The Compassionate Communities Connectors model for end-of-life care: implementation and evaluation

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Abstract

Objectives: This pilot project aimed to develop, implement and evaluate a model of care delivered by community volunteers, called Compassionate Communities Connectors. The Connectors’ principal task was to support people living with advanced life-limiting illnesses or palliative care needs by enhancing their supportive networks with Caring Helpers enlisted from the local community.

Methods: The project was undertaken in Western Australia, 2020–2022. A mixed methods research design incorporated a prospective cohort longitudinal design with two cross-sectional measurements, pre- and post-intervention. The primary outcome was the effect of the intervention on social connectedness. Secondary outcomes were the effect of the intervention on unmet practical or social needs and support from social networks, and the self-reported impact of the programme on social wellbeing such as coping with daily activities, access to formal services, community links, social activity and reducing social isolation.

Results: Twenty Connectors were trained but 13 participated; 43 patients participated but 30 completed the study. Over half of these patients lived alone and 80% of their needs were in the social domain. There were significant improvements in social connectedness, reflected in reduced social isolation, better coping with daily activities and a two-fold increase in supportive networks. The programme was able to address gaps that formal services could not, particularly for people who lived alone, or were socially isolated in more rural communities that are out of the frequent reach of formal services.

Conclusions: This project led to an ongoing programme that has been incorporated by the health service as ‘business as usual’, demonstrating rapid translation into practice. It has laid solid grounds for community capacity building with successful measurable outcomes in line with reports on similar programmes. Ongoing work is focused on replication in other communities to help them establish a similar model of care that better integrates formal and informal networks.

Keywords: Caring Helpers, chronic disease, community Connectors, community networks, compassionate communities, end-of-life care, palliative care, programme evaluation, social and practical needs, social connectedness, volunteers

Introduction

Public health palliative care emphasises community capacity building and holds that all community members have a role in contributing to end-of-life care initiatives. One approach for developing these roles is compassionate communities’ programmes that use community development strategies in volunteering and community engagement. A number
of public health programmes have developed new models of volunteering and fresh understandings of the roles that volunteers and community members may have in supporting palliative care services.\textsuperscript{1–7} Community development strategies build upon the current skills of community members and aim to reduce social isolation by enhancing and supplementing people’s existing social networks. Connector is thus a useful description for this volunteer role, as the volunteers’ focus is upon enhancing or re-connecting relationships within the dying persons’ social networks, recruiting further contributors to those networks, and improving communication between all involved in providing care. There is, however, no generally agreed use of this term, as different projects focus on different sorts of connections.

Public health initiatives do not operate in isolation from or in competition with existing end-of-life care services and strategies but seek to supplement and enhance them. In their ‘new essentials’ model for end-of-life care, Abel \textit{et al.}\textsuperscript{8} propose that a comprehensive model of care should involve the collaborative articulation of four caring sub-systems: specialist palliative care, generalist palliative care, civic action and natural networks. In most healthcare systems, mechanisms are already in place to connect the contributions of specialist and generalist palliative care, even if those mechanisms are often only partially utilised. Civic action can include ‘third-sector’ philanthropic or community-based organisations, but the focus, coordination and reach of these is quite variable, as are their relationships with formal healthcare. Some collaborate well with the healthcare sector and provide some community support but – to generalise – this community engagement addresses individuals more than the informal groups or networks that surround them. Public health approaches tend thus to focus on this gap; on the natural networks in which dying people and their informal caregivers participate, exploring how these networks can be supported or enhanced by resources from the wider community in which they are embedded.

Examples of how these public health palliative care concepts can be operationalised, and the effects of doing so are increasingly available.\textsuperscript{9–16} In the United Kingdom, for example, the ELSA study\textsuperscript{17} found that volunteer befriending services may reduce the rate of decline in quality of life and concluded that clinicians can confidently refer to volunteer services at end of life. A recent Australian study provided insights about the development of local place-based programmes.\textsuperscript{18} This research highlighted the significance of collaborations between health and community organisations and found evidence for the important contribution volunteering and volunteers bring to compassionate communities’ work. It also highlighted the need to educate health providers about community-led initiatives and compassionate communities volunteer roles.\textsuperscript{19}

There is positive evidence emerging from public health palliative care initiatives, including reductions in hospital admissions,\textsuperscript{20} reduced loneliness,\textsuperscript{21} improved death literacy,\textsuperscript{22,23} improved intergenerational connections\textsuperscript{24} and stronger connections between community members and healthcare services.\textsuperscript{25,26} However, recent systematic reviews and research collaborations have acknowledged the challenges associated with researching and evaluating public health palliative care initiatives.\textsuperscript{15,16,27–32} As such, evaluations of community-led initiatives of practical and social support, or those focusing on outcomes involving palliative care volunteers and/or volunteer programmes, are scarce. The Compassionate Connector Program recently trialled in the South West of Western Australia sought to map and mobilise people’s personal and community networks of care. Connectors then enlisted Caring Helpers (community volunteers) to deliver practical and social support to address a variety of needs in the domains of personal care, medical, transport, home, food, social, pets, and preparation for end of life.\textsuperscript{1} This article reports on the implementation and evaluation of this model of care.

