The impact of partnership on capacity building in palliative care among rural communities: a South Australian experience

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BACKGROUND

Palliative care services in Australia have continued to make significant contributions to the health and well-being of people with life-limiting conditions and their caregivers. Most recent services, predominantly community based, emphasise equipping the client to live at home for as long possible.1 There is also the focus on concerted efforts of a multi-disciplinary team in addressing the needs of clients. Embedded in the principles of palliative care is careful attention given to caregivers who often are unrecognised.2,3 Palliative care recognises that caregivers also experience the various stages of dying and also require understanding and support.4

People with life-limiting conditions have many needs and of these psychosocial, emotional and spiritual needs seem to be least understood and spoken about. While there is sufficient literature available on the physical needs and care interventions of people with terminal illnesses, more research is needed on psychosocial and spiritual care and support for clients and caregivers. Yates described psychosocial support as increasingly complex “as health care providers strive to find solutions for difficult problems of meaninglessness, uncertainty, powerlessness and loss of control which characterise the modern experience of death”.5 According to Ashby, Kissane, Beadle and Rodger family members must be acknowledged not only as primary care providers but also second-order patients.6 The challenge for the palliative care service is to provide effective and holistic care to the client and caregiver to maintain dignity and quality of life.

Recent studies have focused on how best to provide these ideals through the reflexivity approach for individualising psychosocial care. Admittedly, individuals respond to dying in different ways and health care professionals, including nurses, must be “flexible and able to continually assess the needs and responses of individuals”.5 Hudson concluded from his study of 106 metropolitan home-based caregivers that good palliative care meant meeting the needs of families. The same author commented that the “current strategies were suboptimal” and recommended that “the way forward is to establish partnerships between government, service providers, general practitioners and researchers to collaboratively explore appropriate evidence-based best practice approaches to home based palliative care”.7 Effective management of psychosocial issues in palliative care needs to be addressed at various institutional levels, i.e. organisational and public policy level.5

The concept of palliative care however has not filtered into some communities, such as people from rural and remote areas and Indigenous communities.8 In geographically isolated and economically deprived areas of South Australia, there is a dearth of information available to the public about palliative care. Within the health care disciplines, there are evidences suggesting that there is a lack of education and training within health care disciplines in
palliative care. There is a lack of co-ordination of services and communication between health professionals.

A team of researchers from the Discipline of Nursing and Rural Health, University of South Australia, Whyalla Campus, in partnership with the Eyre Regional Health Service, Jamestown Hospital and Health Service, Mid North Regional Service, Northern and Far Western Regional Health Service, Wakefield Regional Health Service, and the Pika Wiya Health Service, embarked on a two-year research project to address some of the needs of rural clients and caregivers. The primary aims of our project are two-fold: to identify the specific needs of rural people with life-limiting conditions and their caregivers and to increase access and awareness of palliative care amongst rural community members and health care professionals.

The palliative care project team, consisting of academic researchers, has a genuine interest in the health and well-being of the rural communities. We acknowledge that educational opportunities are limited in rural and remote areas. Our task was to increase the access and education of rural communities equipping them with the capacities and skills in coping with life-limiting conditions and caring for loved ones with life-limiting conditions. Through this research were also able to fulfil our civic responsibility in keeping with the university’s strategic approach on rural engagement. The community views the researchers and the university as a resource or authority in education and health and this project showed that the team could take a lead role in increasing the access and education of palliative care services in rural South Australia.

We consider capacity building and sustainability as crucial requirements of community development, and consider our research approach and its potential for building various types of capacities among rural communities as we describe several methods of partnerships and interrelationships that emerged between the researchers and local communities. Through our research involvement, we have contributed to individual and collective development of clients, caregivers, volunteers and health care professionals.

Community development has been described as “a process in which a community grows or builds its capacity to protect and enhance the health and wellbeing of its members”. In our research we have engaged with the community by meeting the needs of community members in relation to increasing access and awareness of palliative care services, researching palliative care issues of importance to the region and engaging in a diversity of community service activities, such as analysing needs and gaps in services, conducting public information sessions, exchanging information, and identifying key people. The capacity building activities in palliative care extended to resource development, such as social resources that highlight the awareness and understanding of the goals, philosophy and services of palliative care. Such developments may very well lead to individual and community empowerment because empowerment is “the ability of people to gain understanding and control over personal, social, economic and political forces in order to take action to improve their life situations” that is essential for sustainable community development.

