Development of a model for palliative care in rural and remote communities: the “pop-up model”

Kate White, University of Sydney, Lesley Wilkes, University of Western Sydney, Patsy Yates, Queensland University of Technology, Will Cairns, Townsville, Linda Kristjanson, Leanne Monterosso, Edith Cowan University

BACKGROUND

In Australia, approximately one third of Australians live in rural areas¹ and another half a million reside in remote regions of the country. The overall incidence of cancer is similar in metropolitan and rural populations, however, mortality is higher for those individuals who live in rural regions, particularly so for men with prostate cancer and women with cervical or lung cancer. There is recognition that access to health care for individuals living in rural and remote areas of Australia has been problematic.²,³,⁴

The need to develop alternative models for providing effective delivery of an appropriate mix and level of health services to rural communities which differ in size and types has been acknowledged by government and health authorities.⁵ The need is required for a number of reasons and one reason is the gaps in service functions (palliative care and respite).

In a systematic review on organising palliative care for rural populations Evans, Stone and Elwyn (2003) identified that there is limited published work in this area and most of the work identified problems in the delivery of palliative care in rural areas. Most research has been focused on the discussion of needs and barriers. Since the review, White, Wall and Kristjanson (2004) argue that this reaction has diverted attention away from attempting to develop a complementary body of remote area palliative care knowledge. Palliative care services in rural and remote areas need to be ‘responsive’ and a set of broad principles to assist in developing such a service are proposed.

Establishing new models of palliative care delivery involves substantial change in local health services and provides a unique opportunity for planning more integrated care. Previous work carried out by the research team revealed a range of unmet needs for palliative care patients and their families in rural and remote areas, including access to palliative care services, information about illness, practical care and support.⁶,⁷

Rural families have identified problems in accessing practical care.⁶,⁷ In particular, after hours care, where families reported difficulties associated with the provision of care to an ill family member, especially at night. Difficulties included symptom management, assessment of the patient’s condition and uncertainties about how to comfort and solve practical care giving problems. Reduced health care provider input and limited choices for home care were identified and families also had limited knowledge of the existing local services. Economic and physical barriers such as distance, lack of transport and the need to travel as well as reduced services from which to choose from further impacted on the choices and availability of care for these rural families.⁸ Access to specialist counselling services and psychosocial services such as bereavement counselling are also known to be challenging areas in rural and remote communities.⁴
There is consistent evidence to indicate that many people with advanced cancer prefer to be cared for at home, especially in the last stages of life.\textsuperscript{9,10} This need to have care at home may be particularly important to those individuals living in rural or remote areas who would otherwise experience isolation and distress if they were moved to metropolitan centres for their end stage care. A number of studies have illustrated that specialist palliative care services in regional Australia are of high standard, those individuals living in rural and remote areas do not always have access to these services.\textsuperscript{2,3} Therefore, there is a need to explore alternative models for providing palliative care for Australians living in rural and remote areas. These alternative models must be sustainable from both a resource and funding perspective.

**Palliative care**

The definition of palliative care utilised for the purpose of this study is:

… the active total care of people whose disease is not responsive to curative treatment. Care is delivered by coordinated medical, nursing and allied health services which are provided, where possible, in the environment of the person’s choice. Control of pain, of other symptoms and provision of psychological, social, emotional and spiritual support is paramount.\textsuperscript{11}

**Remoteness**

There are two main interpretations of remoteness: remoteness as a geographical construct and remoteness as a cultural construct. Remoteness defines a community by its inaccessibility. That is, it is either difficult to get to and from, or it is distant from major population centres, or it is both inaccessible and distant. Remote places generally are smaller populations when compared to major population centres. In carrying smaller, often more widespread populations, remote areas are less able to demonstrate equal access to equivalent health resources to those found in the major population centres. The Accessibility/Remoteness Index for Australia (ARIA)\textsuperscript{12} was used to define the term ‘remote’ within this study.

