



University of
South Australia

Centre for Regional Engagement

**Partnering with Rural Communities to Improve
Access and Education in Palliative Care**

September 2006

Research Team Members

Associate Professor Mary Oliver

Ms Joy Penman

Ms Cynthia Ofner

Funded by Australian Government Department of Health and Ageing

ISBN 0-9802841-1-2

Published in September 2006

University of South Australia, Centre for Regional Engagement

Enquiries should be directed to:

Associate Professor Mary Oliver
Associate Dean
Research, Teaching & Learning
Centre for Regional Engagement
University of South Australia
111 Nicolson Avenue
Whyalla Norrie
South Australia 5608
Tel: +61 8 8647 6192
Fax: + 61 8 8647 6014
Email: mary.oliver@unisa.edu.au

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EXECUTIVE SUMMARY

This report describes a research project conducted by a team of researchers at the University of South Australia, Centre for Regional Engagement 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, over a two-year period to address some of the needs of rural palliative care clients and their caregivers. The primary aim of this research was 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, health care professionals and caregivers.

During the course of this work the research team members travelled over 6000 kilometres to conduct interviews with participants, attend meetings and conduct community forums on palliative care. Over fifteen public information sessions were held and the researchers 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 notions of palliative care, the process of dying and facing reality, and issues relating to bereavement. There were many opportunities to discuss issues of interest for those attending the information sessions. Over 1200 community members from the various communities participated in these sessions and discussed a wide range of issues including referrals, personal care, pain relief, comfort, emotional and spiritual support, 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.

Through our involvement in this research community engagement, development and support was mobilised for client and caregivers involving rural communities, health organisations, palliative care teams and health professionals.

We have also identified policy development issues and have been advocating bringing these to the attention of local and state governments, Department of Health Services, Department of Human Services, and universities educating health professionals for action. The policy development issues underpin 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 instructions on palliative care for all health professionals
- ❖ The health services need to adopt a coordinated and transparent approach to delivering palliative care services

Associate Professor Mary Oliver PhD

Acknowledgement

The research team is indebted to the following individuals for their input and advice and especially in facilitating this research:

Nicola Champion (Pt. Pirie Regional Health Service), Eunice Power (Northern Yorke Peninsula Health Service), Mary Clark (Jamestown Hospital and Health Service), Val Duffield (Pt. Lincoln Health Services), Pauline Oates (Whyalla Hospital and Health Service), Fiona Coulthard (Pika Wiya Health Service), Ted Lavender (Whyalla Cancer Support Group) and many others who contributed to this research.



INTRODUCTION

Much has been written about palliative care, specifically addressing the needs of clients with life-threatening situations. Palliative care services in Australia are hospice, hospital or community based. Most recent services are predominantly community based, with an emphasis on equipping the client to live at home for as long as possible. Equally, there is emphasis placed on having an interdisciplinary team to address the needs of palliative care clients. An interdisciplinary approach draws the expertise of various professionals to provide holistic and 'state-of-the-art' care of people at the end-stage of their lives. Embedded in the principles of palliative care is careful attention given to caregivers.

The concept of palliative care, however, has not filtered into some community groups. For example, people from rural and remote areas, people from diverse cultural and linguistic backgrounds, and Indigenous communities are not familiar with the concept of palliative care. In geographically isolated areas in the country there is a dearth of information available to the public about palliative care. Anecdotal accounts show that the majority of people are not even cognisant of the term 'palliative'. The majority of people with a life-limiting condition access metropolitan health services for treatments, and/or are referred late, if at all, to the local palliative care team. Moreover, research has shown that there is a lack of education and training in palliative care amongst health professionals. Literature suggests that there is a lack of coordination and communication between health professionals managing the care of people with a life-limiting condition.

There is a lack of awareness among the general public about palliative care services. In addition, with constraints of high workload and staff and funding shortages, the support for caregivers has been difficult, informal and limited.



In 2003 the palliative care research team at the University of South Australia (UniSA), Centre for Regional Engagement (CRE) Whyalla, established a partnership with palliative care teams from rural South Australia to address issues related to palliative care in South Australia. Through in-depth interviews, focus groups and the provision of information sessions to the general community and health professionals, the team identified the specific needs of rural palliative clients and caregivers and increased the awareness palliative care for the public and health professionals. More important was the assistance extended by the research to some caregivers in order for them to cope and continue to care for their loved one. The research also supported rural palliative care teams and workers.

Research Partners

The research involved six collaborators. These were Regional Health Palliative Care Services of the Northern and Far Western, Wakefield, Mid North and Eyre regions, Jamestown Hospital and Health Services and the Pika Wiya Aboriginal Health Service. A representative from Whyalla Cancer Support participated in the steering committee to express the needs of the community.

Research Objectives

The objectives of the research were as follows:

1. To promote awareness of palliative care among the communities of Northern and Far Western Region, Jamestown, Wakefield, Mid North, Eyre and the Pika Wiya community;
2. To enhance the knowledge and understanding of health professionals about palliative care;
3. To improve the knowledge and skills of caregivers in order to help them cope, provide better care for their loved one, and deal with bereavement;
4. To develop strong partnerships between caregivers and palliative care service providers and other health professionals;



5. To develop a sustainable rural partnership model in palliative care that is transferable across rural communities; and,
6. To evaluate the activities undertaken.

Target Groups

The target groups consisted of the community members in rural South Australia, including Aboriginal people and people from culturally and linguistically diverse backgrounds, as well as palliative clients, caregivers and health professionals.

Context of the Research

South Australia's land mass is 984,377 square kilometres (one-eighth of the area of the Australian continent); a significant third of the land has no economical use and a large proportion is considered pastoral land. It has a population of 1,470,057 with approximately 72% living in metropolitan areas and 28% living in inner or outer regional areas and remote areas (ABS, 2001). Approximately 10.3% of the South Australian population are from cultural and linguistically diverse backgrounds (non-English speaking countries) and 1.6% of the population are of Aboriginal origin. Approximately 53% of the total Aboriginal South Australian population live in the country (ABS, 2001). There were seven regional health services in South Australia at the time the research was undertaken.

Funding of Health Regions and Palliative Care Service

The seven health regions in South Australia were funded by federal and state governments, through the Department of Health and Ageing and along with other non-government organisations and agencies. According to the South Australian Generational Health Review (Government of South Australia, 2003), a population approach to funding was necessary to facilitate access to health care across the state. Developing services for population size, however, is not sufficient; other indicators need to be considered to enable the region to provide adequate services.



The Australian government made finances (\$201.2 million) available to support the Australian Health Care Agreements (2003-2008) for palliative care. Of this funding, a sizeable amount (\$188 million) was allocated for continued service provision for all States and Territories and a further amount (\$13.2 million) was allocated for national program initiatives. The Federal government also dedicated a budget (\$55 million) over four years to support improvements in the standard of palliative care offered in local communities in Australia which included the Caring Communities Program (4.7 million) funded by the Department of Health and Ageing (Australian Government Department of Health and Ageing, 2004c). The Caring Communities Program was to support people choosing to die at home and provide a better access to high level of care for palliative care clients all over Australia.

Caring Communities Project

The UniSA CRE research team was funded by the Department of Health and Ageing under the Caring Communities Program to undertake a two-year palliative care research project in rural South Australia. A consortium of palliative care practitioners identified that palliative care service was generally unknown to the public. It was recognised that the term 'palliative' was not understood by individuals in rural communities, especially by Aboriginal people and by culturally and linguistically diverse groups. There were others who had the notion that palliative care meant death and dying. Moreover, health professionals were perceived to lack knowledge on the palliative care approach and holistic caring, which were necessary to maintain or improve the quality of life for people with life-limiting conditions. The core group also identified the need to support the caregivers in smaller communities in the region. Issues of distance, access and equity were acknowledged as barriers for availing of palliative care service. The Caring Communities research entitled 'Partnering with Rural Communities to Improve Access and Education in Palliative Care' was conceptualised to address the needs identified through collaboration between academics, researchers, nurses, allied health professionals, health administrators, and community members.



General environment within which the research took place

The Whyalla campus is the only regional university campus in the state and is responding to the needs of local and regional communities through innovative ways of providing education and support. In engaging with community members, the UniSA CRE contributes to the learning and capacity building of individuals and groups.

LITERATURE REVIEW

Access to equitable health care services remains difficult and problematic for rural communities. The reasons for this difficulty are many and varied, including: limited resources, lack of funding, geographical distance, shortage of health professionals, problems with personnel recruitment and retention, isolation, and inadequate access to professional and personal development for health professionals practising in rural areas (Malko-Nyhan, 1998).

Access to Palliative Care Services

The palliative care service provided since the 1980s progressed from hospital care to home care, which has become more popular with families/caregivers of people with life-limiting conditions. In most parts of Australia, a community-based palliative care service is available to support families and caregivers who wish to care for their loved one at home. The benefits of a palliative care service at home are evident when client's and caregiver's needs and expectations are met (Hudson, 2003). However, access to a palliative care service remains a challenge in rural and remote communities. The non-access of the service is due not only to the lack of knowledge of services but to the unwillingness by some to access the services (Aranda, 1999). Figures from Palliative Care Australia reveal that around 56% of cancer patients have accessed the palliative care service; the reasons that some are unwilling to access the service have yet to be explored. According to the Australian Government Department of Health and Ageing (2003), 42% of caregivers



reported that they had someone close to them who accessed palliative care and noted that the majority of the caregivers had a relatively poor understanding of palliative care. The *Palliative Care Service Provision: Planning Guide* (Palliative Care Australia, 2003) estimated that 70-90% of cancer patients require assessment and consultation from palliative care service while 20% require direct care. It is estimated that a further 30-50% of non-cancer patients will access the service for assessment and consultation but only 10% require direct care. Some patients with life-limiting conditions do not access specialised palliative care services if a general practitioner and local nurse are involved already in their care. In an annual health survey in South Australia, 45.2% of caregivers used the palliative care service (Abernethy, 2003). Improving access to palliative care services is underpinned by promotion of the service to non-cancer palliative care clients, people from non-English speaking and Aboriginal backgrounds, people from rural, remote and isolated areas, and children suffering from life-limiting conditions and their caregivers (Aranda, 1999). Practitioners providing palliative care in rural and remote areas should adopt clinical practices and services to meet the needs of individuals and communities (Fried, 2005).

