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The experience of rural volunteer in-home support, community based health care: an exploration of the factors that facilitate and/or hinder rural volunteer in-home support through urban-based management of rural-based volunteers.

#### Author

Jones, F

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# THE EXPERIENCE OF RURAL VOLUNTEER IN-HOME SUPPORT, COMMUNITY-BASED HEALTH CARE:

An exploration of the factors that facilitate and/or hinder rural volunteer in-home support through urban-based management of rural-based volunteers.

by

#### Fiona Jones

Bachelor of Social Studies - University of Sydney

Submitted in fulfilment of the requirements for the Degree of

Master of Medical Science

University of Tasmania April, 2010

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#### **ABSTRACT**

There is growing recognition of the benefits and increasing need for volunteers providing in-home support to individuals and families in the community. This is particularly the case in the domains of hospice palliative care, due to the impacts of an ageing population, and supporting families with children, due to the challenges presented in the early years of life especially in rural areas. The development of these services in rural areas often entails urban-based volunteer services extending services to rural communities through urban-based management of local, rural-based volunteers. The limited research in this area suggests that rural communities face distinctive complexities in the provision of volunteer in-home support, which are yet to be fully explored and are likely to be unaccounted for in urban-centric models. This highlights the need for new research to guide the reorientation of urban strategies to meet the particular challenges and opportunities associated with rural volunteer in-home health provision.

The aim of this research study has been to explore the experience of rural volunteer inhome support, through urban-based management of rural-based volunteers, in order to further the understanding of this form of service delivery in rural communities. Specifically, it sought to identify factors that facilitate and/or hinder its provision and how their impact may be fostered or ameliorated. The study focused on the domains of hospice palliative care and supporting families with children through the multiple perspectives of urban-based volunteer coordinators, rural and urban specialist service providers and rural volunteers. A qualitative research study design involving 27 predominantly rural participants was undertaken utilising volunteer demographic information, semi-structured, in-depth interviews, a focus group, and thematic analysis of qualitative data.

The findings identified multiple complex and interrelated factors which may facilitate and/or hinder rural volunteer in-home support. The overriding themes which emerged were the crucial importance of a community development approach which inherently considers the local rural context, and some manner of a locally based coordinating presence in facilitating the development of rural volunteer in-home support services which are appropriate to the specific rural setting. A synthesis of findings from the study and issues identified in the literature led to the development of a table of 'flags' or reference points, which provide insight into discerning and responding to particular rural socioeconomic and cultural factors which may facilitate and/or hinder rural volunteer inhome support: precedence of family support; self-reliance; multiple overlapping relationships; intermittent need; fragmented and under-resourced nature of the rural health system; and rural volunteers' strong sense of connection to their local community and volunteer organisation. This study contributes to an understanding of the nature of volunteer in-home support in the rural context, and how urban-based volunteer services seeking to provide services in rural areas may work with rural communities to meet rural exigencies.

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#### **CHAPTER ONE**

#### INTRODUCTION

#### Rationale for research

There is some evidence to suggest that volunteers providing in-home support can make substantial contributions towards meeting the needs of individuals, families and communities in the domains of hospice palliative care and supporting families with children. However, the research is limited and particularly so in the rural context <sup>1-3</sup>. There is a pressing need for these services in rural communities that is associated with the ageing population, a preference to be cared for and die at home <sup>4-5</sup> and the increasing recognition of challenges in the early years of life<sup>6</sup>. Black and Kemp's <sup>1 p 19</sup> finding that "rural communities face some unique difficulties in establishing and managing volunteer home visiting programs" highlights the need for new research to support the development of rural-focused volunteer in-home support services, to help address the inequity in health outcomes among rural populations linked, to a large extent, to poor access to services <sup>7</sup>.