\textbf{Objectives}

The objectives of this pilot project were to:

1. Develop, implement and evaluate a model of care delivered by community volunteers, identified as Compassionate Communities Connectors, to support people living with advanced life limiting illnesses or palliative care needs.
2. Develop and evaluate a training programme for volunteers.
3. Assess the feasibility, acceptability and potential effectiveness of this compassionate community connector model of care.

This article reports on the quantitative findings of the evaluation of this intervention. Forthcoming
articles will report on qualitative findings concerning the experience and satisfaction with the intervention of the three participant groups: patients, Connectors and referring health professionals.

**Methods**

**Ethics**

Ethics approval (RGS3419) was obtained from WACHS Human Research Ethics Committee and La Trobe University Ethics Committee. All participants received a participant information sheet and had the opportunity to ask questions about participation before deciding to take part. Participants signed a consent form and received a copy for their own records. If participants decided to withdraw from the study, they were able to do so at any point without providing a reason and without any future care, treatment or employment being affected.

**Setting**

This project took place in the South West of Western Australia, a region of 24,000 km² with a population of approximately 170,000. It comprises one regional port town, Bunbury and many smaller rural towns and communities. The project was a partnership between the South West Compassionate Communities Network (SWCCN – www.comcomnetworksw.com), The West Australian Country Health Service (WACHS) (involving the SW Palliative Care Team, The Chronic Disease Team and The Older Persons Initiative), GP Down South Chronic Disease Team and the WA Primary Health Alliance (WAPHA). In terms of the new essentials model outlined above, the partnership involved specialist palliative care, generalist palliative care as provided by chronic disease services, and the civic organisation SWCCN.

**Participants**

The study involved five groups: patients, their family carers, the Connectors, the Caring Helpers and the referring health professionals.

**Patients.** Inclusion criteria:

- Patients with cancer, chronic obstructive pulmonary disease (COPD), chronic heart failure or renal disease and other chronic conditions such as neurodegenerative conditions.
- Patients aware of their advanced illness.
- Patients with frequent hospital usage (more than two times in the past 2 months of hospital admissions or emergency department visits) or at risk of hospitalisation for palliative care.
- Patients with unmet social, psychological and practical needs.
- Patients who are socially isolated and rely on just one other person to meet the majority of their everyday needs.
- Patients 18 years and older.
- Patients with capacity to provide informed consent.

**Connectors.** Connectors were community volunteers who provided assistance to the person affected by advanced illness and their family by identifying the additional social and practical support they may require from within their local community and tap into formal and informal sources. Their role was to enhance supportive and sustainable networks around families in need. Names of Connectors who were invited to participate were drawn from the database of attendees of SWCCN educational programmes, anticipating that they 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.

**Caring Helpers.** Caring Helpers were members of the family, friends, neighbours or other people in the community who were willing and able to assist with specific activities such as walking the dog, doing the shopping, collecting a prescription, transport to appointments, going to the library, mowing the lawn, gardening, making a snack, tidying up or sitting with a person who needs a break. Assistance was provided by Caring Helpers without expectation of payment or other reward or benefit.

**Research design**

A mixed methods research design incorporated:
families, the Connectors and the referring health professionals. Findings from interviews will be reported in future articles.

**Training of Connectors**

Connectors attended a training course of 2 days duration delivered by content experts. As part of the training, Connectors were provided with a training resource that was developed specifically to assist them in understanding their role and what is expected of them. Sessions included information on public health palliative care, the importance of compassionate communities and how this project fits in, death literacy and advance care planning, grief literacy, communication skills, self-care, understanding advanced illness and the role of the palliative care and the chronic disease teams, and the volunteer processes and procedures within the health service. This resource will be made available after further development. A community directory was developed to assist Connectors in pointing participants to community resources. Pre- and post-training evaluation questionnaires were administered to assess changes in Connectors’ knowledge and confidence.

**Procedures and data collection**

The health service screened and referred interested families and those suitable for the intervention according to the inclusion criteria. The project coordinator visited the referred families to provide an explanation of the project, seek written consent, and collect baseline information on the demographic and clinical profile of the family, their social and practical needs, the availability of supportive networks, and the extent of their social connectedness. The project coordinator then assigned a connector to each referred family, taking into account the profile of the person requiring support, their age and gender, geographical location, personality and the connector’s availability and experience. Outcome measures were collected also post-intervention.

For the purpose of this time-limited research project, Connectors were guided to visit their assigned families or made contact over the phone (text messaging or video calls) a minimum of six times over a 12-week period per family. Some families required more while others required less contact, and this contact continued between most Connectors and families beyond the 12-week data collection period. The Connectors were encouraged to document their contacts using a Network Enhancement Tool (NET), specifically designed for the project, which specified the domains of needs required by their families and the supports they sought to address the needs. There were eight domains: personal care, home, medical, transport, social, food, pets and preparation for end of life. Where some of the Connectors were not comfortable with paperwork, they could phone or email the project coordinator to provide this information following their visit.

The project team facilitated fortnightly 1 h meetings by Zoom with all Connectors, for the duration of the data collection period. Successes and challenges with families were discussed and advice was provided to one another where required. Connectors were also able to access the support of the project coordinator daily as matters arose.