Access to Professional Development in Palliative Care

The bulk of effective palliative care is provided by general practitioners and community nurses (Ashby, 2000, p. 51), but distance becomes a deterrent for many of these rural health professionals to access continuing education. Health professionals need recent evidence-based information, training and upskilling in palliative care in order to incorporate these new approaches in their practice. The lack of education and training in palliative care afforded to rural health workers contributes to the lack of coordination of services and poor communication between health professionals (Grande, 1997; Grbich, Maddocks & Parker, 2001). Allied health practitioners who provide holistic care are still a handful (Currow & Nightingale, 2003). The care of people with life-limiting conditions involves effective coordination of services, involvement of a multidisciplinary team, and application of an holistic approach (Palliative Care



Australia, 2003; WHO, 2004a). The palliative approach should be a core skill of every clinician to ensure a good quality of life for the palliative care client (Finlay & Jones, 1995, Ahmedzai, 1993).

Initiatives have been put in place to address the lack of education and training in palliative care in rural and remote areas. One initiative is the Medical Specialist Outreach Program (MSOAP), where palliative care specialists visit rural communities and work closely with general practitioners, local palliative care teams and allied health professionals in order to provide them with education and develop their skills in this area. Another initiative is the National Palliative Care Program, which includes the Program of Experience in the Palliative Approach (PEPA) that aims to inculcate the palliative care approach in primary health care professionals. Through a workforce placement within a metropolitan hospital or a regional palliative care service, PEPA delegates are provided with authentic learning experiences and on-the-job training. An initiative of the National Palliative Care program to provide much needed education and training for aged care staff members has been the *Guidelines for a Palliative Care Approach in Residential Aged Care*, prepared by Edith Cowan University and launched in May 2004 (Australian Government Department of Health and Ageing, 2004a).

Palliative care nurses need ongoing professional development. Research is important and necessary so that health professionals can effectively deliver evidence-based practices in palliative care. A review conducted in Australia between 1990 and 1996 reported that research on professional issues and management was evident while there was less evidence of research on families and caregivers (Wilkes, Tracey & White, 2000). Evident in the research was the fundamental role of nurses in providing psychosocial and spiritual care for palliative care clients. In another study, Cramer, McCorkle, Cherlin, Johnson-Hurzeler and Bradley (2003) attempted to describe the characteristics, attitudes and communications of 180 randomly selected nurses working in hospices and caring for terminally-ill patients at community hospitals in Connecticut, USA.



They found that nurses who openly discussed hospice care with patients and families had religious beliefs and also had someone close who had used hospice care. They concluded that nurses were more likely to discuss hospice care with terminally ill patients and their families when their education addressed knowledge and attitudes about hospice care. A survey of 2,344 American oncology nurses revealed that nurses needed education to discuss dying with patients and families (White, Coyne & Patel, 2001). The research found that end-of-life care improved through better communication between key stakeholders including clients, families, caregivers and health professionals. Although these studies were conducted elsewhere, they are just as relevant and applicable to the Australian health care setting.

Palliative Care for Minority Groups

Although there are a number of government initiatives and programs developed recently on palliative care, there is a dearth of information on the impact of these initiatives and programs on rural and remote communities, especially minority groups, such as people from culturally and linguistically diverse and Aboriginal peoples. The palliative care teams provide symptom and pain management, practical comfort advice, bereavement support, and referrals to other services. Research conducted among culturally and linguistically diverse people reveals that they often do not use the palliative care team because of cultural reasons, although pride, fear and ignorance have also been mentioned (Aoun, 2004). Aranda (1993) found that bereavement counselling was not an appropriate service for Greek and Italian people because this was the role of the family. Complex issues challenge palliative care providers when caring for people from culturally and linguistically diverse backgrounds.

To encourage people from culturally and linguistically diverse backgrounds to access palliative care, it is imperative to offer several options of care and tailor the plan of care to suit the clients. The use of interpreters, either through the Translation and Interpreting Service (TIS), the Ethnic Affairs Commission Language Services, and/or an Ethnic Link Worker, has been shown to help



promote communication and improve access to palliative care services. Caution is necessary in the use of a relative or friend to act as interpreter. The *Multicultural Palliative Guidelines* (Taylor & Box, 1999) established practice guidelines for health professionals dealing with people from culturally and linguistically diverse backgrounds and emphasised treating a person individually, yet at the same time being cognisant of cultural beliefs, practices and diversity. 'Human services infrastructure is still learning to come to grips with the challenges posed by diversity' (Aoun, 2004, p. 60), but commitment from communities and the government in general prove positive in assisting culturally and linguistically diverse communities in caring for their loved one with life-limiting conditions. The Barwon South West Regional Palliative Care Service (Barwon South..., 2003) in Victoria has developed protocols and guidelines for palliative care practitioners on the potential and expressed needs of client groups, and included an educational strategy to address these palliative care needs, to better inform health professionals. Recently, the *Indigenous Palliative Care Resource Kit* (Australian Government Department of Health and Ageing, 2004b) was circulated to support staff working in mainstream health services to adequately deliver appropriate palliative care services for Indigenous Australians.

Support for Clients, Caregivers and Family

Research on how best to support clients with life-limiting conditions and their families and caregivers has been conducted worldwide. Qualitative and quantitative research methods have been utilised to ascertain the strength of care and support provided for clients, family members and caregivers. The interventions addressing physical, emotional, psychosocial and spiritual needs have been cited in current literature. Many of the interventions implemented, and the overall effectiveness of these interventions, have not been studied adequately (Harding & Higginson, 2003; McCorkle & Pasacreta, 2001; Yates, 1999). It is also unclear when and how support should be given to impact positively on health and wellbeing.



Hudson (2003) has explored concerns about home-based palliative care and cited a demographic study of 106 Australian metropolitan home-based caregivers who were found to have considerable commitment and stress. Hudson, Aranda and McMurray (2002) conducted focus groups with caregivers and palliative care nurses to determine the guidance and support needed by individuals caring for a loved one suffering from terminal cancer. They found the caregivers to be unprepared for their new role and required more support. More recently, Wilkes and White (2005) conducted a cross-section qualitative research project with families and palliative care nurses in rural New South Wales and concluded that family members needed the ready availability of equipment and basic resources, funding for on-going education, and assistance in providing 24-hour care.

Information is empowering and it prepares people to anticipate the unknown. This is vital for palliative care clients, family members and caregivers to help maintain and improve their quality of life. Wilkes, Tracey and White (2000) found that people need timely and meaningful information and effective delivery of information to be equally important. Similarly Kirk, Kirk and Kristjanson (2004) highlighted the importance of the information content and the actual process of information sharing. They conducted a qualitative study on Canadian and Australian palliative care cancer patients and their families and highlighted the significance of information given to people. Other studies have identified support measures for families caring for a loved one with cancer and these included providing information, practical assistance, and emotional support. Enhancing family communication and instruction on managing finances, especially with the added burden associated with treatment and care, are said to have therapeutic benefits (Kristjanson, 2004). The extent of family access to health services and receptiveness to utilise services to alleviate deterioration of health of vulnerable family members caring for their loved one with cancer must be assessed and explored (Kristjanson, 2004). The Living with Cancer Program, developed by the Cancer Council of Australia (2004), aims to provide valuable information and support to clients, families and



caregivers. This program has been particularly beneficial to clients and significant others in the metropolitan areas where it is accessible. It is unfortunate that it is not readily available in rural and remote areas.

The constraints on rural communities' experiences are related to the inadequacy of different types of services owing to limited resources and funding. Financial constraints and limited resources affect health service delivery, even amongst affluent societies. Guberman, Nicholas, Nolan, Rembicki, Lundh and Keefe (2003) studied the impact of research-based carer assessment tools on palliative care practitioners from the United Kingdom, Canada, Sweden and Australia. They found that the assessment tool gave caregivers a legitimate voice in identifying their personal needs and aspirations and were perceived as a resource. Italy's ESPERTI model assessment tool was developed by Ferrario, Zotti, Ippoliti and Zotti (2003) and tested on eighty cancer caregivers who were economically, socially and emotionally at risk, to identify needs and appropriate interventions to achieve outcomes.

Harding and Higginson (2003) examined twenty-two studies (from different countries) on interventions for caregivers using home care and palliative care services and found that home care, respite care, social networks and activities, one to one interventions and group work were most important and concluded that it was imperative for such interventions to be feasible, acceptable and effective.

In another United Kingdom study undertaken by Soothill, Morris, Harman, Francis, Thomas and McIlmurray (2001) on the psychosocial needs of cancer clients and their caregivers, the researchers considered it was important to maintain good relationships with health professionals and receive honest information. Problems on managing daily life, handling emotions, and social identity were identified by some caregivers. Soothill et al. (2001) called on health professionals to anticipate the various needs of caregivers such as sexual needs, coping with feelings of guilt, loneliness and isolation and post-



bereavement support, which could be prohibitive in terms of cost, time and resources. The distress experienced by clients and caregivers may be reduced by the psychosocial support, respite and education/information they receive (Jarvis, Burge & Scott, 1996).

McCorkle and Pasacreta (2001) reviewed caregiver outcomes in palliative care and found that the preferred type of care for people with life-limiting conditions has shifted from the hospital to the home. Family members and caregivers have an increased responsibility in the care of their loved one, in addition to the demands of their daily lives. The value of an advanced practice nurse is immense as a coordinator of care, with 24-hour back-up care, to maintain independence of clients and reduce overall distress of the spouse (McCorkle & Pasacreta, 2001). The early identification and intervention of physical and psychological problems, and the use of a common set of outcome measures that were sensitive to change should be considered (McCorkle & Pasacreta, 2001). This research has influenced policy making and state-wide continuing education for health professionals.

In a study involving African-American breast cancer survivors, it was found that the psychological wellbeing of caregivers was significantly associated with the sense of coherence (35.7%) and hope (5.3%). Coherence and hope assisted the breast cancer survivors improve coping mechanisms (Richardson Gibson & Parker, 2003). Such mechanisms affect survival, adaptation and facilitate culturally appropriate and competent care. The significance of hope amongst people with cancer has been examined by several others including Kirk, Kirk and Kristjanson (2004), who suggest that hope is conveyed in different ways.

