once again that’s really about making it about the person not about us feeling good. Let them make the decision, don’t make it for them. It’s not taking over for them. Sometimes, people when they volunteer they want to take over. But again, it’s checking they want that, it’s about them it’s not about me (C14).

Timing of referrals from the palliative care service was frustrating when Connectors could not help families with their social and practical needs:

‘We need to get in much earlier . . .’ (C24) and ‘I would say that it would probably be more valuable for people earlier in their palliative care journey. And when they’re still well enough to be connected. Unfortunately, I think what was happening we were getting people, they were too sick to think about going to things or be involved in things’. (C23)

Some Connectors found seeking Caring Helpers to support their clients was a challenge in their geographic areas:

I’d certainly encourage people to do it. I would explain some of the difficulties in trying to find the helpers. I guess I would say try to have a network of people around and I think that’s part of the program that we really need to work on; getting a pool, finding the people that are available to help. (C29)

Others were amazed by ‘how many people want to help’ (C04);

‘I put together a little band for my client and they continue to support her, so I’ve completely let go of that lady, that client because they’ve formed a band around her. I just saw them the other day, has extended beyond whatever I set up, but they’ve actually become like her little keepers. Yes, it’s been fascinating’. (C04)
Reflecting on the difference with traditional volunteering

Connectors acknowledged that the Connector role was different to other volunteering roles they had previously held noting:

You get a lot of self-satisfaction out of it, you get a lot of pleasure out of meeting people. It’s good to learn about other people’s lives, about where they’ve come from, their history. It gives you more of a broad aspect of their humanity sometimes too. I’d recommend it highly. (C20)

It’s not a ‘walk in the park’ like other voluntary positions I’ve had; a whole different level of commitment. But I would do it again, highly recommend it. (C24)

I think that it’s a better project in a way . . . I belong to the hospice as well and do bereavement support there and they’re now just starting an outreach program there but that’s only tailoring sitting with and being with the person who’s the carer. (C07)

Supporting the development of a network of support is a key task for a community Connector role. Although challenging, as noted above, there was also acknowledgement they were engaging in a different kind of interaction with their clients.

We may be there to solve problems but it’s more the social connections that we bring to that person, which I think is really valuable (C02).

It’s a lovely way to do volunteer work. If you really enjoy being with people and talking to people. It’s not physically demanding and its actually, you end up, I don’t know being part of their lives. It’s really fulfilling in that respect. I mean I was lucky too. I had a really gorgeous family. I suppose you could get grumpy people, it’d be less pleasant but I was really lucky (C23).

Discussion

The findings suggest that volunteering as a community Connector is a positive experience for a
number of reasons including having a sense of community, developing relationships with other community members, seeing the difference that the Connector role makes for participants and the perceived growth in emotional capacity and compassion for all involved. Furthermore, the distinct volunteering role of a Connector is also valued as a mutual relationship, and Connectors perceived that ‘their reward was greater than their effort’. These findings are similar to others in the literature, where the impacts of such programmes were about making a practical difference, promoting individual learning and growth and developing community capacity.17,35

What attracted Connectors to the role in the first place is that they are practical people with not only personal experience of caring but also good knowledge of and connections to people, community groups and formal services. That is, they are already community assets and the programme provided them with further opportunities to use their knowledge and skills. Our previous article proposed that Connector volunteers undertake a distinct form of palliative care volunteering.32 As with traditional volunteering models, Connectors provide support to isolated community members and support people living with advanced life limiting illnesses/palliative care needs. The traditional role and Connector role are however distinguished by the nature of this support. Social support provided by traditional palliative care volunteers arises from a relationship managed by the service, while in the Connector approach the relationship is managed by the participants. A further key difference is that Connectors actively help community members build their social and care networks.31,32