**Outcomes and measures**

*Primary outcome.* The primary outcome was the effect of the intervention on social connectedness measured by the Modified Medical Outcomes Study of Social Support Survey (mMOS-SS). The mMOS-SS has two subscales covering two domains in social support (practical or tangible and social or emotional) composed of four items, each designed to maintain the theoretical structure of the original 19-item MOS-SS and identify potentially modifiable social support deficits (Box 1). The psychometric properties of the eight-item mMOS-SS were reported to be excellent by Moser et al.33 Response categories regarding the availability of support for families were: none of the time =1, a little of the time =2, some of the time =3, most of the time =4 or all of the time =5. The higher the score, the more socially connected are the families.

*Secondary outcomes*

- The effect of the intervention on unmet practical or social needs and support from social networks was measured by a tool modified from that developed by McLoughlin et al.34 This tool lists needs in several domains such as personal care, home, medical, transport, social, food and pets. A scale of 0–2 was used to ascertain the extent of unmet needs and networks of support (Box 2). The lower the score, the more dependent on help the person is or the less functional their networks are.
The matrix in Figure 1 guided referrals that were high priority to refer to the Compassionate Connectors Program, the medium priority for those who needed to be monitored by the health service and low priority whose suitability needed to be reviewed.

- The self-reported impact of the intervention on social wellbeing (coping with daily activities, improved formal access, increased community links, increased social activity and reduced social isolation) was measured by a tool developed for this project. Response categories regarding the impact were: not at all = 1, a little = 2, quite a bit = 3, a lot = 4. Both families and Connectors completed this measure post-intervention. The higher the score, the higher the impact.

Evaluation of the training programme

Nineteen questions tested the Connectors’ confidence in tackling matters of caregiving, dying and grieving that were covered in the training programme, such as ‘please rate how confident you are with the following situations’, using a 5-point Likert-type scale, with the following response categories: 1 = not at all confident, 2 = slightly, 3 = moderately, 4 = fairly, 5 = very confident.

Data analysis

Data were collected and managed by REDCap electronic data capture tools hosted by La Trobe University. Descriptive statistics summarised the quantitative data such as frequencies and percentages, means, standard deviations, medians and ranges. Medians and interquartile ranges were used due to skewed distributions. Changes from pre to post were calculated (post minus pre), with the median difference and their corresponding 95% confidence intervals presented. The p-values were calculated using the non-parametric Wilcoxon signed rank test.

Results

Feedback on training programme and Connector participation

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. Figure 2 presents the most significant differences in confidence before and after training.

However, only 13 Connectors were able to participate (12 females and 1 male) for various reasons related to changes in their personal circumstances, and of these, 9 stayed for the whole duration of data collection period (15 months). Families were followed up by Connectors for a median of 18 weeks, ranging from 3 to 52 weeks. The number of families seen by each connector over the study period ranged from one to nine families,
with the average as three. There were 1055 encounters with families and with Caring Helpers that were undertaken by the Connectors during the data collection period, leading to 402 h being spent on the various network-enhancement activities. However, these numbers are an underestimate as not all Connectors have reported this information comprehensively.

Recruitment, attrition and profile of patients
Recruitment of families and data collection took place from July 2020 to April 2022, with a 6-month interruption because of COVID-19, resulting in 15 months of active data collection and access of Connectors to families. Eighty-five families were referred by the collaborating health services, the majority being from the palliative care service, and 43 patients agreed to participate in the study (50% participation rate; Table 1). Reasons provided for declining participation are varied and reported in Box 3, although it should be noted that those who declined were not pressed to explain their decision. However, 30 patients finished the study in terms of completing pre- and post-intervention outcome measurements and undertaking an interview to share their experiences. The 13 participants who could not complete the follow-up either died or were too unwell to do so (30% attrition rate).

Of the 43 patients participating at baseline, 56% were female, average age was 73 years, 47% lived alone, 47% had cancer and 33% had cardiac/respiratory disease. For those who completed the study (n=30), more of those living alone (57%) and more females (63%) were in the sample (Table 2).

Type and extent of supports needed and type of Caring Helpers providing support
This information was obtained from the NET, which Connectors completed fortnightly or reported to the project coordinator to document on their behalf. Just under 80% of unmet needs were in the social domain followed by home and

Table 1. Number of patients referred and participated by referral source.

| Referral source                      | Referred | Participated | Did not participate |
|--------------------------------------|----------|--------------|---------------------|
| Chronic Conditions (WACHS-SW)        | 8        | 4            | 4                   |
| GP Down South Chronic Conditions    | 12       | 8            | 4                   |
| Older Patient Initiative (WACHS-SW)  | 4        | 4            | –                   |
| Palliative Care Service (WACHS-SW)  | 56       | 23           | 33                  |
| Self-referral<sup>a</sup>            | 5        | 4            | 1                   |
| Total                                | 85       | 43           | 42                  |

GP, general practitioner; WACHS-SW, West Australian Country Health Service–South West.
<sup>a</sup>Patients who self-referral found out about the programme from a variety of sources, including brochures from (unidentified) service providers, Connectors, family and friends.