Partnerships and Collaboration

Partnerships, community engagements and networking are strategies used by many health service providers to improve health service delivery in rural and remote areas. Collaboration between government and private organisations, hospitals, community health services, agencies, and academic institutions, is a



successful strategy to improve health outcomes for people in rural and remote communities. In forging ties and linkages with rural and remote communities, specific problems and solutions to problems are identified by community members and stakeholders. Walker (1999) examined a model of partnership in rural Tasmania in the context of changes in health service delivery, education and training of health professionals, and application of information and telecommunication technology. The partnership between the University of Tasmania and the Tasmanian Department of Health and Services resulted in the establishment of a rural health teaching site and the Tasmanian Telehealth network offering educational and communication technology opportunities for rural health professionals (Walker, 1999). Expectations on what the collaboration should achieve and how it should operate were fundamental issues identified in relation to collaboration and networking (Onyett, Pillinger & Muijen, 1997, cited in Fuller et al., 2004). Other issues include finances, coordination of services, and maintaining relationships.

Through participatory action research, undertaken in rural communities of New Mexico, Averill (2003) revealed that building on rural community strengths would assist in transforming the health care environment to attain better health outcomes for the community. Essential ingredients for successful communities included the knowledge and core values of elders in the community, dedicated professional nurses from different work settings who provide up-to-date care and groups of concerned citizens from various organisations who advocate for the community and help plan and evaluate current and future programs. Community representation is extremely important to generate information and questions pertinent to the programs and ensure the success of programs based on community ownership (Green, Daniel & Novick, 2001).



PURPOSE OF THE STUDY

The overarching aim of this research was to improve the access and education concerning palliative care amongst clients, caregivers and health professionals in rural South Australia.

In order to achieve this aim, it was important to determine first the health needs of clients with life-limiting conditions and the needs of caregivers. It was important also to understand the perceptions and experiences of palliative care workers. The information gathered from these key stakeholders informed the educational sessions that were conducted in rural South Australia. The educational sessions aimed to promote awareness of palliative care amongst the general communities of the Northern and Far Western region, Jamestown, Wakefield, Mid North and Eyre Peninsula. The educational sessions and networking aimed to improve the knowledge and understanding of health professionals about palliative care which would facilitate early referral to palliative care services. The sessions conducted were designed to enhance the knowledge and understanding of participating caregivers, which would assist them to cope and provide better care for their loved one. The research was intended to help develop strong relationships between caregivers and palliative care service providers and other health professionals, provide on-going support to palliative care nurses, and facilitate access and referral to palliative care services in participating communities. Central to this research was the aim of enhancing the coordination of care for people at the end-stage of life in targeted rural communities and developing a sustainable rural partnership model in palliative care that was transferable to other rural communities.



METHOD

Research Strategy

A steering committee was established to help achieve the research objectives. The terms of reference for the steering committee were clarified from the very outset. The steering committee members were nominated by the Chief Executive Officers of the regional health services involved in the research. A Memorandum of Understanding was signed by the Chief Executive Officers of the participating organisations.

The steering committee members attended meetings held every three months for the duration of the research. The main functions of the steering committee were to identify issues that impact on palliative care service in their respective communities; nominate key individuals from the community to act as key contacts and facilitate research activities; and participate in establishing information sessions for community members and health professionals.

Research Orientation

A qualitative interpretative approach to research was utilised in this study. Through in-depth interviews and focus groups, qualitative data were obtained to uncover the specific needs of clients and caregivers.

Research Questions

The following questions informed the study:

- 1 What are the needs of rural palliative care clients and caregivers?
- 2 What do clients and caregivers perceive as being important in fulfilling their needs?
- 3 How can caregivers be supported and assisted in caring for their loved one?
- 4 How can strong partnerships between clients, caregivers and palliative care service providers and other health professionals be developed and sustained to benefit communities?



Ethical Considerations

Ethics approval was obtained from the Human Research Ethics Committee (HREC) of the University of South Australia. Consent was obtained in writing from caregivers in order to audiotape interviews and focus group meetings. The tapes and transcripts were stored safely in a locked cabinet at Research UniSA CRE. The data stored on the personal computer of the research officer are password protected and accessed only by the researchers.

Research Procedure

The research was conducted in four phases.

Phase 1: Conduct in-depth interviews with clients and caregivers and follow-up focus groups

Phase 2: Conduct educational sessions; support community groups

Phase 3: Determine the educational needs of health professionals; and conduct educational sessions for health professionals

Phase 4: Provide on-going support to palliative care workers

The participating palliative care teams of health organisations involved in this research were requested to recruit potential interviewees. A letter outlining the research was distributed to potential participants. This included the purpose of the research, the participant's actual involvement, a statement regarding the voluntary nature of participation and assurance of confidentiality of the information provided. Those who agreed to participate were contacted by the research team and arrangements made for interview.

Following the interviews, focus groups were conducted involving 4 to 12 individuals who participated in discussing, exploring, describing and sharing their thoughts and perceptions about palliative care. Recordings from focus group interviews were transcribed verbatim and subjected to thematic analysis.

Educational sessions on palliative care were then conducted with community members and health professionals. These sessions were organised in



conjunction with the palliative care teams of the participating regions. Sessions were promulgated by palliative care team members through advertisements, flyers, and other networking activities. The information sessions were designed to meet the specific needs of a cohort of participants. An evaluation questionnaire was used to determine the usefulness of the education session.

Data Analysis

Interviews and focus group meetings were transcribed verbatim using Quality Solutions Research (QSR), computer software designed to manage qualitative data collected in this study. Data were coded and categorised to identify revelatory phrases and recurring themes.

RESULTS

Interview Participants

A total of seventy-five (75) interviews were conducted at different locations in rural South Australia. Sixteen (16) participants were from Whyalla, eight (8) from Port Pirie and surrounding areas, twenty-three (23) from Port Lincoln and surrounding areas, five (5) from Wallaroo, three (3) from Jamestown, five (5) from the Pika Wiya Aboriginal Health Service, ten (10) participants from Port Augusta, and five (5) from Clare and surrounding areas. Of those 75 interviewed there were sixty-eight (68) caregivers and seven (7) were clients with life-limiting conditions. Three (3) focus group meetings were conducted with a total of thirty (30) participants.

Recurring Themes

From the data collected, several recurring themes emerged. These themes described the perceptions of participants, mostly caregivers, about their role, their experiences in caring for their loved one, and ways and means by which they were supported in their caring role. The following themes emerged from the data: caring for the loved one, support from family and friends, challenges of caring, role change from partner to carer, the meaning of comfort, facing death,

feelings of emptiness following death, emerging from the losses, involvement of health care providers, and issues affecting rural palliative clients and caregivers.

Theme 1: Caring for the loved one

Most of the caregivers interviewed were spouses of clients with life-limiting conditions. There were only a small number of caregivers interviewed who were caring for either a parent or a son or daughter. In caring for their loved one, the majority of caregivers appreciated the information given by palliative care team members about their 'journey' with their loved one. They desperately needed to know how the condition would progress, what their loved one would be experiencing, how to care for their loved one, and how they could be assisted during this difficult time. Many caregivers stated that timely information was important. Equally important was the continuity of care provided by the palliative care nurses, who were perceived as being sensitive to the needs of the families and a great help in caring for their loved one. These findings are supported by Wilkes et al. (2000), who found that meaningful and timely information were imperative for clients and caregivers. Many caregivers stated also that they needed to be supported and encouraged in how to best carry out their role as caregivers. They explained that they did not want to disadvantage their loved one by looking after them at home, and were concerned about depriving their loved one of professional care available at the hospital. They appreciated feedback and affirmation from nurses. The caregivers were encouraged by the affirming remarks about the care given and knowing that they were doing exactly what their loved one wanted. The caregivers reported how they had to adjust quickly and learn basic nursing skills to assist them in their day to day caregiving role. Moreover, the caregivers needed to be able to talk about things openly and to be assured of support from nurses when needed.

Some caregivers reported that they were very happy to look after their loved one and willing to undertake the journey with them. One caregiver stated that,

Yes, it was something I wanted to do. The doctor suggested that I sleep in another room but I knew I wouldn't sleep in another room so I slept in the bed so that I was aware of what he was doing and when he was getting up and that sort of thing to help him to the bathroom.



The following excerpt describes the experience of a grateful daughter caring for her dying mother:

It has been an absolute privilege to be able to take care and look after her after all that she's done for me.

Another caregiver described his experience of caring for his wife in the following way:

People expect it to be terribly hard or an imposition when you look after someone. It is not. My wife and I were married in 1965. We have known each other all our lives, it was just a matter of course that you love someone, you look after them. We both took our vows seriously.

The commitment of the spouses and members of the family to care for their loved one was described as an act of love while some described it as a call of duty. They acknowledged the need to be able to call on professional support when necessary, especially a support person known to the client. Their fears and insecurities were alleviated when someone who understood their specific situation handled their queries. The caregivers declared that being able to vent their feelings with someone they trusted helped them cope. It is important to recognise that many caregivers claimed that there was enough physical support to get through daily life but it was the 'psychological burden' that some caregivers found difficult to deal with.

Some caregivers explained that their husbands expected them to be psychologically strong, as conveyed by an ex-caregiver: 'He expected me to be strong for him.' Another participant commented,

When I got teary or anything, he just didn't want to know and that's why I was determined not to let him see that I couldn't cope.

On the other hand, open communications between family members proved helpful in most instances, as demonstrated by the following:

I think I am coping relatively well and I think my husband is as well. I keep my family informed as much as I possibly can inasmuch as when I go to the doctor and he wants to maybe change my drugs then we discuss everything.

A son-in-law found openness and truthfulness beneficial in his relationship with his wife's mother. He said:



I wouldn't beat around the bush. I'd say straight out, Mum I've got something to tell you, ... we got on better by being straightforward.