**Significance**

Access to palliative care outside of the specialist palliative care model is problematic leading to large sections of the Australian community being disadvantaged. For rural and remote communities with limited access to health resources overall, this can be even more difficult. This project outlines an innovative approach to assist this disadvantaged group of Australians and has the potential to guide the development of new approaches for sustainable and cost effective delivery of palliative care services to rural and remote areas in Australia. This project recognises that each community may be unique; therefore, the model is designed to be flexible and meet the diverse needs of rural communities in providing palliative care. This project builds upon previous research undertaken by the research team in rural health, rural palliative care and developing and implementing alternative models of palliative care in rural areas.

**Aim**

The overall purpose of this study is to develop a sustainable yet flexible model for providing palliative care whereby rural and remote communities develop a framework to support their palliative care needs and to develop their model for palliative care.

Specifically this project aims to:

- develop, implement and test a cost-effective model for providing palliative care services specifically tailored for rural and remote communities;
• develop a structured program to assist communities to utilise the model to meet their communities palliative care needs.

**METHODOLOGY**

**Research design**

This study contains two phases drawing from an action research design. Action research is participatory, collaborative research that develops from a shared concern or goal to improve practice, in this case the delivery of palliative care to rural communities. Action research aims to improve practice in co-operation with participants shaping the changes or models that are to be implemented.

**Phase 1 — Development and pilot of the Palliative Care Tool Kit**

The Palliative Care Tool Kit (PKTK) was developed using an evidence-based approach. The PKTK was sent to the research team members for review and was then refined on the feedback received from the research team.

There are five key principles to the kit such as:

1. **A community initiative** — where the community needs to be involved in all stages;
2. **A facilitative process** — where implementation requires a facilitator and must be someone from within the local community who is competent to fill the role requirements;
3. **Leadership** — where the facilitator will be required to provide initial leadership in starting the building process and liaising with other potential team members
4. **Work focused** — in that the facilitator will be responsible for bringing the community group together helping it to start its work
5. **Group effort** — where the community group and the clinical team will be responsible for using the Palliative Care Tool kit to develop and maintain services.

The Palliative Care Tool Kit has two components, the pop-up framework and a resource kit.

The PKTK uses the principles of the world health organisation definitions of palliative care and draws upon the best evidence available. The PCTK has a structured approach that guides the facilitator through two phases and provides assessment questions, guiding principles and practical strategies. The PCTK assists in guiding the development of the community group by reviewing the existing approaches to palliative care and in establishing the palliative care service.

In regards to developing the palliative care service, the PCTK guides the development of an integrated team and choosing an integrated approach. The kit also provides guidance with providing physical and practical care as well as psychosocial, spiritual care and bereavement care. The resource kit includes information such as current definitions of palliative care, tips on team building, information of web based resources, and brainstorming techniques.

The expert advisory panel was drawn from a representative group of those involved in, or with an interest in palliative care and rural health. Sixteen members were recruited for the panel that including palliative care clinicians, rural health providers, consumer advocates and Indigenous
health workers. A number of those approached were unable to join due to current obligations. It was recognised that many professional bodies face competing demands for representation. National and state groups that were unable to participate in the expert advisory panel, continued to receive newsletters and project updates on the project to ensure they had the opportunity to be involved.

The PCTK was then refined on the basis of the feedback received and distributed to the expert advisory panel. A modified version of the Delphi data collection technique was utilised for the evaluation for the Palliative Care Tool Kit with the Expert Advisory Panel. The Delphi technique facilitates obtaining or determining a consensus from a group of experts. A series of questionnaires were administered that assessed the model and the kit on the clarity, readability, relevance, practicality, the palliative care content and practicality for the rural and remote communities and consensus was achieved. Final recommendations were presented to the expert advisory group and the Palliative Care Tool Kit was further refined before being presented for trial.

One area within Western Australia was chosen as the pilot site (Phase 1) for the PCTK. This area was chosen because it was classed as a Moderately Accessible site (ARIA score = 4.81) at that present time, and did not have an established palliative care service.

The pilot period for the Palliative Care Tool Kit was completed in mid 2003 to evaluate content, the process of forming a community team and the implementation process. It is important to point out that the purpose of the pilot (phase 1) was not to use the kit in providing palliative care but instead to look at the process. The pilot results showed the PCTK to be useful, with a sound structure, clear diagrams, and an easy to follow process. The feedback suggested that community support for such a project is directly proportional to the value placed on the project by the community, as represented by a local committee or board, which appears to be directly related to the funding requirements of the project. The suggested changes are highlighted in Table 1.