Box 3. Reasons for declining to participate.
- Overwhelmed with people already, treatments or appointments, frequently in hospital
- Too late in their journey, want to be with family only
- Would have been more useful during their treatment journey
- Did not want to take away from others who may need it more
- Protecting self, due to medical condition and COVID-19
- Already well supported
- Did not want others knowing their business
- Condition deteriorated faster than expected
- Family reasons, anxiety with new people

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| Variables                      | Number (N=43) | Percentage (N=43) | Number (N=30) | Percentage (N=30) |
|-------------------------------|---------------|-------------------|---------------|-------------------|
| Gender                        |               |                   |               |                   |
| Females                       | 24            | 56                | 19            | 63                |
| Males                         | 19            | 44                | 11            | 37                |
| Age                           |               |                   |               |                   |
| Mean (SD)                     | 73.1 (12.2)   |                   | 75 (11.14)    |                   |
| Median (range)                | 74 (34–90)    |                   | 76 (36–90)    |                   |
| Living alone                  |               |                   |               |                   |
| Not living alone              | 23            | 53                | 13            | 43                |
| Living alone                  | 20            | 47                | 17            | 57                |
| Primary diagnosis             |               |                   |               |                   |
| Cancer                        | 19            | 44                | 12            | 40                |
| Cardiac or respiratory disease| 14            | 33                | 10            | 34                |
| Neurological                  | 6             | 14                | 4             | 13                |
| Other                         | 4             | 9                 | 4             | 13                |
| Marital status                |               |                   |               |                   |
| Married                       | 23            | 53                | 14            | 47                |
| Widowed                       | 7             | 16                | 6             | 20                |
| Divorced                      | 5             | 12                | 5             | 17                |
| Single                        | 5             | 12                | 3             | 10                |
| Separated                     | 3             | 7                 | 2             | 6                 |
| Employment status             |               |                   |               |                   |
| Retired                       | 37            | 86                | 26            | 87                |
| On disability pension         | 5             | 12                | 3             | 10                |
| Carer                         | 1             | 2                 | 1             | 3                 |
| Education level               |               |                   |               |                   |
| High school                   | 24            | 56                | 17            | 57                |
| University degree             | 11            | 26                | 7             | 23                |
| Diploma/certificate/trade qualification | 8 | 19 | 6 | 20 |
| Ethnicity                     |               |                   |               |                   |
| Australian                    | 22            | 51                | 15            | 50                |
| Other English-speaking background | 20 | 47 | 15 | 50 |
| Non-English-speaking background | 1 | 2 | 0 | 0 |

SD, standard deviation.
Table 3. Type, frequency and examples of support (n = 238 for multiple responses from 43 patients).

| Support type          | Frequency (%) | Examples                                                                                                                                 |
|-----------------------|---------------|------------------------------------------------------------------------------------------------------------------------------------------|
| Social                | 76.9          | • Sourcing people for social visits  
• Sourcing groups to belong to [dancing, art, men’s shed, Returned & Services League (RSL), board game or card playing, craft, walking groups]  
• Sourcing like-minded community members to visit  
• Helping with calendar to organise ‘life’  
• IT support  
• Building driving confidence  
• Assisting with writing life story  
• Sourcing surrogate grannies for family with children |
| Home                  | 16.8          | • Gardening, including backyard garden blitz, pruning, removal of green waste  
• Supporting to increase care package for house cleaning  
• Decluttering house and wardrobe  
• Sourcing house and window cleaners |
| Transport             | 16.4          | • Sourcing transport to appointments and medical tests  
• Sourcing transport to social occasions  
• Sourcing ACROD (disability) parking permit |
| Medical               | 12.2          | • Picking up prescriptions  
• Supporting decision-making  
• Sourcing specialists or follow-up appointments  
• Sourcing medical information on patient’s condition |
| Food                  | 10.9          | • Sourcing and delivering pre-made meals  
• Organising meal train  
• Making food or providing garden produce |
| Preparation for end of life | 10.9 | • Sourcing legal documents: Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Will, Advance Health Directive (AHD)  
• Supporting decision-making  
• Supporting loved ones in decision-making  
• Organising witnesses for legal documents |
| Pet or animal         | 8.4           | • Sourcing dog walkers  
• Bringing own dog to visit |
| Personal care         | 4.2           | • Mobile hairdresser home visit  
• Support with increasing care package for personal care  
• Support to locate continence devices |
| Bereavement support*  | 2.1           | • Sourcing counselling  
• Supportive listening  
• Sourcing community bereavement groups |

ACROD, Australian Council for Rehabilitation of Disabled; IT, information technology.

*AThis extended to a few families where Connectors wished to continue the relationship during the bereavement phase, although it was not part of the initial brief of the project.

transport (17–16%), medical (12%), food and preparation for end of life (11%; Table 3 and Figure 3).

A quarter of Caring Helpers were individual members in the community followed by people from community service groups (18%) that Connectors sourced for tasks like gardening, transport and the various social activities. Sourcing Caring Helpers from the inner circles of these families was less frequent with family (8%), neighbour (6%) and friend (12%; Table 4).
About 26% of Caring Helpers came from naturally occurring networks of the patients (family and friends) and 59% from external networks facilitated by the Connectors (community individuals or groups; Figure 4).