Theme 2: Support from family and friends

Caregivers expressed that they needed support from health professionals as well as family and friends. Family members who were strong were very useful in these critical situations. Most caregivers felt that family members and friends were necessary to better cope with their caring responsibility. Usually, family members helped out with the physical aspects of care and provided respite for the main caregiver. More often, they were close geographically to provide physical, emotional and psychological support to the main caregiver. Consider this comment from a participant:

I have got a lot of help. This one here is especially good (pointing to a brother-in-law). I don't know how I would cope without his brothers. I have my off days, sometimes I get a bit depressed but you know I haven't had one of those for a while.

Many caregivers valued the assistance they received from family and friends. The support, either tangible or intangible, warmed the hearts of those at the receiving end. It was understandably advantageous for clients if a family member or close friend had a nursing background. Many made particular mention of the benefits of having a health professional close to the family as these people were considered as a resource or authority in the area of caring. They explained the condition, manifestations, tests, procedures, medications, and disease process, in ways that were sensitive and understandable.

Some communities rallied behind the clients and their families. Community members showed empathy, sympathy, compassion and concern for clients with life-limiting illnesses and their caregivers. Such support is touching and praiseworthy. According to the caregivers, support was shown in various ways, from cooking meals, offering fresh produce, visiting and having coffee, and even lending a comfortable chair for the client.

In rural areas, maintaining confidentiality could be difficult and many community members are aware of this difficulty. In one instance, a family



member did not wish the community to know about their situation because 'cancer was shameful'; whereas other families were delighted to have the community support and involvement. In most cases, the clients and caregivers determined the support that they accepted from neighbours and community members.

Theme 3: Challenges of caring

People with life-limiting conditions have many needs and these include physical, emotional, psychological, financial and spiritual needs. Caregivers themselves have a variety of needs that need to be met. Most caregivers experienced the physical strain of caring for a loved one, especially those rendering care continuously. Consider for example the strain of care delivery twenty-four hours a day, seven days a week. The lack of sleep, lack of time to relax, and lack of time to attend to personal tasks, took its toll on most caregivers, affecting their physical and emotional wellbeing. A few caregivers were not well themselves and two caregivers had to postpone an operation or special procedure because of their responsibilities. Many stated that their recreational and leisure activities came to a halt because they did not wish to spend time away from their loved one. Some caregivers reflected that they found very little time for themselves doing what they wanted to do because the clients' needs were a priority. A few caregivers talked about not being able to plan anything ahead, like a short trip away to visit family or taking up new employment. Future planning was perceived to be impossible and unrealistic. The responsibility of full-time caring was extremely challenging for some caregivers, necessitating them to relinquish their caregiver role. Consider the statement of this elderly parent acting as a caregiver for her daughter: 'I stopped looking after my daughter at home because she was getting harder to manage.'

Caregivers worried initially about their ability and competence in assuming the care of their loved one. They became confident and competent in caring activities such as showering, administering medications, preventing pressure sores, and other activities of daily living. There were others who discussed their



willingness to look after their loved one and this gave them confidence as one caregiver stated: ‘The help was there if I needed it but I felt I could do it and he would rather me do it for him than have outside help .’

Some caregivers discussed the financial burden they had to endure when their loved one became infirm. Money was needed to purchase supplies, aids and medications needed on a continual basis. While some equipment was borrowed, other caregivers purchased their own equipment and this depleted their savings. A number of caregivers wished to access alternative therapies, which were often difficult to access and costly. One particular caregiver, who looked after her parents living in a ‘granny flat’ in her backyard, complained that there was no support from the government to help defray expenses for electricity, water, or telephone. Caring for her loved ones would have been facilitated had she received some financial assistance.

A few caregivers discussed the strain on family relations caused by the burden of caring. Caring for a loved one also had an impact on other relationships because family members felt left out, jealous or ignored. Such relationships became problematic for the families concerned, especially when children were involved. In one instance, a frustrated son ceased providing care for his dying father because of the relentless demands of caring, much to the disappointment of the mother.

Though the challenges of caring at times meant that caregivers succumbed to emotional and psychological turmoil, nothing could be more painful than seeing their loved one deteriorate and waste away. Many caregivers lamented that this was probably their worst experience – to watch their loved one ‘go downhill’.

The following narrative captures the experience of caregivers:

As he went downhill, I felt sadness for him and loneliness for myself ...
... I knew of the impending death but felt depressed, sad and lonely.
... I tried to keep [name] out of the hospital for as long as I could but ... who was I
to think I could cope with all this?

Caregivers felt very isolated and stated that: ‘People from bowls are staying away, they are scared to visit.’ They also talked about the difficulty in facing people from the community.

Families from farming areas perceived themselves to be self-sufficient and independent and had a network of friends and relatives. When faced with a life-limiting condition, these families were reluctant to access services available in the community and consequently many of them often felt over-burdened by the caring experience. Other caregivers talked about their desire for independence, which hindered them from accessing services. They offered the following explanation:

I think it is my very character, I’m an independent critter and I know that I should probably be tapping into some services that are available but I’m too independent. I had my son’s support. If I needed support I talked to the nurse and that but I really just kept going on my own.

Many caregivers explained the enormous pressure they felt while caring for their loved one during the night. They shared this experience by stating that:

We got a lot of assistance during the day, for example, a lady comes to do housework and things like that but the worst time is night time because you are alone.
Well, you are asleep but you are awake, if you know what I mean. You have to be alert all night ...
...he was tossing and turning, moaning and groaning. He was so uncomfortable. He was in pain, but he already had his Kapanol. I wanted to call the nurses to help him be comfortable but it was midnight ... only in his last days that they gave him PCA (patient-controlled analgesia).

Some caregivers explained that caring for a ‘good patient’ made their task lighter and uncomplicated. They clarified what was meant by a ‘good patient’ in the following way:

He is so good, so good. He never complains and he never grizzles, that is half the battle.
She did not show a lot of emotion but when she got sick she completely changed and she was just a lovely old lady, wasn’t she? (Looking at another family member) She was grateful for everything we did for her...

Caregivers from culturally and linguistically diverse backgrounds expressed that interpreters and Ethnic Link Workers could be very useful if requested by families. Otherwise, a nominated family member became the spokesperson for



the group. Some of these caregivers talked about insensitive language used by health professionals, which other groups of people might also find insensitive. The caregivers thought health professionals were insensitive when they spoke of such things as:

This equipment will be used until the client dies.
... she doesn't have long to go, I think she will die this evening, she will definitely not make it to the morning ...

The majority of clients from culturally and linguistically diverse backgrounds preferred day-to-day care provided by their spouses and were reluctant to access respite care. This attitude contributed unwittingly to over-burdening themselves. As one caregiver stated:

It is a hard job for me because he wants me to be by his side 24 hours a day. He wanted me to bathe him, feed him and help him to the toilet. He wouldn't allow anybody else to do these things for him ... clean him ... only me.

Interviews conducted with Aboriginal people from Port Augusta revealed that the palliative care service was unknown to them. For people with cancer or other life-threatening conditions, treatment in town or interstate was frightening and overwhelming. Also, they were concerned with the financial repercussions of the treatment, which entailed travelling, accommodation, food, child-care, and whether their partner could accompany them for these treatments. Many agreed they would rather be cared for in 'their country' and be cared for by 'their people'. Superannuation was a topic brought up by an Aboriginal working couple, who stated that they should be able to use some of their superannuation because the partner needed interstate treatment. They stated that:

If I could get access to my superannuation now to make things much easier to go for treatments ... because I know I will not probably be around to spend it anyway.

Another Aboriginal caregiver intimated that she wanted the husband's family to be involved in his care as he was deteriorating. She was exhausted and she had children to care for and at the same time look after her dying husband.

Some caregivers spoke about the need to continue their hobbies to help them cope with the demands of caring for their loved one. They used a variety of strategies which included the following:

Doing crafts is calming. I think you have to do something like that otherwise you would go around the bend.
I filled in for the girls at bowls because they were short but I got tired walking those ends after not bowling for three months or more.
Humour has helped me cope throughout the experience. My daughter comes over, washes me (client) and says funny things you know ...
He had his sense of humour to the very end. Always joking around. Always making me laugh ...

Many caregivers felt that crying brought them relief and they pleaded with God for assistance. As one caregiver stated:

We had many tears and a lot of crying and I think that was good because you could feel it building up and you know, you sort of had a few tears ... '
I cry myself to sleep. I pray to God, I cry, pray, and cry some more. But, I put on this brave face when I am with him ... '

Getting respite care is a 'blessing' according to some caregivers. These caregivers conveyed their dependence on respite and how it had helped them:

I looked after my husband and used respite. Just knowing that he was safe and also that our son was having time out too because I think he needed that and I needed it too.
I was so pleased that respite care was available through aged care in our community. I wouldn't have coped if not for this service. I used the time to pay bills, shop for food, visit friends and so on.

Theme 4: Role change from partner to caregiver

In the rural pastoral areas of South Australia, the caregivers talked about their change of roles from partner to care provider. The family dynamics were altered through the process of illness and caring. The role change was that the husband, who normally cared for the family, was now being cared for, while the wife who normally took the supporting role was now the provider for the family and caring for the sick husband. In many instances, this role change brought anxiety and concern. Decisions about the property and their livelihood needed to be made and some of the wives were ill-prepared to make such decisions. The wives explained that they needed strength to shoulder the responsibility of their partners. Other wives in rural communities were challenged by their altered role in caring for their husbands who became completely dependent on

them. In addition, they needed to learn quickly how to pay bills, maintain the house and barns, engage the services of shearers and harvesters and cope with other concerns that they did not have before their husbands became ill.

Some commented on their partners' features and the characteristics that had changed dramatically through the disease process. According to one spouse:

I was already losing him... I have lost a partner because he wasn't a partner anymore; he was almost like a child. No, he doesn't show any emotions, he just gets tired and worn out. He can get so exhausted even after doing something small. He was an active man, big stocky guy and now..., you can just carry him on one arm. There is nothing left on him.

Most partners accepted their caregiving role as a huge responsibility, which was self-sacrifice and contained lots of love. Learning new skills to run their households was necessary. One male partner stated:

I had to learn more or less all the household duties, I had very limited experience, had to take a crash course in cooking and housework, washing and ironing.