**METHODS**

**Research orientation**

A qualitative interpretative approach to research was adopted for this study; as this was very much a project requiring the development of relationships with key stakeholders such as regional health services palliative care clients and caregivers, community members and health care professionals. Through in-depth interviews and focus groups qualitative data were
obtained to uncover the specific needs of clients and caregivers and to examine the impact of our project.

The focus of our paper is the impact of partnerships on capacity building and as such the following research question is addressed and supported by the interview data generated in the project.

Research question:

- How can strong partnerships between clients, caregivers and palliative care service providers and other health care professionals be developed and sustained to benefit rural communities?

**Ethical considerations**

Ethics approval to conduct the study was obtained by the Human Research Ethics Committee (HREC) of the University of South Australia upon submission of a protocol according to the National Health and Medical Research Council (NHMRC) guidelines. Consent was obtained in writing from participants in order to audiotape interviews and focus groups.

**Sample, data collection and data analysis**

All residents of the Northern and Far Western, Jamestown, Wakefield, Mid North and Eyre Peninsula regions and Pika Wiya Community Health Service were invited to participate in the public information sessions on palliative care. Clients and caregivers, consisting of spouses, partners, family members, and volunteers residing in the target areas were also invited to participate in the interviews and focus groups that followed.

Through newspaper, radio and television advertisements, and flyers, community members of the various localities were invited to attend the public information sessions. Letters were also sent introducing the project to the Chief Executive Officers, Directors of Nursing, and/or Department Heads of various rural health services. The letters included the purpose of the study, participant’s actual involvement, statement regarding the voluntary nature of participation and assurance of confidentiality of information provided.

Experiential data from over seventy (70) interviews were obtained by tape-recording the interviews, and the three (3) focus groups that followed, which were audiotaped, and transcribed verbatim for analysis. Responses were entered into the qualitative data management package QSR N5 in order to identify revelatory phrases and recurring themes and phrases. Queries were made regarding experiences in caring for a loved one with a life-limiting condition, how one makes sense of the experience, how caregivers may be assisted in caring for a loved one and how carers might be supported as well.

**DISCUSSION**

At the time of writing this paper our palliative care project has been in progress for eighteen months and the research team had travelled in excess of 6000 kilometres to conduct interviews with research participants, attend meetings and conduct community forums. From our research, a rural community partnership model emerged which strengthened the process and means by which rural communities developed the necessary skills, capacity and expertise to support palliative care clients and caregivers. Our rural community partnership model is depicted in the following diagram.
The rural community partnership model is essential for illustrating the impact that our research has had on the rural communities of South Australia. The palliative care clients and carers were the focus of partnerships that emerged and pivotal to such partnerships was the leadership role of the research team in driving its agenda to achieve the goals and objectives of the project. Community ownership of the research was important in developing strategic partnerships with health services and palliative care teams. Capacity building involved the transactions between the research team and health professionals, service providers, clients and carers, and the strategies involving education and support that was put in place. Such strategies need to be sustainable in that once the research project is completed the health services need to be responsible for the ongoing education and support.

We have provided over fifteen (15) public information sessions in the four (4) health regions and invited community members and health care professionals to these sessions. The project team worked closely with local palliative care teams in conducting these educational sessions. While the content of the sessions varied between communities, common to them were the notion of palliative care, death and the process of dying and facing reality, and issues relating to bereavement and beyond. There were also many opportunities to discuss issues of interest to those attending the information sessions. Over 1200 community members from the various regions have participated in these sessions and have discussed a wide range of issues including referrals, personal care, pain relief, comfort, emotional and spiritual support, and use of complementary therapies, symptom management, funeral arrangements, and support for volunteers in the outreach setting. Many listened to people’s narratives and reflected on their personal experiences.