Outcomes
Social connectedness. On a total score from a minimum of 8 to a maximum of 40, there was a significant improvement in the primary outcome of social connectedness ($p < 0.01$) as measured by...
the validated tool the Modified Medical Outcomes Study of Social Support (mMOS-SS), with a median of 28 at pre-intervention increasing to 36 at post-intervention. The two subscales of practical or tangible and social or emotional support also showed a significant improvement between the two time periods (Table 5).

Dependency to meet practical or social needs and availability of supportive networks. On a total score from a minimum of 0 to a maximum of 12, participants had the same moderate to high dependency pre- and post-intervention score (5); however, their supportive networks had improved twofold between the two time periods from low to high functionality to meet their needs (from 5 to 10; Table 6 and Figure 5).

Self-reported impact of programme on social wellbeing. On a scale of 1 lowest to 4 highest, the self-reported highest impact of programme on families was in reduced social isolation (3.4), followed by coping with daily activities (3), and increase in community links (2.7). Connectors perceived that the impact of their work on families was also highest for reduced social isolation, although lower than rankings provided by patients for each domain (Figure 6).

Discussion
The programme has been effective in improving social connectedness (primary outcome), reducing social isolation and increasing supportive networks (secondary outcomes). This is echoed by the social unmet needs being the most prevalent for this study group (nearly 80% of total needs). These outcomes should not be underestimated in their importance. Social relationships are a primary determinant of health.37 The biological mechanism for this, and
the evolutionary imperative of social connectedness, are well described, at molecular and immunological levels.\textsuperscript{38,39} Public health emphasises the importance of social relationships as a positive aspect of people’s lives complementing medical models, which emphasise the treatment of disease and management of symptoms.\textsuperscript{40} At end of life, Public Health Palliative Care continues to emphasise the importance of social relationships in supporting quality of life and supporting healthy dying. Horsfall \textit{et al.}\textsuperscript{19} emphasised the central role of community alleviating social isolation, an impact found in our study, and Leonard \textit{et al.}\textsuperscript{41} looked at the impact of engaging communities and found that the size of networks increased during the caring experience, also a finding in our study. Thus, engaging communities in health matters leads to improvements in health and wellbeing, capacity and longer-term community change.

In our study, the majority of support was sourced from the outer informal networks or the community at large (or called externally facilitated networks) rather than from within the inner informal networks of participating families, as depicted in Figure 4 of circles of care.\textsuperscript{36} This reflects the fact that over half of the families participating in this study lived alone and hence did not have their own inner informal networks to support them. The programme seems to have filled the gaps that formal services could not, particularly for people who live alone, and those who are socially isolated in more rural communities that are out of the frequent reach of formal services. The activity of network

### Table 6. Dependency for unmet needs versus availability of supportive networks (\(n = 30\)).

|                           | Pre-intervention mean | Post-intervention mean | \(t\)-test \(p\) value |
|---------------------------|-----------------------|------------------------|------------------------|
| Dependency for unmet needs| 5.17                  | 5.27                   | Not significant        |
| Availability of network support | 4.93                   | 10.03                  | <0.001                 |

![Figure 5. Changes in level of dependency for unmet needs versus availability of supportive networks, before and after the intervention.](image-url)
building, using both personal and community resources, works at a practical level to increase participants’ sense of social connectedness.

Social connectedness is also important in mitigating long-term negative consequences that may arise from bereavement. Relationships established during the period of caring for someone who is dying last in the long term.19,42 The evidence provided by Aoun et al.43 in their population-based survey showed that the most valued aspects of received bereavement support related first to attachment (emotional support), followed by reliable alliance (practical support) and social integration (sense of belonging or connectedness). This support was provided during the bereavement phase by family and friends (90%) who were already involved in the everyday lives of those recently bereaved.43 The social and physical morbidities of bereavement may be severe, along with increased mortality in the bereaved, particularly those who are socially isolated.44

A vital component of a public health approach, captured by the new essentials model, is developing a way of connecting and enhancing the informal care networks already present in community life.8 In the study reported here, links between specialist and generalist primary care services were established through the foundational partnerships of the project. Links between these services and community resources were to be facilitated by the other major partner, SWCCN, which supplied and supported the Connectors. The role of Connectors in this study turned out to be primarily to mobilise support available through civic groups to supplement the reduced resources of many patients’ natural networks. In other circumstances, and for other client groups, Connectors might have found their role focusing on supporting and enhancing existing natural networks, or advocating for civic organisations to pay attention to end-of-life concerns, or representing unmet patient and family end-of-life need to services with the capacity to meet those needs; for example, encouraging chronic disease services to realise their potential as providers of generalist palliative care. This research builds upon the research describing the links between informal and formal care36,42 by examining the impact of this relationship from multiple perspectives and supports the growing body of international research and evaluation reporting the outcomes of compassionate communities.6,7

When estimating the intervention impact on the social wellbeing of families (Figure 6), it is interesting to highlight that the Connectors seemed to have underestimated the impact of their work in all five domains, while the families have perceived benefits that were greater than the Connectors’ ratings. This finding is consistent with previous research that found that informal care networks

Figure 6. Scores of self-reported impact of intervention (n = 30).
tend to underestimate the impact of their support
to carers. Palliative care volunteers have been
identified as the ‘lynchpin’ between formal and
informal care and are considered an essential
part of hospice and palliative care workforce. It
is interesting that even in the community connec-
tor model, volunteers do not fully appreciate the
positive impact that informal support has for peo-
ple who are dying and their family carers. This
intangible care provided through the actions of
‘being there’ and the ‘linking’ needs continual
highlighting from policy makers and volunteer
managers.