A caregiver described her experience in caring for her husband who had Parkinson's disease and heart problems. She articulated how she felt about looking after her husband who became totally dependent on her. She remarked:

I don't think many carers really enjoy it. I don't think you ever think you are going to have to do those kinds of things for another human being and they don't like it either. It's demeaning, the inability to use your hands or to even get to the toilet on your own is just difficult to handle.

Theme 5: The meaning of comfort

The caregivers shared their experiences comforting their loved one. Giving comfort is defined as providing a soothing feeling to a patient (Anderson, 2002). Many derive comfort from relief of physical symptoms, such as pain, vomiting, constipation, and other complaints associated with terminal conditions. Comfort also meant finding solace in the company of a person they trusted, whether it was the partner, a family member, pastoral care worker or someone in the community. Some caregivers explained that comfort included not only physical measures, but emotional, psychological and spiritual measures as well. As one caregiver stated, caring is about 'verbal and non-verbal interaction and being sensitive to the other person's needs'.

The perception of caregivers was that all the palliative care nurses provided comfort. Comfort was the single most important measure for people in the terminal stage of disease. The caregivers gained information about management of symptoms necessary to care for their loved one with life-limiting conditions. However, pain relief continued to be a problem for most clients and caregivers. Pain resulted in suffering and according to caregivers:

I knew he was suffering but I was unable to make him comfortable.
I want him back but there is no way I would have him back in that condition; I think they need to look at pain control for people with terminal cancer.
Sometimes I had to fight for sedation, fight for pain relief and I don't think that's right and I know I did fight and I was acting as an advocate for him.

The role of complementary therapy in providing comfort for palliative care clients cannot be underestimated. Many caregivers mentioned that complementary therapy was used for relaxation, alleviation of some symptoms and improvement of general well-being. One client in particular requested massage and intimated that: 'I would love someone to come and massage my feet but in saying that I have not asked anyone yet.'

The researchers conveyed the client's request to the outreach nurse and hand, foot and body massage was commenced for this client. Another client said: 'I was given a massage a fortnight ago and have not had a headache since. I enjoyed that ... I also slept well after the massage.'

Personal grooming was invaluable in promoting well-being as one client explained: 'After having my hair done, I felt so much better.' Another caregiver proudly recounted a typical day for her husband, which started with a shower and personal grooming. The wife remarked: 'He felt good when he had a shower. It lifted his spirit and [he] was ready for the day.'

Nourishing food was another comfort measure. Caregivers talked about how they felt content when their loved one consumed food. They talked about difficulty in obtaining a variety of food in the country to suit the client's taste.

One caregiver felt helpless as she had access to a very limited choice of food stuffs for her loved one, who already lacked appetite and was fast becoming cachexic.

Theme 6: Facing death

The whole experience of looking after a dying family member was described by one caregiver as ‘a very full-on experience’. In facing the impending death, the majority of caregivers reflected on their past experiences with death and these experiences helped them cope. A caregiver remembered how his loved one had a history of physical conditions and how he considered his last illness, which was metastatic lung cancer, to be just ‘one of those things’, which he had to accept. There were other individuals who thought that the death of elderly parents was ‘*easier to handle*’ as opposed to that of a daughter or son who was afflicted with a life-threatening condition. Many caregivers talked about getting their affairs in order by way of making a will, funeral arrangements, resources available for the family, and many other concerns in preparation for the impending demise of the loved one.

Many of the caregivers deliberated upon the actual dying experience, which was described by some caregivers as very untimely, even if they had been prepared sufficiently for the inevitable death. Below are a few quotes extracted from their experiences:

Her death was a big surprise. She was only diagnosed a few weeks ago and then she was dying ... it all happened very quickly. We were all shocked (husband cries).

His death reminded everyone of one’s mortality which no one wanted to know ... (pauses) ... even the church members were not able to give her support.

How could this have happened? He was a devout Catholic, how could God let this happen?

In the midst of these difficulties, they talked about how they coped with the death of their loved one. After weeks and months of grieving, they chose to look positive and even hopeful. They recommitted their lives to others without forgetting their loved one. This renewed outlook seemed to help them cope with the experience of death. As one caregiver pointed out:

I cried, that's my only outlet when I felt really down I just cry and pick myself up, and dust myself off and think well come on. I've got a lot more living to do yet so let's get on with the job.'

Many declared that they were hesitant to talk about death with their loved one who was dying. This is common in western cultures, where talking about death is taboo. People are reluctant to talk about it and treat it as something very personal. One caregiver commented:

It (dying) used to come up every now and then in conversations, she would bring it up, but, we never spoke about death, just took note of everything. She had it all organised.

For many caregivers, facing death and bereavement meant taking things one step at a time. The following excerpt portrays their experience:

He had great faith and knew what was going to happen but we sort of took one day at a time and we grew very close in that time. We were able to... we didn't talk about the end, each day... how we were going to get through it.

Another caregiver described the importance of being with that person:

Just being here and being with him and if he has a problem we talked about it and if we can't sort it out then we get help...the bereavement counsellor in town is a great one for that.

Theme 7: Feelings of emptiness following death

Most caregivers spoke of the demise of their loved one. There was a feeling of emptiness, a great void that enveloped the grieving person. One described this experience as:

It just all stopped, you are so busy and then it just comes to a standstill and that is the empty feeling I've got.
There is this great void in your life that nothing can ever fill. You see blackness ... the colour is gone!

Six months after her husband's death, an ex-caregiver commented:

There's been no anger, no denial, but I thought at times this wasn't going to happen but I think I really did know. There was depression, sadness and loneliness and there's this dirty great big hole in my life that now has to be filled but that will pass too and I mean time will heal. I give [myself] permission to tread water at the moment and that's what I'm doing.

Some caregivers found comfort in keeping the ashes of their loved one for a short time at home. Two caregivers commented:

I've kept her ashes on the table, not very far.
I've kept the ashes of my husband for a few months. Those times were most difficult ... and then ... (long pause) ... I released the ashes when I was ready to let him go ...

Following the passing of a loved one, many caregivers were grateful for the thoughtfulness of others. They mentioned receiving follow-up calls from palliative care workers and bereavement support staff. As one caregiver stated:

She rang on the very best day of the holidays when I was feeling the lowest, it was an incredible feeling, someone listening to me, they were answering my prayer, it was just amazing, you know and I know there were people there and they were God-sent ...'

Some caregivers sought more intense counselling after their loved one had passed away as they had more time for themselves now. The caregivers were aware that counselling was provided by the church, community health centre, and/or by the palliative care service. The counselling service provided recognised that the grieving and support required were different for each person.

Theme 8: Emerging from the losses

The caregivers were exhausted and talked about their poor state of physical and mental health after the loss of the loved one. Many succumbed to depression and mood fluctuations. For instance, one caregiver explained:

Yes, I am depressed all right...just on anti-depressants for a little while, not 'cause I want to but I think I need to because it might just help me get through this. I am not a pill person. I just can't believe that he is not there, you know. Yes, I will talk to somebody, I just need some time to sit and think, you know...that might help later on.

Another caregiver explained her experience in the following way:

There is no letting up. It's not like I have recovered from the experience, it's more like a roller-coaster ride. At one time I'm really okay, but then, I think of him, I am reminded of him by something, ... and I sink to depression again, you know ...

Many caregivers were aware of their physical and emotional state after the caring experience had ended and were consoled by the fact that they knew whom to go to and where to go for support and assistance should they need these. Knowing that help was available was crucial for the well-being of these caregivers.

Another caregiver who was not elderly talked about looking for work since her husband passed away. She was anxious about her prospects of work because she had never worked and did not have any training. Many caregivers explained how they kept busy with work, exercise and sport. Others socialised with club and church members, and went on trips with the local day care service. Maintaining relationships with friends and making new friends was highly valued by some caregivers.

Many caregivers discussed how they coped with some misplaced feelings. As one caregiver said:

I just go day by day. I mean I don't really care very much what happens to me any more. What have I got? My son is happily married in Adelaide, and my daughter's in Darwin and has got a beautiful family.

Other caregivers complained about loneliness at night, but looked forward to what the next day would bring. A few of the caregivers explained that their faith and religious beliefs kept them strong. One caregiver declared:

What I do for the last 10 years, I always read the bible if I got a problem. Take a bible around me and use verses as my guide. And that is what I use to survive.

Many reflected on the meaning of the experience they had gone through. Many discussed future hope as well as their gratitude for how life had treated them. Some considered becoming volunteers or participating in a support group. Most of the caregivers illustrated how they coped with their experience. While some thought that having a patient who was cooperative and accepting of their condition helped them cope with their experience, others simply gained confidence in looking after their loved one. One caregiver stated that it was her genetic constitution that helped her adjust to the situation:

That's right, I am physically and emotionally strong. You could get so many different opinions on what's been going on in my life because I realise that there are some women my age not so fit. It's the genes, it all comes from who you come from and it is up to you to look after what you've got.

Some spoke about their previous experience in looking after dying family members, which assisted them to get through the situation. Some found the support from family, friends and health professionals as being crucial during this

time. Religious and spiritual beliefs and practices, prayers and going to church were very important for some caregivers. The loss the caregivers experienced was not just the loss of a husband, rather the loss of a friend, partner, lover, companion, father and much more, explained some caregivers. Another caregiver exclaimed:

You have the family around, they give you comfort or whatever but it is at the end of the day when they walk out that door that you feel the emptiness...

One caregiver from a culturally and linguistically diverse background disclosed the fears at night. She stated:

I can manage myself now after his death. The only problem that I have is at night-time. I just do not want to be alone. I'm still not ready to be alone. Sometimes my girlfriend comes to sleep at my house or I go to sleep at her place. I'm scared I might have nightmares or scared I might be crying all night.

The researchers directed her to where she might obtain appropriate help in the locality, but recovery was very slow for this caregiver.

Theme 9: Involvement of health care providers

Clients and caregivers expressed the importance of having good relationships with healthcare professionals and they appreciated honest information regarding the clients' prognosis. Overall, the caregivers interviewed were content with the care and support they received from palliative care services. They rated palliative care service highly and had only kind words for the workers.