We obtained participant feedback on the information sessions through a short evaluation instrument. Participants indicated their satisfaction of the information provided by identifying its relevance, usefulness, and opportunity to share their experiences with others, establish connections, identify key people, explore support mechanisms and gained strength to continue in their journey. Evaluation of educational sessions is vital for on going community involvement to assess whether aims have been met and to provide guidance for future initiatives.
The in-depth interviews with clients with life limiting conditions and caregivers revealed that they needed support to continue caring for their loved ones, as at time they felt helpless, isolated and alone. The support and care clients and caregivers require cannot be overestimated. They need to know about palliative care and what options are available to them because most of the caregivers are committed to caring for their loved ones at home. They need an awareness of how the condition would progress and the implications this would hold for the client and caregiver in their capacity to care for them. They also need to know how much support they can expect from the health care professionals. The candid discussions, which followed, enabled them to explore these issues and seek answers to these issues. What has emerged from these sessions is a paradigm shift away from the traditional notions of caring for someone with a terminal condition to one that defines the concept of palliative care practice. This information has now filtered into the communities in the regions involved in our research.

The following table illustrates the indicators, definitions, involvement and the impact on people that this research has had on achieving its goals and objectives and developing partnerships and capacity building in palliative care among rural communities.

Table 1 The impact of our project on building partnerships in rural communities

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<thead>
<tr>
<th>Indicator/definition</th>
<th>People involved</th>
<th>Impact on people</th>
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<tr>
<td>Human capacity skills, knowledge, self-confidence, job readiness, ability to network and interact</td>
<td>Communities, clients and caregivers, palliative care teams</td>
<td>Increase knowledge and awareness, able to contribute to the development of future projects, identify support mechanisms, establish links</td>
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<td>Leadership capacity ability to influence others to work towards a common goal</td>
<td>Palliative care teams, caregivers leading support groups</td>
<td>Increase ability to organise public forums, generated and supported community skills to direct, provide, lead or otherwise contribute to the provision of education on palliative care services, community members assuming a leadership role in the local community with regard to palliative care</td>
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<td>Organisational capacity ability of the organisation to work together for a common purpose while still retaining their identity</td>
<td>Rural health services</td>
<td>Able contribute to the development of future projects, able to link and network with other organisations, resolve conflicting information, direct more resources to palliative care</td>
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<tr>
<td>Community capacity ability of a community to achieve a common vision</td>
<td>Communities, palliative care teams, health services</td>
<td>Appreciate the value of palliative care and pass on knowledge, establish links and networks</td>
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<td>Individual resilience openness to new ideas, actively engaging with community, capacity to seek external resources, independent</td>
<td>Caregivers and health care professionals</td>
<td>Identify key people to approach, able to establish links with other organisations and health providers in the community</td>
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<td>Community resilience respond proactively to change, organisations and networks working together, providing leadership and resources, developed a shared vision and strategies that address social and economic issues through integrated solutions</td>
<td>Regional health services, university research team</td>
<td>Identify resources, links and networks, promote palliative care issues</td>
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<td>Social capital refers to the networks within a community and the level of trust, mutual support and participation by people in the community in activities that strengthen their sense of social belonging and community well-being</td>
<td>Communities, health services, palliative care teams, university research team</td>
<td>People involved in the educational sessions retain knowledge, skills and interests in the community, engagement of people in palliative care issues</td>
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Adapted from Finlay J., editor.13
Our findings in rural community development is supported by Eade, stating that “strengthening people’s capacity to determine their own values and priorities, and to organise themselves to act on these”. In partnering with clients, caregivers, health care professionals and services, the project team’s resources and talents fuse with that of the community’s resources to achieve common aims, develop creative solutions to pressing problems and to strengthen relationships. Community capacity can be described as “the combined influence of a community’s commitment, resources and skills that can be deployed to build on community strengths and address community problems and opportunities”. Capacity building, referring to increasing ability to solve problems and identifying opportunities, involves innovation, recognising individual worth, contributing to improved quality of life, and sharing experiences and good practice. Actively involved community members serve as the “mainstays of community development and social cohesion’ and constitute “an interesting, active and strong community”. Moreover, only local people can build community capacity. We have uncovered through our research that partnerships with communities and research teams at universities have such an enabling role in community-driven development.

We have identified the following policy development issues through the course of this research and bring these to the attention of local government and state governments, Department of Health Services, Department of Human Services, and universities educating health professionals for action.