The training programme seemed to have pre-
pared the Connectors well for their role. As the
programme progressed and we acquired more
learnings, the training programme became even
more tailored to Connectors’ needs using real
experiences or scenarios to discuss with a new
group of Connectors. The training programme
was just the foundation as the learning continued
through the fortnightly Zoom meetings. As there
was an interest from Connectors to keep follow-
ing families into bereavement, a more expanded
grief literacy training will be incorporated in
future training sessions.

Recognition for this relatively short-term initiative
was manifested by the connector programme being
a finalist in the Palliative Care Awards 2021 com-
peting with well-established hospices in the cate-
gory of ‘outstanding regional/rural team delivering
holistic palliative care and/or a compassionate com-
munity approach in any setting’. As a consequence
of the success of the programme, the Compassionate
Connectors Model of Care has been adopted by
the health service (WACHS) as ‘business as usual’
(BAU). This meant that the Connector initiative
has moved from being a time-limited project to
being absorbed into BAU functions of WACHS
with the potential to be scaled up by both SWCCN
and WACHS. This is a clear example of a rapid
translation into practice. While the workforce com-
pliance components required by WACHS are
absorbed into the existing hospital volunteer pro-
gramme, the Connectors also fall under the
SWCCN governance and risk management, mod-
els discussed in our previous publication.

**Strengths and limitations**

Public health palliative care interventions, such as
this community-based intervention, are imple-
mented in real-world settings, which are complex
systems in which to undertake research, and so
present a challenge to traditional research meth-
odologies. However, with the mixed methods
approach we have employed, and the balance
between using a validated tool for the primary
outcome and other pragmatic tools to measure
the perception of participants of the impact of the
programme, the reported quantitative findings in
this article point to the success, feasibility and
viability of this model of care. The interviews
undertaken with the participant groups reinforced
these quantitative findings and will be reported in
a forthcoming article.

What we have realistically aimed for, as outlined
in the published protocol article, was achieved in
terms of at least 10 Connectors and 30 families
participating and completing the study. Given the
exploratory nature of this study, our conservative
estimates were based on the relatively small size
of the initial study population (about 100 pallia-
tive care patients), on what was feasible within the
initial data collection timeframe of 10 months
(stretched to 15 months because of the pan-
demic), and on the need to find enough families
willing to participate (50% participation in this
study) and then be able to complete the study
(30% attrition in this study). Half-way through
the data collection period, it became apparent
that recruitment needed to be supplemented from
other patient groups who have a chronic or life-
limiting illness but are not too close to end of life
(four additional services as per Table 1). As pal-
liative care patients may have been referred quite
late to the palliative care team, their subsequent
referral to the Connector programme was often
too late to pursue network enhancement, and
many were lost to follow-up through death or
feeling too unwell, challenges that are well
reported in the literature. An added challenge of
the pandemic was that the enforcement of vacci-
nation status by the health service led some
Connectors, who did not at that stage wish to be
vaccinated, to exit the programme. It should also
be noted that there are challenges to generalisa-
bility due to the small number of participants in
this study.

Only 15 family carers agreed to participate out of
a possible 23 for those patients not living alone –
14 carers were spouses and one a daughter. In
general, family carers participated with patients in
completing the pre- and post-outcome measures
and interviews as a family unit. However, future
research may need to focus solely on the needs of
family carers and promote it as such so carers do not feel they are competing with the needs of patients, a challenge encountered in previous research.49

The research-related paperwork was always not welcomed by consumers and service providers49 and may have discouraged some families and Connectors from signing up at the start or continuing with the programme. Families needed to sign consent forms, and respond to questionnaires, albeit brief ones, at the start and end of the intervention. The majority of Connectors did not like completing the one brief tool (NET) on needs of families and Caring Helpers they sourced for these needs. One workable solution was for the project coordinator to reach out to the Connectors after their visits and collect the necessary information from them by phone or by e-mail. We anticipate as the programme moves forward, without the research component, these administrative challenges will greatly diminish.

Conclusion
This project has provided the evidence that such Compassionate Communities Connector models of care are effective in improving social connectedness. Moreover, it demonstrated the viability of a working relationship between informal community networks and formal health networks, mediated by the Connectors. The COVID-19 pandemic has demonstrated the importance of local networks of care and the understanding of the Compassionate Communities Connectors approach to care thus gained is relevant and timely, given the need for community capacity building in the wake of the pandemic.

This trial has tested procedures for applicability and feasibility and appraised the likely rates of recruitment and retention of participants that need to be considered in future studies or larger trials. If more or larger communities participate in a research study that could achieve a larger sample size, then other outcomes would be possible to measure such as the impact on health service utilisation using a control group and economic effectiveness.

This pilot project has laid solid grounds for building community capacity, enhancing health services capacity and potential replication into other communities, with successful and realistic measurable outcomes, which are in line with what is reported in the international literature for similar programmes. Ongoing work is focused on rolling out the Connector training to a number of interested communities in other geographical regions to help them establish a similar model of care, meaning further programme applications and better integration of formal and informal services.

