

# Final Report

## GICS Grants Program 2020/21

<b>Project title</b>	Exploring how peer support can be optimised for carers of cancer patients receiving palliative care
<b>Funding allocation</b>	\$10,000
<b>Prepared by</b>	Kerry McKenzie
<b>Organisation</b>	Cancer Council Victoria
<b>Version</b>	Scoping Grant
<b>Date</b>	28/04/22

### 1. Problem definition

Briefly describe the background to the project, including:

- The issues or problems that led to this project being developed
- Any available evidence of the issue or problems

*“Being a carer is not just one job, it’s many jobs. Everyone worries, ‘Am I doing it okay?’ It’s always right; just do the best you can to care for the person you love. That person loves and respects you for it.” – CCV peer support volunteer*

Recognising the vital role that carers play in supporting someone with cancer, the Victorian Cancer Plan 2020 – 2024 commits to implementing the Victorian Carer Strategy 2018–2022. The strategy notes that rural and regional carers in particular are less likely to have support services nearby, may be physically isolated and where support services do exist, they may be less likely to be drawn on.

Additionally, if a person is caring for someone with advanced cancer, their likelihood of experiencing increased distress, anxiety or depression can be profound, and often is greater than the overall distress experienced by the patient themselves.<sup>i</sup> For this reason, we are pleased to see the Cancer Plan also calling for tailored and compassionate support of carers of palliative patients.

The advent of COVID-19 has brought additional challenges and has had a negative effect on cancer patients, their carers and families. We know that carers experienced isolation and heightened anxiety associated with the responsibility of providing care for their dying loved one when many Victorians have no experience of supporting this<sup>ii</sup>. Between March and November 2020, we heard directly from over 2000 carers and family members of cancer patients about the immediate and lasting impacts of COVID-19. More than 25% of these were from rural and regional areas and made contact for psychological or emotional support.

Increased support for carers of palliative cancer patients is a clear need in order to maintain their social, emotional and physical health and to allow them to continue their vital role in cancer care.

## 2. Project overview and method

### Briefly describe the aims and objectives of the project.

In this project we aimed to conduct interviews with current carers and clinicians to explore ways to optimise and tailor peer support programs for carers of cancer patients receiving palliative care within the Grampians region.

The objectives were to understand:

- the lived experience of regional and rural carers of people receiving palliative care for cancer,
- the role of peer support in meeting carers' needs in regional and rural settings, and to
- make recommendations about how future peer support models may be structured with carers to meet their unmet support needs.

### Briefly describe the project including key activities, stages, noting outputs and outcomes.

This project used a qualitative study design using phone interviews with carers and clinicians from regional and rural areas in Victoria.

Ethics approval was obtained from the Victorian Cancer Council (HREC 2105) and from Deakin University (2021-362).

Participants were recruited from the region covered by the Grampians Integrated Cancer Service (GICS) in Victoria, comprising 12 Local Government Areas.

Participants were A) informal carers defined as a family member or friends or B) clinicians including medical oncologists, surgeons, nurses, allied health assistants and other health professionals who meet the following inclusion criteria:

- Adults over the age of 18,
- The ability to speak English without the aid of an interpreter,
- Carers providing care to someone receiving palliative cancer care, or clinicians who work in palliative care
- Living within the Local Government Area covered by the Grampians Integrated Cancer Service (GICS): Ararat, Ballarat, Golden Plains, Hepburn, Hindmarsh, Horsham, Moorabool, Northern Grampians, Pyrenees, West Wimmera and Yarriambiack

Interviews were conducted over July – October 2021.

Bereaved carers were included via an ethics amendment from August 2021.

Interviews were tape recorded, transcribed and analysed according with a thematic analysis.

12 carers and 4 health professionals were interviewed. Of the carers, 100% were bereaved, with no recruitment of active carers.

The majority of carers were female (85%) and were on average 58 years of age (SD=10), health professionals were mostly female (75%) and were a mean age of 52 (SD=17). Two health professionals had 2-5 years' experience and two had > 10 years' experience. See Table 2 for the full demographics.

Interviews lasted an average of 58 minutes (53-91minutes) for carers and 40 minutes (28-45 minutes) for health professionals.

Thematic analysis suggests data saturation occurred.

Four themes were evident:

#### **Theme 1: The caring context.**

- Caring for someone with advanced cancer was challenging and overwhelming
- The distinction between palliative care and end of life care was not well described
- Carers struggled to manage care needs throughout the palliative care period and as deterioration occurred
- Some carers described accessing supports early on during palliative care, however during end of life care all carers preferred that time to be spent just with their loved one
- Carers were able to find support from their family, friends, neighbours, community groups and some supportive services such as hospice care, GPs, counselling and the hospital

**Theme 2: Caring in the time of COVID-19.**

- Carers providing support to their loved one throughout the COVID-19 pandemic noted feeling particularly affected by the impacts of lockdown, and unable to seek support from their social connections
- The ability to seek support extended into bereavement as carers were at times unable to fulfill funeral wishes and maintain human connection after the loss of their family member.
- The ability to offer peer support was also impacted as many carers now also expressed the preference for face-to-face support. They often noted the importance of a “backup” that could be accessed during COVID-19 lockdowns and similar periods of isolation and uncertainty in the future