The experience of rural volunteer in-home support services in southern Tasmania appears to support the views expressed by Black and Kemp <sup>1</sup>. Community-based services providing volunteer in-home support, in the domains of hospice palliative care and supporting families with children, were first established in an urban context through localised community action by small grassroots, non-government organisations. Their expansion of services into rural communities, with paid urban-based volunteer coordinators providing training and support to local rural volunteers through urbanbased management, has had mixed, though often poor, success (personal correspondence, discourse, and professional experience based on the researcher's two positions as a Community Health and Specialist Palliative Care Social Worker in southern Tasmania). It appears that rural communities may not be fully benefiting from the assistance that rural volunteer in-home support services can provide. This may be particularly detrimental in rural areas where Wilson et al.<sup>2</sup> argue there may be a heightened need for end-of-life (EOL, also referred to as hospice palliative care) volunteers as a consequence of the paucity of specialised EOL care programs and specialists. Families with children living in rural environments with a prevalence of high rates of socioeconomic disadvantage (as is the case of rural southern Tasmania), have a strong risk factor for poorer health outcomes for children and may be further disadvantaged by the lack of rural volunteer home visiting support <sup>89</sup>. An exploration of the experience of two rural volunteer in-home support services in the chosen domains may potentially provide: a sufficient number of participants in the study (given the limited number of rural volunteers); opportunities for shared learnings through the commonality of the provision of rural volunteer in-home support; and insights into possible collaborative action amongst volunteer services. It may be the case that a deeper understanding of rural place and culture is required to facilitate rural volunteer in-home support <sup>5</sup> 10.

#### Orientation to volunteer in-home support

#### Volunteer in-home support in the domain of supporting families with children

Volunteer in-home support in the domain of supporting families with children is generally referred to in the literature as home visiting. In this study, volunteer in-home support and volunteer home visiting share the same meaning. The terms are used to describe the strategy of providing volunteer support through visits in the home. In-home support is a more neutral term, because although volunteer home visiting occurs in both domains of care that are the subjects of this study, home visiting in the literature is more commonly used in, and associated with, the domain of supporting families with children. In the domain of hospice palliative care, volunteer in-home support is more commonly (though not exclusively) referred to as home visits <sup>11 Module 2 p 47</sup>. The promotion of home visiting as a means of supporting parent-child relations from birth is encouraged at the highest level by the World Health Organisation (Wilkinson and Marmot, 2003, p 15, cited in <sup>12 p 56</sup>). According to Jenkins <sup>6 p 11</sup> it "is increasingly being advocated as a promising intervention for tackling health inequalities", such as in the Australian and State Government Stronger Families and Communities Strategy, Communities for Children <sup>13</sup>. Jenkins <sup>6 p 11</sup> describes home visiting as:

...not a single or uniform intervention; the programs differ considerably in their aims and objectives, their target recipients and their mode, content and timing. They may be provided by nurses or midwives, or by lay people [paid non-professionals and unpaid volunteers] with differing degrees of education and training.

Weiss <sup>14</sup> contends that this variability may be home visiting's strength, with roles including social support, parenting information and linking to other services.

The 'Best Practice Guidelines for Volunteer Home Visiting', facilitated by the Good Beginnings National Parenting Project (Australia) <sup>15 p 1</sup> offers the following description of volunteer home visiting:

Volunteer home visiting programs for families with dependent children are family-focused services, working with individuals and family units in an holistic way, to reduce their vulnerability, strengthening the community as a whole. Home visiting commonly refers to a supportive and/or complementary service provided in or near the family home.

Referring to the peak body Volunteering Australia, Vangelista <sup>16 p 11</sup> defines volunteering as an activity which:

- benefits the community and the volunteer
- is undertaken of the volunteer's own free will and without coercion
- does not receive financial payment

• is underpinned by the Volunteering Australia's "Principles of Volunteering"

Vangelista <sup>16</sup> contends that the voluntary status of the volunteers affords them the potential to empathically provide social, emotional and practical support as peers steeped in the understanding of the local context. There are special features which characterise home visiting and distinguish it from non-home-based intervention strategies which Weiss <sup>14 p 118</sup> relates to meeting people on their own "turf". Home visiting may encourage more equality and less formality in the client/volunteer relationship; reach more geographically, socially, psychologically isolated people by the volunteer taking the initiative to travel to them; and the volunteer, by meeting in the client's home, can gain a more holistic understanding of the client's circumstances, including the social context <sup>14</sup>. However, there is potentially a "down side" <sup>14 p 119</sup> as well, such as possible safety risks to volunteers, and families experiencing home visits as intrusive (Lyons-Ruth, Botein, and Grunebaum, 1984, cited in <sup>14</sup>).