According to one caregiver:

Palliative care staff were wonderful; they seemed to be one step ahead. They were there with information when you desperately needed it. Palliative care services have been good; the nurses make the patients feel good.
... the nurse came around regularly, checking on my husband, she said to call her any time when he was in pain and comes to give him morphine. He had too much fluid in the belly and the nurses took him to the hospital to drain some fluid out.

Clients and caregivers acknowledged the many advantages associated with the involvement of health professionals in the care of their loved one. They recognised the value of timely referrals to a metropolitan hospital, rural community and regional health service, and home support. Health professionals facilitated referrals to other services, instigated early referral necessary to better support clients and caregivers, and informed them of options and alternatives



available to them. Many caregivers in rural areas were unaware of the services available for palliative care clients and caregivers, hence, the value of information that would empower them to assist themselves.

Caregivers were grateful to palliative care staff for their visits, phone calls and attendance at funerals. As one palliative care coordinator explained, she never realised how much attending funerals meant to caregivers until one gentleman said to her: ‘When I saw you at the funeral I knew then that the person who cared for my wife cared about my wife....’

The celebration of remembrance days organised by the palliative care service is one activity that assuages caregivers. A palliative care worker often tells her clients: ‘It’s all right to grieve; it’s okay to miss our loved one.’

Theme 10: Issues affecting rural palliative care clients and caregivers

Rural palliative care clients and caregivers in South Australia identified the issues that needed to be addressed to better care for their loved one with life-limiting conditions at home. Palliative care clients, caregivers and health professionals contended that most services and support were available in regional areas, but were found wanting in smaller rural and remote communities. Some of the gaps in service delivery were evident, the needs varying from one regional health service to the other. The needs identified by the caregivers in this study were, availability of equipment, palliative care nurses, grief and loss counsellor, home visits by medical practitioner, allied health and pharmacy support, and the availability of a palliative care room, medical practitioner visiting the client in hospital, medical directives, honesty, 24-hour service, transportation, lack of continuity and coordinated care, the role of volunteers, greater flexibility in providing care, education for caregivers, early referral and support groups in rural and remote communities. All these issues are central to palliative care clients and caregivers.



Equipment

The interviewees' opinions differed about the availability of equipment. In some areas clients and caregivers stated:

Equipment was readily available.'

We were offered most of the equipment that were available including adjustable beds, wheelchairs, lifters, oxygen concentrators, commode, urinals, air mattress, morphine pumps or syringe driver, shower chairs...

Some caregivers mentioned purchasing equipment such as incontinence sheets, portable toilet, and intercoms, which were all expensive. Most of the standard equipment for palliative care patients is available in regional areas and are loaned to outlying areas as needed. The problem, however, is that there is only a small pool of items and some may miss out when there are many palliative care clients needing the equipment at the same time.

Palliative care nurses

Some caregivers stated that a health professional, preferably a palliative care nurse, who would visit weekly, was needed to check on both the client and caregiver. The regular visits were necessary to ensure that the client and caregiver were coping and to ensure appropriate care and support was provided. The caregivers explained that a qualified professional was able to give an objective assessment, to support the caregiver, and to monitor changes or deterioration in the client's condition. As one caregiver explained:

A carer is with the loved one all the time and doesn't necessarily know when these changes are happening until all of a sudden you are having a problem.

Although palliative care nurses were not available in some smaller towns, in the communities where they were available, the clients and caregivers were very grateful for the services they rendered. Many caregivers commented positively about palliative care nurses, saying: 'We could not look after our loved one at home without the caring palliative care nurses.'

Grief and loss counsellor

In some rural communities, there were no trained grief and loss counsellors to assist with emotional and psychosocial issues of palliative care clients and



caregivers. Some communities have a bereavement counsellor, who will be consulted three to six months or even longer than a year after the death of the loved one. The caregivers felt that counselling should be readily available when needed and not subjected to a limited time frame.

Medical practitioner home visits

A few interviewees stated the need for medical practitioners to do home visits. However, the researchers recognise that medical practitioners have many demands on their time especially where visits outside the community are requested. The researchers are also aware that there is no available funding for travelling long distances.

Palliative care clients were often debilitated, emaciated and too weak to wait in the doctor's surgery. Some clients and caregivers revealed: 'We have to travel to the next rural community to see a medical practitioner for a quick check-up or for repeat prescriptions.'

These caregivers were very much aware of the realities of living in rural areas where there were shortages of medical practitioners and health providers, but they thought that the medical practitioner's home visits were essential to support them as they looked after their loved one at home.

Allied health and pharmacy support

Some caregivers expressed an inadequacy in the allied health services available to them. This was to say, that health professionals such as a physiotherapist, occupational and speech therapist, dietician and podiatrist were inaccessible in their rural areas. In the opinion of the majority of the caregivers, allied health services were 'hard to come by in rural areas' but were essential services for people with life-limiting conditions and their caregivers. According to some caregivers, the services offered by complementary therapists, including masseurs and aromatherapists, were not covered by Medicare. Individuals who wanted to use these services needed to pay for them in full, unless they had

private insurance. In addition, some caregivers from the rural areas conveyed that pharmacy services need upgrading. A systematic and effective mechanism must be in place in order to provide medications for clients and caregivers without delay.

Palliative care room

The majority of caregivers appreciated the use of the palliative care room at local hospitals. This room is dedicated to palliative care clients, their families and caregivers, is designed to provide a special area that is private and comfortable and where families and friends can be with their loved one during the final stages of the illness. A caregiver reflected on the experience of using this room by stating:

I could stay with him and I could look after him and that was really good otherwise I would go home to sleep at home and hurry back to the hospital.

It is worth noting that some rural hospitals and aged care facilities have only recently established palliative care rooms. Older facilities need upgrading according to the caregivers, who recommended the following modifications: having outside access, easy access to the courtyard, provision for more privacy, and additional amenities. Some perceived that the palliative care room is ‘the place where people came to die’ and some people were generally averse to this idea. One rural community hospital referred to the room as the family room in order to eliminate the stigma attached to the facility.

Medical practitioner visits to palliative care clients in hospital

The caregivers discussed their expectations and support from their doctors. A caregiver conveyed her wish explicitly when she stated:

The medical practitioner doesn't come in very often and I thought perhaps even if they could come in once every second day... it would be supportive.

Most caregivers thought that visits from medical practitioners were necessary, if only to show concern and give moral support. The doctor-client relationship does not end with a terminal illness. Both clients and caregivers drew comfort and strength from knowing that their doctor was checking up on them, even



though the prognosis was poor. Most of the caregivers were not expecting further intervention or miracles from them, only for the family doctor to show that he/she cared for them.

Medical directives

Client history-taking on admission to hospital was a sensitive issue for some caregivers. According to them, whenever the client with a life-limiting condition was admitted to hospital, they were always asked about medical directives. Medical directives are instructions to staff about how to proceed should the client become unable to determine the care they wish to receive. It would determine whether the client would like life-saving measures to be instigated should they experience a medical emergency. While the idea is worthwhile considering, many relatives found it distressing to answer questions about medical directives. They wanted hospital staff to be more compassionate and sensitive when dealing with these matters.

Honesty

Families wanted honest information about their loved one's prognosis and stage of illness so that decisions and arrangements could be made prior to the impending death. Some families had relatives and friends that needed to travel long distances to be with their loved one. The caregivers valued factual information from health professionals. A caregiver related her experience in being given wrong information, which affected her expectations and subsequent course of action. She said:

I was told by one doctor not to give up on my husband. That was when I bought the bed and other stuff ... because I thought that when he comes through all this we would be able to go home again but then when my husband suffered pneumonia a doctor from New Zealand told me that my husband was dying and he did not have long to go. ... And I thanked him for that because I could ring my family and tell them. I think it is very important to keep people informed so that they can prepare for the impending death. This is better for everybody...

24-hour service

The provision of a 24-hour palliative care service was necessary according to palliative care clients and caregivers. In many rural and remote areas, after-hours care was not available. Clients and caregivers strongly suggested that a 24-hour palliative care service was required, especially for those in need of support and reassurance. Those who had access to this service found it to be comforting and reassuring. Clients and caregivers should be assessed and categorised as to their level of risk for distress, and be assisted with their urgent concerns and emergencies, which may occur after hours.

Transport

Transport was an ongoing issue for rural and remote families and caregivers. The government recognised that clients needed to travel distances for treatment and had made available taxi vouchers for transport to and from the hospital. This was a big help for those who could not drive or did not possess a vehicle. There was also the Patient-Assisted Transport Scheme (PATS), which financially assisted clients and caregivers to travel in excess of one hundred (100) kilometres for diagnosis and treatment. The issue however was that some clients and caregivers were not informed about these subsidies early enough. Moreover, one client opted to travel regularly to a metropolitan hospital for chemotherapy and blood transfusion. It would take the whole day to travel to the hospital and back. She said:

My chemotherapy could be done in our country hospital. But blood transfusion was a problem. I have no alternative but to travel as I don't have relatives in Adelaide. When these services are offered here, I will have these treatments done locally, I'm sure...

Lack of continuity and coordinated care

In small outlying rural and remote areas, community nurses that specialised in palliative care were not readily accessible. In many of these areas, general nurses and health workers were instructed and guided by palliative care coordinators located in regional areas. Caregivers were sometimes instructed to call an 1800 number for information; this distressed the caregivers who reported



that the service was impersonal and unproductive. Palliative care clients and caregivers preferred to call on someone they knew and who knew them in turn.

One client articulated her care needs as follows:

I have been from one doctor to another and one hospital to another. ... I hope someone is keeping track of my history and medications. I came home ... but there are no services here for me. I was told to call this number, but how could I seek the advice from a stranger who does not have any idea of my situation? What I need is a health worker who I have rapport with, who I have continuous contact, who will provide me with resources to help myself, and will advocate for me.

Coordination of services was indeed a concern in rural and remote areas. Consider for example the issue of respite care, which provided temporary relief from the demands of the client's care. This was an essential service for clients and caregivers and yet many people could not access this service because access to trained respite staff was limited. Caregivers indicated that: 'Respite particularly at night time would help caregivers as this is where problems begin.'