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.

Robyn Richmond: Data curation; Formal analysis; Methodology; Software; Writing – review & editing.

Kerry Gunton: Data curation; Formal analysis; Methodology; Project administration; Software; Supervision; Writing – review & editing.

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

Julian Abel: Conceptualisation; Investigation; Writing – original draft; Writing – review & editing.

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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**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 article. Interested and qualified researchers may send requests for additional data to Samar Aoun at samar.aoun@perron.uwa.edu.au.

**Trial registration**
Australian and New Zealand Clinical Trial Registry: ACTRN12620000326998.

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**References**
1. Aoun SM, Abel J, Rumbold B, et al. The Compassionate Communities Connectors model for end-of-life care: a community and health service partnership in Western Australia. *Palliat Care Soc Pract* 2020; 14: 2632352420935130.
2. Mckee M, Kelley ML, Guirguis-Younger M, et al. It takes a whole community: the contribution of rural hospice volunteers to whole-person palliative care. *J Palliat Care* 2010; 26:103–111.
3. Sallnow L, Bunnin A and Richardson H. Community development and hospices: a national UK perspective community and hospices. In: Wegleitner K, Heimerl K and Kellehear A (eds) *Compassionate communities: case studies from Britain and Europe*. London: Routledge, 2015, pp. 1–14.
4. Noonan K, Rumbold B and Aoun S. Compassionate community Connectors: a distinct form of end-of-life volunteering. *Prog Palliat Care*. Epub ahead of print 17 July 2022. DOI: 10.1080/09699260.2022.2090051.
5. Pfaff KA, Dolovich L, Howard M, et al. Unpacking ‘the cloud’: a framework for implementing public health approaches to palliative care. *Health Promot Int* 2020; 35:160–170.
6. Pfaff K, Krohn H, Crawley J, et al. The little things are big: evaluation of a compassionate community approach for promoting the health of vulnerable persons. *BMC Public Health* 2021; 21:2253.
7. Dumont K, Marcoux I, Warren Alem ÉF, et al. How compassionate communities are implemented and evaluated in practice: a scoping review. *BMC Palliat Care* 2022; 21:131, https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-022-01021-3
8. Abel J, Kellehear A and Karapliagkou A. Palliative care: the new essentials. In: Abel J and Kellehear A (eds) *Oxford textbook of public health palliative care*. Oxford: Oxford University Press, 2022, pp. 30–36.
9. Paul S and Sallnow L. Public health approaches to end-of-life care in the UK: an online survey of palliative care services. *BMJ Support Palliat Care* 2013; 3: 196–199.
10. Barry V and Patel M. *An overview of compassionate communities in England*. London: National Council for Palliative Care Dying Matters, 2013.
11. Wegleitner K and Schuchter P. Caring communities as collective learning process:
findings and lessons learned from a participatory research project in Austria. *Ann Palliat Med* 2018; 7(suppl. 2): S84–S98.

12. Abel J and Townsend D. Developing community support networks at the end of life in Weston-super-Mare, UK. In: Wegleitner K, Heimerl K and Kellehear A (eds) *Compassionate communities: case studies from Britain and Europe*. London: Routledge, 2016, pp. 15–29.

13. Abel J and Kellehear A. Palliative care reimagined: a needed shift. *BMJ Support Palliat Care* 2016; 6: 21–26.

14. Abel J, Bowra J, Walter T, et al. Compassionate community networks: supporting home dying. *BMJ Support Palliat Care* 2011; 1: 129–133.

15. D’Eer L, Quintiens B, van den Block L, et al. Civic engagement in serious illness, death, and loss: a systematic mixed-methods review. *Palliat Med* 2022; 36: 625–651.

16. Vanderstichelen S, Dury S, de Gieter S, et al. Researching Compassionate Communities from an interdisciplinary perspective: the case of the Compassionate Communities Center of Expertise. *Gerontologist*. Epub ahead of print 9 March 2022. DOI: 10.1093/geront/gnac034.

17. Walsh C, Dodd S, Hill M, et al. How effective are volunteers at supporting people in their last year of life? A pragmatic randomised wait-list trial in palliative care (ELSA). *BMJ Support Palliat Care* 2016; 14: 203.

18. Horsfall D, Psychogios H, Rankin-Smith H, et al. Researching Compassionate Communities in Australia: a short-term longitudinal study, 2020, https://doi.org/10.13140/RG.2.2.31469.67046

19. Horsfall D, Noonan K and Leonard R. Bringing our dying home how caring for someone at end of life builds social capital and develops compassionate communities. *Health Soc Rev* 2012; 21: 373–382.

20. Abel J, Kingston H, Scally A, et al. Reducing emergency hospital admissions: a population health complex intervention of an enhanced model of primary care and compassionate communities. *Br J Gen Pract* 2018; 68: e803–e810.

21. Sallnow L. *Collective social capital: a study of new public health and end-of-life care*. Doctoral Thesis, The University of Edinburgh, Edinburgh, 2017.