Table 1 Suggested additions and changes to the kit from the pilot stage

<table>
<thead>
<tr>
<th>Category</th>
<th>Issue</th>
<th>Additions/changes required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding</td>
<td>Temporal sequence in kit</td>
<td>Should be further forward in the kit, with greater emphasis.</td>
</tr>
<tr>
<td>Forming a Team</td>
<td>Clarity</td>
<td>Introduce a diagram to clarify the worksheet “Forming an Integrated Team”.</td>
</tr>
<tr>
<td></td>
<td>Local media involvement</td>
<td>Representative from local media could be part of the community team.</td>
</tr>
<tr>
<td>Training</td>
<td>Development of Manuals</td>
<td>The development of manuals and protocols for volunteers is necessary.</td>
</tr>
<tr>
<td>Bereavement</td>
<td>Content</td>
<td>More bereavement care information/ resources required.</td>
</tr>
<tr>
<td>Maintaining the Service</td>
<td>Process</td>
<td>Monthly meetings for volunteers and on-call nurses to discuss issues and carry out ongoing training.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Invite GP and allied health to meetings and send the minutes if unable to attend meetings.</td>
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<tr>
<td></td>
<td></td>
<td>Publish outcomes of meetings in local newspaper to maintain community interest and involvement.</td>
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Phase 2 — Implementation and analysis of the Palliative Care Tool Kit

Three sites were chosen for the implementation of the PCTK (Phase 2), one site in WA, NSW and QLD. The Accessibility/Remoteness Index for Australia (ARIA) was used to define the term ‘remote’ within the study. Table 2 illustrates the ARIA score for each site. Site one was in Western Australia, 420 Km south of Perth and has a population of approximately 450 people. The second site was in QLD, 500 kilometres west of Townsville, with a population of
approximately 800 people. Site three was located 662 km north-north-east of Sydney. At 872m above sea-level it has a population of approximately 300 people and functions as a service centre to farming, grazing and mining. Data was collected from all three sites.

### Table 2: ARIA scores and classifications

<table>
<thead>
<tr>
<th>Town</th>
<th>ARIA Score</th>
<th>ASGC Classifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site 1 WA</td>
<td>6.08</td>
<td>Remote Australia</td>
</tr>
<tr>
<td>Site 2 QLD</td>
<td>13.82</td>
<td>Very Remote Australia</td>
</tr>
<tr>
<td>Site 3 NSW</td>
<td>4.16</td>
<td>Remote Australia</td>
</tr>
</tbody>
</table>

### Ethical considerations

Participation in the project was totally voluntary. The selection of rural sites was determined on the expressed interest to be involved. All data collected from the surveys and interviews will be de-identified to ensure participants remain anonymous. No participant names will be identifiable in any report or publication. All data is stored in accordance with the NHMRC guidelines and will be destroyed after a period of five years.

### RESULTS

This paper will focus on the key themes from the qualitative interviews with staff and community participants. Data was collected at each site by conducting a series of semi-structured interviews with staff, local community members, patients and family carers involved at each site. Any palliative care patients or family/family caregivers that each site had during phase 2 were also invited to be interviewed. Information was given to all participants and signed consent was obtained from all participants who took part in an interview. All interviews were audio-tape recorded and were transcribed verbatim. Transcripts were read by two independent readers and themes and categories were identified. Once the two researchers reached consensus on the themes and categories a third researcher was also asked to read transcripts and verify the data. Table three illustrates the main themes and sub-themes for all sites for both staff and community participants.

### Table 3: Key themes for staff and community participant

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Challenges</th>
</tr>
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<tbody>
<tr>
<td>Transferability</td>
<td>Lack of support</td>
</tr>
<tr>
<td>Validation of knowledge</td>
<td>Isolation</td>
</tr>
<tr>
<td>Collaboration</td>
<td>Volunteers</td>
</tr>
<tr>
<td>Adaptability to settings, and patients</td>
<td>Existing problems</td>
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</tbody>
</table>

Three main themes were identified within the transcripts from the staff involved in phase 2 across the three sites. The themes were Benefits, Challenges and Improvements. Each of these themes contained a number of categories. Overall for the three sites the PCTK was perceived to be beneficial, easy to use and adaptable to site needs.