Connectors, working within a Compassionate Communities framework,33 have a particular focus on network enhancement and helping people to connect with formal and informal support. This mobilisation of resources was evident with 59% of help sourced through externally facilitated networks rather than naturally occurring networks as about half of the families were living alone and the majority of the caring helpers were not family or friends.33 Moreover, the size of networks increased by two-folds during the intervention period,33 a finding experienced in other studies.36 Figure 1 illustrated the activity of connections between the person with the illness, their immediate family and friends (inner networks), their community at large (externally facilitated networks) and the formal services. Looking through the lens of the ‘New Essentials Model’, these essential elements within a public health model have worked together to address quality and continuity of care as well as barriers to access.37

Until recently, the social and community building aspect of end-of-life volunteering was rarely addressed in the literature. This research provides further insight into the social processes involved in building networks around vulnerable and isolated people. Grindrod38 has, for example, emphasised the importance of changing and challenging social norms about asking and receiving help. Lewis et al.39 noted that sustaining caring relationships within a palliative care context would benefit from a social capital framework. The volunteer Connectors in this research reflected on the impact of both the formal and informal networks, and there was some evidence that the volunteer experience was most positive when caring networks in which they actively participated could build social capital.22,40 The Connectors, as noted above, were already community assets, and through participation in the programme were able to develop further their own capacities as well as increase through their connection work the resilience and capacity of their communities.

The participants’ responses reinforce the need for the Connectors to operate on the basis of primary care referrals as palliative care referrals are usually too late for this type of intervention. As palliative care patients may have been referred quite late to the palliative care team, their subsequent referral to the Connector programme was often far too late to pursue network enhancement, highlighted in theme “Frustrations when not achieving everything you want to”, ‘Frustrations’. The vignette in Box 1 illustrates the benefits of the programme when the person is not in the final days of their life.

Conclusion
This research has added to our understanding of how these new volunteering models are experienced by volunteers and how they nurture the growth of compassionate communities. This Connector model of volunteering has been shown to enhance autonomy, agency and opportunity for capacity building. With the reported shortage of traditional volunteers16 it is worth considering whether it may have greater appeal to those who have become jaded by, or are not attracted to, the
activities offered by most traditional volunteer programmes. Such supervised and directed activities provide practical support but make a limited social contribution to networks and services already established by the programme that manages the volunteers. The social contribution of the Compassionate Communities Connector programme however extends well beyond this, providing a means by which Connectors can develop their contribution as citizens in their local community. Rather than simply supporting structures already established by a health service, the Connectors programme gives Connectors an opportunity as citizens to create new social connections and build social capital, thus enhancing civic society in their local area.

A public health approach based on a close partnership between health services and communities/civic institutions is the optimal practice model and the participating health service has integrated this model of care into their chronic disease care standard practice. From their perspective, the Connectors have endorsed this model of care as being feasible and acceptable. The next article in this series will report on the feedback from families and their referring health care professionals, completing our evaluation of the feasibility and acceptability of this volunteer-led model of care in partnership with health services and various civic programmes.

Declarations

Ethics approval and consent to participate
The study was conducted according to the guidelines of the Declaration of Helsinki and approved by the WACHS Human Research Ethics Committee (RGS3419) and La Trobe University Research Ethics Committee.

Consent for publication
Participants provided written informed consent prior to the start of data collection.

Author contributions
Samar M Aoun: Conceptualisation; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Software; Supervision; Validation; Visualisation; Writing – original draft; Writing – review & editing.

Kerrie Noonan: Formal analysis; Investigation; Validation; Visualization; Writing – original draft; Writing – review & editing.

Kerry Gunton: Data curation; Formal analysis; Methodology; Validation; Writing – review & editing.

Bruce Rumbold: Conceptualization; Formal analysis; Investigation; Methodology; Validation; Visualization; Writing – original draft; Writing – review & editing.

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Availability of data and materials
Ethical approval precludes the data being used for another purpose or being provided to researchers who have not signed the appropriate confidentiality agreement. Specifically, the ethical approval
specifies that all results are in aggregate form to maintain confidentiality and privacy and precludes individual level data being made publicly available. All aggregate data for this study are freely available and included in the paper. Interested and qualified researchers may send requests for additional data to Samar Aoun at samar.aoun@perron.uwa.edu.au.

**Trial registration**
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