22. Noonan K, Horsfall D, Leonard R, et al. Developing death literacy. *Prog Palliat Care* 2016; 24: 31–35.

23. Patterson RM, Gibb C and Hazelwood MA. End of life aid skills for everyone in Scotland. *Palliat Care Soc Pract* 2022; 16: 26323524221076511.

24. Kleijberg M, Ahlberg BM, Hilton R, et al. Death, loss and community – perspectives from children, their parents and older adults on intergenerational community-based arts initiatives in Sweden. *Health Soc Care Community* 2020; 28: 2025–2036.

25. Duggleby W, Pesut B, Cottrell L, et al. Development, implementation, and evaluation of a curriculum to prepare volunteer navigators to support older persons living with serious illness. *Am J Hosp Palliat Care* 2018; 35: 780–787.

26. Pesut B, Duggleby W, Warner G, et al. Volunteer navigation partnerships: piloting a compassionate community approach to early palliative care. *BMJ Palliat Care* 2017; 17: 2.

27. Collins A, Brown JEH, Mills J, et al. The impact of public health palliative care interventions on health system outcomes: a systematic review. *Palliat Med* 2021; 35: 473–485.

28. Librada-Flores S, Nabal-Vicuña M, Forero-Vega D, et al. Implementation models of compassionate communities and compassionate cities at the end of life: a systematic review. *Int J Environ Res Public Health* 2020; 17: 6271.

29. Milton B, Attree P, French B, et al. The impact of community engagement on health and social outcomes: a systematic review. *Community Dev J* 2012; 47: 316–334.

30. Noonan K, Sallnow L and Richardson H. Ten years of public health palliative care conferences: a critical reflection for the next decade. *Prog Palliat Care* 2020; 28: 78–82.

31. Quintiens B, D’Eer L, Deliens L, et al. Area-based Compassionate Communities: a systematic integrative review of existing initiatives worldwide. *Palliat Med* 2022; 36: 422–442.

32. Sallnow L, Richardson H, Murray SA, et al. The impact of a new public health approach to end-of-life care: a systematic review. *Palliat Med* 2016; 30: 200–211.

33. Moser A, Stuck AE, Silliman RA, et al. The eight-item modified Medical Outcomes Study Social Support Survey: psychometric evaluation showed excellent performance. *J Clin Epidemiol* 2012; 65: 1107–1116.

34. McLoughlin K, Rhatigan J, McGilloway S, et al. INSPIRE (INvestigating Social and PractIcal supports at the End of life): pilot randomised trial of a community social and practical support intervention for adults with life-limiting illness. *BMJ Palliat Care* 2015; 14: 1–10.

35. Harris PA, Taylor R, Thielke R, et al. Research electronic data capture (REDCap) – a metadata-driven methodology and workflow process for
providing translational research informatics support. *J Biomed Inform* 2009; 42: 377–381.

36. Abel J, Walter T, Carey LB, *et al.* Circles of care: should community development redefine the practice of palliative care? *BMJ Support Palliat Care* 2013; 3: 383–388.

37. Holt-Lunstad J, Smith TB and Layton JB. Social relationships and mortality risk: a meta-analytic review. *PLoS Med* 2010; 7: e1000316.

38. Slavich GM. Social safety theory: a biologically based evolutionary perspective on life stress, health, and behavior. *Annu Rev Clin Psychol* 2020; 16: 265–295.

39. Slavich GM and Cole SW. The emerging field of human social genomics. *Clin Psychol Sci* 2013; 1: 331–348.

40. Abel J. Health and well-being. In: Abel J and Kellehear A (eds) *Oxford textbook of public health palliative care*. Oxford: Oxford University Press, 2022, pp. 64–71.

41. Leonard R, Horsfall D and Noonan K. Identifying changes in the support networks of end-of-life carers using social network analysis. *BMJ Support Palliat Care* 2015; 5: 153–159.

42. Rosenberg JP, Horsfall D, Leonard R, *et al.* Informal caring networks for people at end of life: building social capital in Australian communities. *Health Sociology Review* 2014; 24: 29–37.

43. Aoun SM, Breen IJ, White I, *et al.* What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach. *Palliat Med* 2018; 32: 1378–1388.

44. Naito R, Leong DP, Bangdiwala SI, *et al.* Impact of social isolation on mortality and morbidity in 20 high-income, middle-income and low-income countries in five continents. *BMJ Glob Health* 2021; 6: e004124.

45. Abel J, Kellehear A, Mills J, *et al.* Access to palliative care reimagined. *Future Healthc J* 2021; 8: e699–e702.

46. Arantzamendi M and Centeno C. Intangible values of palliative care. *Eur J Palliat Care* 2017; 24: 72–74, www.ejpce.eu.com

47. Vanderstichelen S and Deliens L. Complexities and challenges in public health palliative care research. In: Abel J and Kellehear A (eds) *Oxford textbook of public health palliative care*. Oxford: Oxford University Press, 2022, pp. 245–250.

48. Aoun SM and Nekolaichuk C. Improving the evidence base in palliative care to inform practice and policy: thinking outside the box. *J Pain Symptom Manage* 2014; 48: 1222–1235.

49. Aoun S, Deas K, Toye C, *et al.* Supporting family caregivers to identify their own needs in end-of-life care: qualitative findings from a stepped wedge cluster trial. *Palliat Med* 2015; 29: 508–517.