**Theme 3: Potential peer support model.**

- Theme 3 included considerations for how peer support could be delivered
- Many people thought peer support would be beneficial but it would need to be flexible:
- Face-to-face sessions were preferred
- Some indicated they did not feel comfortable in a group format
- The idea of informal support was valued, where people could connect and contact each other when needed and meet when possible.
- There was a lack of consensus as to the optimal model, suggesting flexibility and tailoring are required.
- Peer support was often seen as sharing of experiences with other carers in a similar situation. Carers also liked the idea of resources such as “clinician chats”

**Theme 4: An embedded model.**

- Bereaved carers may be more engaged – something to consider for future interventions.
- Participants reflected about the overwhelming nature of caregiving
- Carers stated that a peer may have been helpful to:
  - Debrief with
  - To normalise their experience, and
  - To share practical tips.
- But would have that been likely? Many said maybe not
  - Carers reflected that their focus on the patient

**Outcomes of the project:**

The project report has been shared with palliative care services in the Grampians region in order to help inform future services.

An academic publication is planned

Podium presentation planned for Cancer Nurses Society Australia annual conference in June 2022.

Results and recommendations will inform any future peer support offerings developed by Cancer Council Victoria.

**Briefly outline how deliverables were achieved and any change management strategies used or challenges experienced.**

Clinicians were recruited from healthcare services within this region; the project was introduced to clinicians by a Cancer Council representative during in-services, including to the clinical network facilitated by Grampians Palliative Care Consortium (GPCC), through introductions promoted by a GICS Cancer Services Improvement Coordinator and internal promotion by Ballarat Hospice Care Inc (BHCI). Digital project flyers were distributed for printing and sharing electronically with potential participants. A landing page on the Cancer Council Victoria (CCV) website was designed and provided potential participants with more details and contact information.

To reach carers the project was advertised on the Cancer Council website, through newsletters and social media, through promotion via BHCI, GPCC and clinicians at the various healthcare services within the GICS region.

Interested carers and clinicians initiated contact with the project manager who screened individuals for eligibility, completed informed consent and demographic questionnaires and scheduled phone interviews. Prior to phone interviews participants were informed that phone interviews would be audio recorded.

A key challenge for the project was that despite broad approaches to recruitment, no current carers indicated an interest in participating in the project. The scope of the project was expanded after several months of recruitment to include bereaved carers. This occurred with an ethics amendment, and to allow a direct referral of a potential carer participant by a health care professional to the project.

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### 3. Stakeholders, consultations & communication

Describe how consumers were engaged during your project

Listening to the lived experience of participants was central to the success of this project. The insights and lessons learned through the cancer journey, particularly while their loved one was receiving palliative care, was integral to informing and developing the recommendations. Involving the consumers as key informants will allow any future projects to be based on the insights and lived experience of consumers, and will facilitate co-design on future projects. Consumers were also part of the assessment panels responsible for assessing the grant proposal.

### 4. Budget

Provide final budget expenditure in table below

Item expenditure	GICS Grant \$	CCV contribution (in kind) \$	Expenditure \$
Deakin University: instrument development, interviews, full analysis and report	\$8,000		\$8,000
Project Management and coordination – Cancer Council Victoria (3 hours per week for 7 months)	\$2,000	\$9,500	\$11,500
Advertising content development, communications consultation and support (total of 5 days)		\$3,000	\$3,000
<b>TOTAL EXPENDITURE</b>	<b>\$10, 000</b>	<b>\$12,500</b>	<b>\$22,500</b>

### 5. Monitoring & evaluation

How was the project evaluated and what were the outcomes? (limit 200 words)

Once data collection was complete, Deakin University analysed the interviews and provided a detailed report with four key recommendations that can be used to inform future peer support projects, tailored to the needs of this population. These were; 1) having a flexible and tailored program for carers, 2) engaging carers using strategies such as codesign to develop a peer support program; 3) Broadening the target group beyond active carers, and 4) Exploring existing services.

Feedback was also provided to all participants; carers were provided with a brief summary of what the project results; health professionals were invited to a one-hour presentation of results and recommendations relating to the project.

All results were de-identified.


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## 6. Sustainability / future direction

Explain how the project benefits will be sustainable over time OR what are the future plans for project outcomes achieved so far? (limit 100 words)

- Project report has been shared with palliative care services in the Grampians region in order to help inform future services.
- An academic publication is planned
- Podium presentation planned for Cancer Nurses Society Australia annual conference in June 2022.
- Results and recommendations will inform any future peer support offerings developed by Cancer Council Victoria.

## 7. Project authorisation

Signature	
Name of Executive Director	Danielle Spence Date 27 / 04 / 2022

<sup>i</sup> Alam, S., Hannan, B. and Zimmermann, C. (2020) Palliative Care for Family Caregivers. *Journal of Clinical Oncology* **38**(9):926-936

<sup>ii</sup> Palliative Care Victoria (2020) *COVID-19 impacts on palliative care*. Submission to Inquiry into the Victorian Government's Response to the COVID-19 Pandemic. Available at: <https://www.parliament.vic.gov.au/1000-paec/inquiry-into-the-victorian-government-s-response-to-the-covid-19-pandemic/4499-submissions> [Accessed 20/01/21]