Community development principles such as collaborative action, partnerships, community participation, building on family and community strengths, and family and community capacity building, are promoted as integral aspects of developing volunteer home visiting services and their part within the broader services for families and children in the early years <sup>6 8 12 13 15-17</sup>. Such initiatives may aid in ensuring sensitivity to local community cultural values and geographic realities <sup>6 17</sup>. Rural volunteers, as members of their communities, may play an important role in home visiting services connecting with local communities, provided they reflect the diversity of members of the community, and both volunteers and families participate in the planning of the service <sup>15</sup>. However, in the Tasmanian context of supporting families with children, it is considered:

...still early days in bringing services together, and the process of true engagement with communities is only just beginning.  $^{8\,\bar{p}\,71}$ 

There appears to be a need for further knowledge and understanding of the nature of home visiting services in the rural context to help facilitate community development approaches, a requirement which may have increased importance when it is urban-based services seeking to extend services to rural communities through urban-based management of rural-based volunteers. Elix and Lambert's <sup>18</sup> study of volunteer home visiting to families with children in a small rural community offers some insights into the impact of issues such as confidentiality, limited other family support services and increased family isolation influencing the need for local paid coordinators, and highlights the need for additional research on the influence of rurality and volunteer home visiting.

#### Volunteer in-home support in the domain of hospice palliative care

According to Rumbold <sup>19 p 64</sup> palliative care in Australia, as elsewhere, originated from the grassroots community hospice movement, based on Cicely Saunders' St

Christopher's Hospice in London in 1967. It was created as an alternative to the medicalisation of death in the hospital setting, and included not only the concept of hospice as a separate place for the dying, but also as a philosophy of holistic care comprising of interdependent physical, social, emotional, cultural, and spiritual aspects <sup>20</sup> <sup>21</sup>. The 1980s saw a shift towards a community-based service, emphasising home care and community involvement to help support people being cared for and dying at home, with the participation of volunteers being a common feature of contemporary models of service delivery in Australia, in both hospice and community settings <sup>22 23</sup>. Rumbold <sup>19</sup> argues that in Australia mainstreaming of community-based hospice programs in the 1990s, while resulting in sustainability and improved access to palliative care, has shifted the holistic hospice approach towards clinical care and weakened alignments with local communities. In response to this, Allan Kellehear was instrumental with introducing health promoting approaches to Australian palliative care, and at the same time other models also emerged, the palliative approach and needs-based population health approach 1924. As in the area of supporting families with children, community capacity building features as an important – however not always well understood <sup>25</sup> – element in palliative care <sup>19</sup>.

The lack of uniformity in the use of terminology in the domain of palliative care can cause misunderstandings <sup>21</sup>. In the palliative care literature, the terms palliative care, hospice, hospice palliative care, hospice/palliative care and end-of-life care, are often used interchangeably. In Australia, the 'Palliative and End of Life Care Glossary of Terms' <sup>21</sup> was developed by the peak body, Palliative Care Australia, in response to much confusion over terminology stemming from changes in the experience of dying and in the delivery of care to people at the end of life over the past three decades. There has been a shift of focus in palliative care from predominantly cancer patients and their families/carers at the end of life to a broader inclusion of people with chronic and complex conditions, indeed all people at the end of life; and a proliferation of care service delivery models and terms used to describe them <sup>21</sup>. While the glossary makes a commendable start to improved communication and understanding in the area of palliative care, much variation in the use of terms and uncertainty of their meaning still exits.