### Benefits

Overall a number of benefits were identified when participants were asked about the PCTK. The benefits related to both the toolkit and the palliative care service they provided. The
categories that were identified within Benefits revolved around Transferability, Validation, Adaptability and Collaboration.

Throughout the interviews there were multiple references to the kit acting as a reinforcement for the palliative care work being conducted in each of the three sites.

… Well I think it’s worthwhile … for the simple reason it probably defines palliative care and what we should be doing basically … and following a process … but to actually follow a process that’s written down that someone can access. (Site 2)

… it’s worked really well and like we’ve been able to use it. (Site 3)

The PCTK was also perceived to improve community knowledge and awareness of the health care professionals. Staff interviewed suggested the resources (ie team building) would be useful across disciplines and that the kit would be a good base that could be passed on if there were staff changes.

… See even the things … the twelve tips for team building and the brainstorming strategies and those sorts of things, will be valuable for our inter-agency meeting. So it’s got some good tools in it that will be useful for development of community services … (Site 1)

… For someone who didn’t have a great knowledge of the community I found it very beneficial to actually look outside the square of just what Health offered. So knowing what community organisations were available, knowing the key people within the community that could assist us to provide that level of care. I think it will be very beneficial for the next person who steps into the palliative care role here as well … (Site 2)

Transferability

Transferability related to the transfer of knowledge between staff which would provide continuity of care for patients. The PCTK was viewed and experienced in some sites to assist with this issue. For example, one site had used the PCTK to formalise their own working policy document that can be used by all staff, including relief staff. The transferability was also identified in relation to using a similar framework for other medical conditions.

Collaboration

Collaboration refers to illustrating good teamwork, good communication, involvement of allied health professionals. As well as Collaboration that has occurred by using the PCTK’s resources or what the PCTK helped them to identify what the resources were.

… For someone who didn’t have a great knowledge of the community I found it very beneficial to actually look outside the square of just what Health offered. So knowing what community organisations were available, knowing the key people within the community that could assist us to provide that level of care. I think it will be very beneficial for the next person who steps into the palliative care role here as well … (Site 2)

One site that had drafted a working copy to illustrate collaboration and placed it on the wards so everyone can access it. They also placed it into their policy and procedure processes. The project became that of the community, not just a health care providers.

… It probably was already in place informally … but I don’t know the community that well … I just, went in on a consultative basis. So in their absence (nurses) it was nice for me to actually think, well have I thought about … are these people are available, what about utilising their skills. So it wasn’t just Health owning the project it was a whole of the community approach that I really enjoyed. I thought it was a great idea … (Site 2)
Adaptability

The PCTK was seen to assist the three sites to adapt their care and the service to meet the changing needs of both the community and the individual patient.

But then if you use … this palliative service, when … new patients are the ones who pop up in your community and you activate your services and, and then you make the service work for that patient. Rather than make the patient fit into the service. (Site 3)

Participants can see how the kit can be used throughout health area

… I really like it because it fits into a primary health care model but it also gets people thinking about the specialty areas that may be required for someone with palliative care needs. So it fits nicely into the primary health care model … (Site 2)

Validation

Validation referred to the PCTK formalising the current knowledge base on the team and in doing so validated and reinforced the palliative care services they currently provide. The PCTK also was seen to help with role definitions,

yes, having like a actual formula and sort of worrying about going about setting up your services and working out where you’re going and having … like your facilitators for each patient … like all the different roles and everything that they’ve, they’ve set out in the toolkit … is how I’ve sort of gone through and set out our service because it makes it more formalised and easier to follow and know what steps you’ve got to address and resources and everything in here as well were really good to use. (Site 3)

Challenges

A number of challenges were identified when participants were asked about the PCTK. The challenges related to both the toolkit and the palliative care service they provided. The categories that were identified under Challenges revolved around Lack of Support, Isolation, Volunteers, Continuity of Care and Existing Problems.