Furthermore, the caregivers pointed out that it was cheaper to go into respite care than to pay the hourly rate for respite services in their home. In many rural communities, the demand for respite care was very high and only available after pre-booking months in advance, during which time some clients passed away and their caregivers were deprived of respite care.

The role of volunteers

Some caregivers commended the service provided by volunteers who were highly valued by clients and caregivers and helped them in many ways. The volunteers shopped for them, sat with the loved one while they attended to errands, cooked meals, read the newspaper to clients. However, the numbers of palliative care volunteers in rural areas continue to decrease. The reasons for the demise of volunteer groups, according to clients and caregivers, were: lack of interest, lack of training, diminished support, advancing age, lack of appreciation and health problems. Some caregivers stated that they were willing

to offer their service as volunteers to help alleviate the distress of others. They acknowledged that palliative care volunteers were an important community resource that should be nurtured and supported. However, it was found that the supervision, training and coordination of palliative care volunteers in most rural and remote communities remained ambiguous.

Greater flexibility in providing care

Palliative care clients have many needs, which fluctuate from day to day. In the opinion of caregivers, the palliative care services and health workers should be more sensitive to the needs of palliative care clients. A case in point is lack of time for providing care. Domiciliary staff organised their schedules to assist several clients perform activities of daily living during the day. Staff needed flexibility with their time and this was evident to a caregiver who stated:

They were anxious because...the day cannot be planned by using domiciliary care services because the clients and caregiver's routine sometimes conflicts with the domiciliary service.

Education for caregivers

Educating caregivers presents a challenge to rural and remote communities. The caregivers emphasised the need for education and training to increase their confidence in looking after their loved one at home. Many undertook their own research about the health condition and treatments, but the value of face-to-face explanations and demonstration of procedures cannot be over-estimated. The interviewed family members and caregivers requested education on moving clients, hygiene and grooming, pressure area care, and good nutrition. They wanted to understand the symptoms and how these might be managed. Some caregivers stated that they used their common sense because they were given very little information to go by in caring for their loved one at home. Information on follow-up care after chemotherapy or other special procedures was perceived to be essential because caregivers had no knowledge about the treatments and the consequences of the treatments. For example, a caregiver resented not being told that, post-radiotherapy, the skin is photosensitive, requiring the use of creams to protect the affected area. On the other hand, those



caregivers who were visited by local palliative care nurses testified that they were given sufficient and relevant information on how to care for their loved one and they greatly appreciated the information. The above account demonstrates the importance of regular information updates that caregivers need, if they are to adequately care for a loved one at home.

Early referral

The need for early referral to the palliative care service was imperative for adequately managing the care of terminally ill clients. Early referral must happen to establish support mechanisms as quickly as possible. The majority of clients and caregivers recognised this need and were satisfied when they were referred to the palliative care service. However, there were a number of participants who thought that the general public, medical practitioners and health professionals were not cognisant of the benefits of early referral. There was stigma attached to the term 'palliative care' and as reported by a caregiver:

I did not like mum being referred to palliative care because that was associated with death and dying, she was not dying ... she did not belong to that category ... I thought.

Support groups in rural and remote communities

There were a handful of participants who talked about the value of support groups. Support groups shared a similar experience or understanding and acknowledged the benefits of interacting with like individuals. Support groups are considered the backbone of rural and remote communities because the community hinges on its members helping, supporting and empowering each other in an organised manner. The caregivers often found that joining support groups, such as Carers' Association and Cancer Support Group, enabled them to move forward and facilitated their bereavement. During the time of the study, some rural communities were in the process of establishing support groups in their areas, and were assisted by health professionals.



Palliative Care Education

Community education sessions

In order to increase access and education about palliative care amongst rural communities, during the second year of research information sessions were conducted across rural and remote South Australia. There were over 500 community members who attended these sessions; some of them were caregivers and former caregivers. The sessions involved close collaboration with health agencies and organisations, health professionals and other members of the community. These sessions provided information about the palliative care health service in the area, palliative care experts, and community members involved in palliative care. A total of eight (8) educational sessions were conducted and one session was targeted at volunteers. The educational sessions varied in terms of program and delivery; common program content included the palliative care approach, research aims and findings, networking for caregivers and resource availability.

Survey findings from community education sessions

A brief survey conducted with community members who attended the community education sessions revealed: 28% of respondents stated that they gained knowledge on how to access palliative care service; 27% of respondents professed better understanding of palliative care; 11% responded that they understood palliative care to be a service that supported the client from an early stage and the caregiver right up to bereavement and care after death; 9% stated the information gained helped them personally; 6% stated they learned about how to meet palliative care needs; another 6% learned about the commitment and care provided by the palliative care health professionals; and 5% stated they gained knowledge of issues in palliative care, for example, caring for minority groups such as Aboriginal people and culturally and linguistically diverse people.

Thirty-six percent of respondents identified that the most useful take-home information from the educational sessions was bereavement support, medical



directives, Centrelink information for carers, funeral arrangements and pastoral care. Eighteen percent of respondents found that the general information was useful, 18% of the respondents stated that knowing about the palliative care team and the available community services was important, 5% stated that information on the need for advocacy and links to service was useful, and 5% commented that information about cultural needs and grieving support available in the community was useful.

Twenty-five percent of the respondents indicated a need for more educational sessions, 23% of the respondents suggested using past clients' testimonials and experiences in future sessions. Thirteen percent of them suggested the use of clinical cases to demonstrate problem solving in future sessions, 15% of respondents commended the good presentation provided during community sessions and 10% suggested that future topics for discussion could include issues on death and dying and culturally appropriate care for minority groups.

Education sessions for health professionals

About 200 health professionals from various health backgrounds attended the education sessions conducted in hospitals, community health centres, and aged care facilities. In total five (5) health professional education sessions were conducted across South Australia.

The education sessions for health professionals differed from sessions designed for the general public in terms of depth of content and approach. These sessions aimed also to achieve the following:

1. To equip health professionals with adequate knowledge and understanding of the concepts upon which palliative care is based;
2. To familiarise health professionals about the many challenging issues surrounding the care of people with life-limiting conditions that may be disadvantaged by distance and lack of resources;



3. To emphasise the need to include family members and caregivers in the plan of care; and
4. To highlight emotional, psychosocial and spiritual needs and support that may sometimes be overlooked in providing holistic care of people with life-limiting conditions, caregivers and families.

The education sessions consisted typically of an introduction about palliative care service, the purpose of the research, and discussions of the principles of palliative care and the various dimensions of care. Input from the palliative care coordinator, bereavement counsellor, pastoral worker and/or other palliative experts was incorporated in the session. Concepts such as personhood, *being with* as against *doing for*, life review, *meaning of life*, and the *self* in relation to others were included in discussions with health professionals. The importance of partnerships between clients, family members, caregivers and health professionals was central to these sessions. These sessions were well-received by participants. The program would end with an evaluation of the activity.

Survey findings from health professional information sessions

The responses to the survey by the health professionals who attended the professional information sessions showed that 23% gained increased knowledge of the research, while 23% gained information on issues involving palliative care, and another 23% of the respondents stated that the information session confirmed previous knowledge and affirmed current practice. Eight percent indicated the need to communicate and network with other health professionals in the regions, another 8% stated they gained knowledge on holistic caring and the need for more staff development, and 8% of the respondents commented on the need to improve on their practice.

Twenty-nine percent of the respondents agreed that the most beneficial aspect of the session was learning about the holistic approach inherent in palliative care and understanding of the emotional, psychosocial and spiritual dimensions of care. It was encouraging to note that 36% of the participants indicated the need



to improve practice through better communication with clients, family members, and caregivers; thorough assessment of clients and caregivers, using health indicators for palliative care clients and caregivers; and advocating for ways of improving practice. Fourteen percent identified the need to be cognisant of beliefs and practices of people from different cultural and linguistic backgrounds and to understand the role of caregivers, 14% declared that smaller towns are missing out on some services and the need for these rural and remote areas to be better informed, and 7% of the respondents pointed out the need to support staff members both personally and professionally.

Feedback about future sessions revealed that a majority of the health professionals who attended the professional information sessions required updates on the recent developments in palliative care and evidence-based practices in palliative care. More than half of the respondents requested further sessions on approaches to death and care of the dying.

DISCUSSION

The concept of palliative care has changed over time as a direct result of better understanding of disease processes and technological advancements that have allowed improved quality of life for palliative care clients. The ultimate goal of palliative care is to humanise the experience of the clients and their caregivers (Meghani, 2004). The health professionals involved in palliative care have been paving the way for a better service for clients and their families. Palliative care clients and caregivers are not only assisted by health professionals but by others who come in contact with them, including friends, other family members, pastoral care workers, home support workers, volunteers and their community.

Collaboration and partnerships among clients, family members, caregivers, palliative care workers, and other health professionals are necessary and these may be fostered through good communication and networking. The dissemination of information by the research team and stakeholders has helped



to raise awareness and education about palliative care. Through research, essential information has been disseminated to community members equipping them with knowledge and information they may need in the future. Further, we have informed caregivers who attended the educational sessions about support services available to them, of which they may not have been aware. We advocated for greater consideration of family dynamics when making decisions concerning the client and the caregiver. The value of using holistic care plans highlighting equally the physical, cultural, spiritual, emotional and psychosocial dimensions was promoted through our research. The financial implications of succumbing to a life-threatening illness and the effects on family have also been given attention.

We have focused on ways by which people with life-limiting conditions and their caregivers may be empowered in spite of their situation. This was achieved by establishing partnerships with clients, caregivers and palliative care workers and by encouraging continuous support for clients and caregivers. Clients needed to be told honestly about their prognosis and provided with information about their conditions and treatments. They needed to know about the services at their disposal. Caregivers, on the other hand, needed reassurance that their caring was vital and that they were an enormous help to the client. The caregivers needed practical solutions to their problems and guidance in their particular caring situations. They appreciated relevant and timely information, which allayed fears and anxieties. They needed to be affirmed that they were doing the right thing for their loved one. Community members and health providers should be sensitive to the beliefs and practices of clients and caregivers.