For the purposes of this study, the terms 'hospice' and 'palliative' have been linked to form the terms 'hospice palliative care' and 'hospice palliative care volunteer'. This was chosen in an effort to avoid any misconceptions that the use of the word 'hospice' on its own might infer care limited to a place of care, that is, 'a hospice', as opposed to its broader meaning of both a place of care and a holistic philosophy of care (as described above) which can be offered in a variety of settings – for example, people's own homes, hospitals, residential aged care facilities, hospices. Claxton-Oldfield, Guigne and Claxton-Oldfield <sup>26 p 439</sup> in their study noted the shift in Canada from the term "palliative care" to the nationally accepted term "hospice palliative care" to reflect the different settings in which people die. In Australia, the shift is towards the use of the term 'palliative care'. This is evidenced by the peak body changing its title from the Australian Association for Hospice and Palliative Care to Palliative Care Australia <sup>27</sup>; and when an Australian nationally recognised volunteer training resource kit was

developed in 2008 in acknowledgement that "volunteers play a vital role in the palliative care field" <sup>11</sup> Introduction p 5</sup> it was titled 'Palliative Care Volunteer Resource Kit' <sup>11</sup> and refers to volunteers as palliative care volunteers.

However, the rural volunteers participating in this study are members of an urban-based association established in 1984 which works independently, but in collaboration with, the state government operated specialist Palliative Care Service and the volunteers bear the title 'hospice care volunteers' or more simply 'hospice volunteers'. The association's use of the term 'hospice' reflects the broader meaning of the hospice holistic philosophy of care which can be applied to multiple settings, as the volunteers' support is not limited to the urban-based specialist Palliative Care Unit, also popularly known as 'the hospice' or 'Whittle Ward' after its benefactor. In the city, the hospice volunteers offer care in the client's home through home visits; in specialist palliative care units; at the tertiary hospital; in private hospitals and some residential aged care facilities. In rural areas, hospice volunteers provide support in the client's home through home visits; in district hospitals, multi-purpose centres or services. In the community setting, volunteers offer respite for carers, companionship, assistance to complete tasks, errands or outings. While the primary focus of this study is on rural volunteer in-home support through home visits (also described as "home visiting" by Wilson et al. <sup>2 p 253</sup> in their study of end-of-life care volunteers) some insights into the experience of what this study terms 'rural hospice palliative care volunteers' in the local rural health facilities is also examined.

Palliative Care Australia's <sup>28 p 6</sup> description of end-of-life care in Australia as one of "inequity and inconsistency" refers to the state of care in the community, amongst others. Limited access to community care, of which volunteers can play a valuable part, may impede people's ability to be cared for and die at home <sup>28</sup>. Robinson et al. <sup>5 p 253</sup> contend:

Geographic inequities in access to palliative care are expected to rise as aging populations amplify the demand for palliative care associated with life-limiting illnesses and death.

There are calls for greater understanding about rural community supportive care needs and the barriers to their use <sup>29 30</sup>. A study of palliative care clients living on their own in urban and rural settings, particularly recommended a pool of volunteers and paid caregivers <sup>4</sup>. Wilson et al. <sup>2 p 255</sup> assert:

The role of the volunteer is not without challenge...both for the individuals who volunteer and the organizations that must orient them and provide a meaningful role for them.

A richer understanding of the experience of rural hospice palliative care volunteering may assist in ascertaining and meeting the challenges and ensuring that the services address the needs of specific rural communities. The need for a community-specific focus is in recognition of the heterogeneity of rural communities.

It appears that there may be factors pertaining to operating in the rural context which impact on volunteer in-home support. The growing attention to the role of 'place' and geographic location as determinants of health and the provision of health services <sup>5</sup>, encourages furthering the understanding of the experience of parenting in the rural context and living with an eventually fatal condition (Palliative Care Australia preferred term <sup>21 p 8</sup>) in the rural context, and how volunteer in-home support services may be of benefit and operate successfully. Kilpatrick <sup>10 p 36</sup> contends that:

Understanding rural place facilitates alignment between health programs and community, assists incorporate community resources into health care and provides information about health needs.