Lack of support

Lack of support was identified through competing projects, staff turnover, changes in workload, organisational structure, and funding issues. For instance at one site there were other projects that were happening within the community where they may have been viewed as more important.

A lack of funding for after hours support was also identified in two sites:

… We don't have provision for after hours permanent care in terms of I’m on call for emergencies only … (Site 1)

Staff shortages may also be funding related:

… there’s a rural nursing shortage you know, so to try and get replacement is very, very difficult for everything … (Site 2)

An issue was identified across two sites, was lack of local services. There difficulties that evolve due to the need to travel to access treatment was identified as a major ongoing challenge.

Isolation

Isolation was identified as an ongoing challenge for the individual and their family, and the health care team in providing care.
… but there’s a tremendous amount of pressure put on the family regardless of whether its palliative care or not because the simple fact is it’s five hundred kilometres to [town] (Site 3)

As noted by patients, the health professional is also aware that isolation and travel were major concerns for patients and often mentioned to the health professionals.

… Isolation here … and long distances for seeing consultations for … different type of things. Even for radiotherapy. You know … Travel, I mean they’ll go to [city] or, and it’s a long way being away from their families. That’s, that’s really hard on them … (Site 2)

The isolation also has implications for education for members of the health care team.

… most of the training is in [City] and it’s pre-planned at the beginning of the year and if it doesn’t fit in with your needs it’s tough luck … but probably what I would see as also being useful would be having someone come in to speak to the staff members about caring for dying relatives and their families in general terms. You know … help with personal care but not know how to talk to someone about death or not know, be a bit apprehensive or what if, what if they die while I’m there or what if they talk to me about, what do I say, you know … (Site 1)

**Volunteers**

The issue of volunteers was identified also identified as challenge. There was an issue of privacy, trust and confidentiality with using volunteers across all sites. Site three adapted and utilised the support networks they found with their patients regarding volunteers.

… because it’s a bit harder in this town because people don’t want to know other people’s business and one particular family we’re involved with, we used all their, already set up networks and resources and everything to be able to care for that patient at home. (Site 3)

… It was also a role in small towns of confidentiality — which … there’s none … And you find that people, particularly when they’re dying are self conscious enough in front of their families when they lose their functions, when they are losing their faculties so they really don’t want … non family members … (Site 1)

It can be hard to keep volunteers interested and available as they tend to find they drop off after time either through their own commitments, their ability to take on additional volunteer roles as many already had multiple volunteer roles and being an aging group.

… We did identify some people with some skills and abilities but they’re already overloaded, they’re not young and already overloaded and you know, you can only stretch people so far … They have their families and their commitments. (Site 2)

**Existing problems**

Within one site there were some existing problems with collaboration and with education from hospital and outside services. Participants acknowledged that the PKTK was useful for supporting collaboration, providing direction to move forward.

**PRINCIPLE OUTCOMES**

In conclusion the outcomes of this study:

- The development and evaluation of a mechanism to support small rural communities to develop sustainable models for providing palliative care to rural and remote communities utilising existing health care and communities services.

- The establishment of models for providing palliative care with wide applicability across a diverse range of rural and remote communities
• A model of palliative care that has been developed collaboratively with rural practitioners, community members, rural palliative care experts and researchers

• The development of a formalised approach to assist rural and remote communities identify their palliative care needs and approaches within their own community.

ACKNOWLEDGMENTS

We would like to thank Project Officers David Wall, Laura Emery and Shantala Mohan for their contribution to the project. We would also like to acknowledge and thank the staff involved at all three sites for their valuable time and involvement.

REFERENCES


Kate White has recently been appointed Professor of Nursing at the University of Sydney. Kate has more than 22 years’ experience in clinical practice, education and research in cancer care, the past eight years in joint academic-clinical appointments in NSW and Western Australia. Professor White is a member of working parties and project teams such as the Rural Scholarship Working Group, NBCC Psychosocial Expert Advisory Group and the NBCC Specialist Demonstration Project team. She is currently undertaking several studies, such as an analysis of the practical needs of rural and remote adult and paediatric patients and their families when in the city for cancer diagnosis and treatment.