**Policy development**

Policies may need to be developed underpinning the following:

- more conversation and dialogue about palliative care with rural communities are imperative
- medicalisation of the dying process, we need to stop treating dying as a medical condition
- palliative care should form a part of the undergraduate curricula for all health professionals, including medical students
- staff development programs must include giving instructions on palliative care for all health professionals
- the health services need to adopt a co-ordinated and transparent approach to delivering palliative care services

**CONCLUSION**

Through our involvement in this project community engagement, development and support was mobilised for client and caregivers involving rural communities, health organisations, palliative care teams and health professionals. Community capacity building as a concept originated from early community work by Alinsky, followed by Deschooling Society by Ivan Illich, Social Development in Communities by Schonenberg and Rosenbaum, and more recently by the World Bank and Garlick’s work in regional Australia. The scope of this paper does not lend itself to an exploration of the work undertaken by the above writers but suffice to say that although community capacity building as a concept originated some four decades ago it has not been until quite recently that the impact of knowledge, skills, capacity and strategic partnerships have been considered as influencing community change that is sustainable. The data generated in our study is convincing of the impact our partnership has on capacity building among rural communities in South Australia.
The University of South Australia, Whyalla Campus, is the only regional university campus in the state and has been responsive to the needs of local and regional communities through innovative ways of providing education and support. The Campus has deployed its human resources of staff knowledge and skills to enrich community social capital through dynamic networks, education and connection with diverse groups. These are maintained and expanded through the sustained sharing of knowledge and provision of mutual support, thus transforming local people into a community resource impacting positively on individual and community well-being. In engaging with community members, the campus contributes to the learning and capacity building of the individuals and groups involved. At the same time, individual and collective capacity on the campus is built through the extension of staff experience and networks.

The fact that community have requested sessions on the specific areas of education and training that they believed were needed was the key factor in the successful links with the community members. As Mitchell highlights, education and training benefit community members profoundly if the community spearheads them. In most of these sessions participants’ knowledge about health matters has been developed, expanded and challenged. The capacity of community members to identify their health needs and care is encouraged through the process of study and reflection on the options available to them. Some of these sessions were proactive rather than reactive and health measures were learned so that they can prevent repercussions of health problems rather than simply responding to them. They have also gained insight into health-promoting activities. For example, grief following the loss of a spouse may lead to depression, which could lead to insomnia. Management strategies, solutions and alternatives are presented, either affirming what they are already doing or encouraging them to adopt new approaches, such as in one case using relaxation techniques and/or changing sleeping habits. Thus, creating ownership of knowledge acquired enabling them to more effectively manage change in their health status and to manage a variety of chronic conditions. Access to useful information and contacts is critical to making decisions that will improve quality of life.

In addition, the regional health services have become proactive and as a direct result of our research two of the rural health services have funded dedicated palliative care rooms for their community members. They have taken an active role in the educational forums and sought specialised information for local health professionals. The regional palliative care teams have embraced technology and developed an on-line discussion forum to discuss issues concerning service provision, sharing information and as a means of linking palliative care workers by way of providing on-going support to staff in regional and rural locations.

REFERENCES


PRESENTERS

Mary Oliver is the Head of Discipline Nursing and Rural Health at the Whyalla Campus. She is the Chief Investigator of the research project entitled ‘Partnering with rural communities to improve access and education in palliative care in regional South Australia’. She has established research partnerships with key stakeholders in the health industry, especially in regional SA, including Eyre Regional Health Service, Jamestown Hospital and Health Service, Mid North Regional Service, Northern and Far Western Regional Health Service, Wakefield Regional Health Service, Pika Wiya Community Controlled Health Service, Inc and the Whyalla Area Cancer Support Services. Mary has been project leader for several other projects involving multi-disciplinary members.
Joy Penman holds Bachelor and Master’s degrees in Nursing and Pharmacy and is currently pursuing her doctoral studies at the University of South Australia. Joy is currently a lecturer teaching both science and nursing courses at the Discipline of Nursing and Rural Health, Whyalla Campus. She has over seventeen years’ teaching experience locally and abroad and many years’ nursing experience in various health care facilities. Joy has extensive experience in research and community service as well. She is the co-investigator of the Caring Communities Palliative Care Project.

Cynthia Ofner is the Project Officer of the project ‘Partnering with rural communities to improve access and education in palliative care in regional South Australia’. She is also the co-investigator of another research project on occupational stress in rural nursing. She has been a registered nurse since 1986 and has extensive occupational experience in medical and surgical nursing. She also worked in the community as a Chronic Disease Nurse Educator.