Improved understanding and knowledge of the experience of rural volunteer in-home support may aid urban-based volunteer in-home support services with an urban outlook to help refocus through a rural lens.

#### Aim and purpose of the study

The aim of this study has been to explore the experience of rural volunteer in-home support through urban-based management of rural-based volunteers, in order to further the understanding of the nature of this form of intervention strategy in rural communities. The research question which thus followed and served to orient the direction of the literature review, methodology, findings and analysis, and discussion was:

What are the factors that facilitate and/or hinder rural volunteer in-home support through urban-based management of rural-based volunteers?

To achieve this aim, this research undertook a qualitative research study design utilising semi-structured, in-depth interviews and a focus group, and thematic analysis. The study focused on the experience of rural volunteer in-home support in the domains of hospice palliative care and supporting families with children through the perspectives of volunteer coordinators, service providers and volunteers.

#### Significance of the study

This study adds to the literature on rural volunteer in-home support by identifying factors which facilitate and/or hinder rural volunteer in-home support through urban-based management of rural volunteers. The pivotal findings indicate that a community development approach which inherently considers the local rural context and some manner of a locally based coordinating presence, are key factors which may facilitate the development of rural volunteer in-home support services appropriate to the specific rural setting.

The study is significant in helping to address the gap in the literature concerning the nature of the provision of rural volunteer in-home support in the domains which were the focus of this study, hospice palliative care and supporting families with children, and may also apply to varying degrees to other volunteer in-home support service domains.

At the service level, it offers Table 5.1 'Flags of the experience of rural volunteer inhome support health care' for the use of urban-based volunteer in-home support services, the service providers, rural volunteers, and rural communities they work with. The 'flags' represent reference points against which urban-based services may consider the local rural relevance and applicability of their service, while the examples summarise some of the potential effects of the 'flags' and possible adaptive responses. The study offers insights into rural influences on the experience of volunteer in-home support described in the table under the 'flags': precedence of family support; self-reliance; multiple overlapping relationships; intermittent need; fragmented and under-resourced nature of the rural health system; and rural volunteers' strong sense of connection to their local community and volunteer organisation. In doing so, it may enhance the delivery of rural volunteer in-home support services responsive to the specific needs of the rural communities.

#### Structure of the thesis

#### **Chapter One: Introduction**

This chapter briefly outlines an orientation to volunteer in-home support as a strategy for providing a service to individuals and families and the rationale for the research. It describes the aim and purpose of the study, the research question and provides comments on the significance of the study. It finishes with an overview of the structure of the thesis.

#### **Chapter Two: Literature Review**

The literature review chapter provides a critical review of the literature as it pertains to rural volunteer in-home support and addressing the research question: What are the factors that facilitate and/or hinder rural volunteer in-home support through urban-based management of rural-based volunteers? It commences with an examination of three 'big picture' issues in the volunteering literature: the impact of economic rationalism; varying models of volunteer management; and the linking of social capital, community capacity building and volunteering. It then proceeds to focus on an orientation to some of the issues arising in the rural health literature, under the heading of rural context and rural practice. It examines rural socioeconomic and cultural factors, environmental determinants, the role of the family, and a primary healthcare approach. Finally, the attention turns to the literature on volunteer in-home support in the domains of hospice palliative care and supporting families with children, considering the place of rural volunteer home in-home support within the broader picture of healthcare services, and rural concerns centred on the importance of a community capacity approach. The

chapter finishes with a review of the implications of the literature review findings for this study.

#### **Chapter Three: Methodology**

The chapter commences with a background to the study and the position of the researcher, prior to an explanation of the rationale for, and discussion of, the qualitative research study design. It then proceeds with a detailed description and discussion of the measures undertaken in conducting the study, including selection and recruitment of research participants, data collection and data analysis strategies.