Moreover, the role of community members needed clarifying as many community members were very willing to assist in the care of people with life-limiting conditions, if only they were instructed. Palliative care clients, family members, and caregivers must be told that it is acceptable to seek help and be helped. Receiving help from the community should be viewed positively. This



is a reflection of the strength and spirit of the community. Our research has shown that partnerships between families, health professionals and community members benefited the community as these fostered feelings of belongingness, camaraderie, and kinship.

Mention was made about the use of complementary therapies. These should be offered to clients and caregivers to enhance their quality of life. Ways by which the use of these alternative therapies might be more affordable and accessible need to be explored.

When dealing with life-limiting conditions, medical care seemed to be the focus of attention, but the key to promoting the well-being of the dying person is to extend support to the family members and caregivers (Stewart, Teno, Patrick, & Lynn, 1999). Hence, caregivers should be encouraged to use regular respite care and time-out through organised respite services, volunteers or family and friends. Ways in which respite care might be facilitated must be explored because in some rural areas respite care is limited or unavailable. Caregivers should be encouraged to seek help and advice as needed and should not feel guilty of becoming a burden to the care providers. The use of the 24-hour service (if available) was encouraged and this gave assurance to the caregivers that help was only a phone call away. For most caregivers, knowing that the palliative care nurse or community nurse would visit was enough to comfort the client and the caregiver. It was important, however, that the community nurse kept a flexible schedule to best serve their clients.

Caring should extend to other family members, such as the grandchildren, nephews and nieces, in-laws and even friends. This is especially important at a time when these individuals are trying to make sense of the experience and impending loss. Efforts must be made to include them. Family members who are not coping need to be identified, offered counselling, or referred to an appropriate person. Early intervention through appropriate referral should be encouraged to avoid further complications. Most importantly the client and



caregiver should be able to achieve their desired level of control over their functioning and daily activities. The health professionals should be aware that although some families hesitate to avail themselves of the services offered, they should ensure that all possible services/interventions were offered so that clients and carers could make informed decisions.

CONCLUSION

This research helped articulate and communicate to the government agencies and other organisations, palliative care services, rural and regional health services, health professionals and the general public the many needs of rural palliative care clients and caregivers. To improve outcomes for both the palliative care client and caregiver, effective research and dissemination of research are necessary to influence change in practice.

The services offered in the community provide support for both the clients and the caregivers. But the caregivers' strengths, such as their networks, inherent strengths, the community and their life experiences, assist them to cope when faced with the difficulties of looking after a loved one with a life-limiting condition. Most of the caregivers interviewed were elderly spouses who had become resilient, as they lived through life and developed strength and coping strategies. Giving meaning to the experience of caring for their loved one helped them evaluate the experience with positiveness and hope necessary to get them through the experience of death and bereavement. The themes identified in this research are considered to be interconnecting and free-flowing experiences of clients, their caregivers and family. The findings of this research are supported by literature on positive self-evaluation by the caregiver resulting in better mental health.

From this research a rural partnership model emerged which articulated the process and means by which rural communities develop the necessary skills,

expertise and capacity to support palliative care clients and caregivers. The rural partnership model, depicted in Figure 1, is a shared model of care supported by palliative care teams consisting of health professionals, rural communities, health services and a team of researchers that resulted in community ownership of this research. Integral components of this model are strategic partnerships, capacity building and sustainability that are related to rural communities.

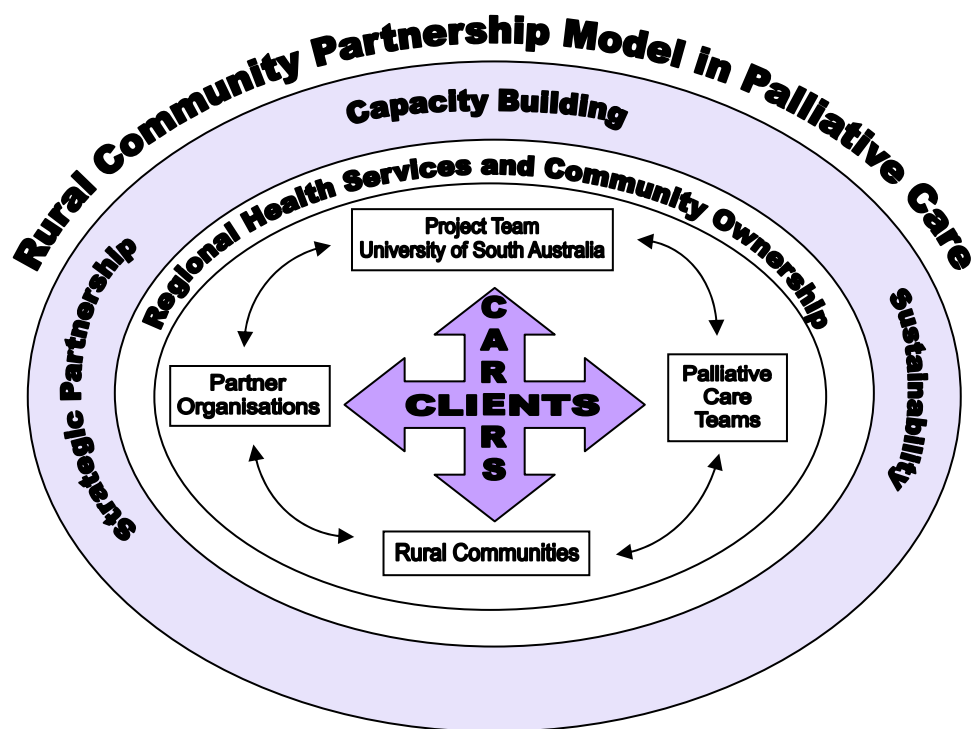


Figure 1. Rural community partnership model

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 caregivers were the focus of partnerships that emerged. Pivotal to such partnerships was the leadership role of the research team in driving its agenda to achieve the goals and objectives of the research. 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 the health



professionals, service providers, clients and caregivers, and the strategies involving education and support that were put in place.

The aims of the research were realised through engagement with the community, ownership of research and developing strategic partnerships with palliative care teams in health services to support clients and caregivers. Strategies that were found to be helpful involved education, support and capacity building of health professionals, service providers, clients and caregivers. Research outcomes should be sustainable because once the research was completed the health services needed take responsibility for the ongoing education and support of palliative clients and caregivers (Oliver, Penman, Ofner, 2005).

Palliative clients and caregivers look for ongoing support from health providers. The research undertaken in the course of two years has had a positive impact on the individuals involved from the community. The caregiver concerns were given voice through this research, especially in articulating the experience of caregivers. Through this research the caregivers came to know where to obtain assistance. Equally through the research the health professionals reported a heightening awareness of the unique needs of palliative care clients and their caregivers. Difficulties in communication and lack of resources were a burden to the caregivers. Empowered by this research, the palliative care nurses who were involved in this research established an on-line discussion group for sharing information. The on-line forum enabled these nurses to access information, share ideas and resources for supporting their clients and caregivers.

The impact of our research on the community could be summarised as: the community awareness about palliative care was heightened as the community discussed their unique issues and concerns that mattered to them. Community strengths were demonstrated by activities such as cooking for people, sharing personal property, visiting and spending time with clients and caregivers and



even fundraising for equipment; a greater awareness of palliative care and the needs of rural people and ways of supporting each other. During the course of this research, a community hospital and an aged care facility opened a dedicated palliative care room and community nurses were employed to help support the palliative care clients and their caregivers in these communities. Through this research, we have discerned the emergence of community pride and community cohesiveness, which attest to the resilience of rural communities and community development.

Ongoing research in palliative care is necessary for future developments in this field. The World Health Organisation has advocated more research and training in palliative care and for researchers to study and determine needs in a sensitive way, to synthesise patients' and relatives' views and to find effective solutions to problems (WHO, 2004b p. 28). Our research illustrated the communities' commitment to supporting palliative care clients and caregivers in rural areas. Through this research the needs of rural people have been identified and recommendations made to advance rural palliative care. The changing concept of palliative care will give rise to new models of care grounded in the everyday practice dependent on the commitment of health professionals, health service providers and government funding.

The benefits derived from this research were as follows: promotion of awareness in palliative care principles and service amongst partner communities; enhanced knowledge and understanding of rural health professionals on palliative care; improved knowledge and skills of caregivers in palliative care; improved access to palliative care services; development of strong partnerships between caregivers and palliative care service providers and other health professionals; development of strategies to sustain support to rural and economically disadvantaged people with life-limiting conditions; and development of a sustainable rural partnership model in palliative care that is transferable across rural communities.



RECOMMENDATIONS

The following are the key recommendations of our research:

- Adequate funding for rural palliative care including staffing is essential for sustaining rural health services;
- Increased funding for research in rural palliative care is vital to discovering models of best practice;
- Palliative care in Aboriginal communities warrants special attention and should be taken up by health services;
- Education on the palliative care approach for all health professionals is essential and should be built into undergraduate curricula and staff development programs;
- Palliative care education for all rural nurses should be embedded in the Bachelor of Nursing curriculum;
- Generalist palliative care nurses are a reality in rural health and aged care services, which should be recognised by health service providers, professional bodies and universities responsible for nursing education, and
- Appropriate education should be provided to up-skill generalist palliative care nurses



POLICY DEVELOPMENT

Policy development in palliative care should be underpinned by the following:

- More conversation on palliative care with rural and remote communities is imperative.
- There is a need for moving away from medicalisation of the dying process to recognise that death in palliative care is inevitable.
- Palliative care should form a part of the undergraduate curricula for all health professionals, including medical students.
- Staff development programs should incorporate training in palliative care for all health professionals.
- The health services need to adopt a coordinated and transparent approach to delivering palliative care services and solicit consumer satisfaction by way of improving services.
- More emphasis should be given to pastoral care, counselling and support for clients, their family and caregivers.
- Empower General Practitioners to promote early referrals to palliative care service.

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ABBREVIATIONS

ABS	Australian Bureau of Statistics
UniSA	University of South Australia
CRE	Centre for Rural Engagement
MSOAP	Medical Specialist Outreach Program
PEPA	Program of Experience in Palliative Care Approach
TIS	Translation and Interpreting Service
HREC	Human Research Ethics Committee
QSR	Qualitative Solutions and Research N5