#### **Chapter Four: Findings and Analysis**

The chapter structure is divided into four headings which serve to illuminate the most fundamental issues arising from the data: the marked importance of ensuring a commitment to the permeation of the local rural context into all aspects of the establishment and implementation of rural volunteer in-home support by urban-based services; and some manner of locally based coordination. They are:

- adaptation of volunteer in-home support service delivery according to local rural context
- local rural context and heightened ethical issues
- coordination at a local level
- beyond formal volunteering.

#### **Chapter Five: Discussion**

This chapter examines a synthesis of the outcomes of the findings and analysis chapter, further refined from deeper data analysis and represented in Table 5.1 entitled 'Flags of the experience of rural volunteer in-home support health care'. The 'flags' or reference points are:

- precedence of family support;
- self-reliance;
- multiple overlapping relationships;
- intermittent need;
- fragmented and under-resourced nature of the rural health system;
- rural volunteers' strong sense of connection to their local community and volunteer organisation.

#### **Chapter Six: Conclusion**

This final chapter provides a summary of the study, considers strengths and limitations and suggestions for further research.

#### **CHAPTER TWO**

#### LITERATURE REVIEW

There is recognition at the highest levels, by the National Health and Medical Research Council (NHMRC) and Volunteering Australia (VA), that volunteering is an integral part of the Australian rural healthcare system <sup>31</sup> and critical for the success of rural communities <sup>32</sup>. Despite this, the field of volunteering is considered "under-researched" <sup>33 p i</sup>, with a "scarcity of Australian literature on volunteer programmes" <sup>34 p 7</sup>.

There is a long tradition of volunteer in-home support in the domains which are the focus of this study: hospice palliative care and supporting families with children <sup>14 35</sup>. Historically, in-home support originated in urbanised environments <sup>14</sup>, as is the experience in southern Tasmania, where, as noted in Chapter One, the services expanded to rural areas with variable success.

Tasmania has a significantly dispersed, rural population which has implications for health and health service delivery, as Tasmania's Primary Health Services Plan <sup>36 p 44</sup> states:

The disaggregated and highly rural nature of the Tasmanian population means that there are significant issues in providing viable and sustainable health services across such a large number of small communities.

A growing body of research is focusing on the challenges of rural health and highlighting the influence of aspects such as socioeconomic and cultural factors <sup>9</sup> and environmental determinants <sup>37</sup>. It may be the case that there are factors related to operating in a rural context which influence the experience of rural volunteer in-home support, which this critical review of the literature aims to explore.

This review commences with an examination of some of the issues concerning the general state of volunteering and the potential ramifications for the rural context. It includes an exploration of the rural health literature and how it might relate to rural volunteering. It then considers the literature on volunteer in-home support in the domains of hospice palliative care and supporting families with children with specific attention to rural studies. Finally, this review concludes with a summation of points of interest examined in the literature review which, through their exploration in the research study, may contribute to an understanding of the experience of rural volunteer in-home support.

#### Volunteering – 'big picture' issues

There is an emphasis in the volunteering literature on three 'big picture' issues which may be of particular relevance and concern to rural volunteer in-home support: the impact of economic rationalism; varying models of volunteer management; and the

linking of social capital, community capacity building and volunteering. They directly influence the fundamental elements of volunteering which also garner much attention: recruitment, motivation, education, training, and support. This section will consider these issues, and possible implications for rural volunteer in-home support.

#### **Economic rationalism**

This exploration of the state of volunteering in the Australian context might best start with the recognition of the impact of economic rationalism and the concomitant shift of social health/welfare provision from the state to the non-government sector (charities and non-profit organisations), with the use of volunteers as a pivotal element <sup>38 39</sup>. The research suggests that this has led to the development of particular funding and service models impacting differently in urban and rural settings <sup>32 40</sup>.

Economic rationalist approaches by government have resulted in the outsourcing or contracting out of government services to the private and not-for-profit sector. With this comes the attendant complex dispositions of tendering, brokerage of services, corporate contracts, collaborations, and partnerships, which tend to favour the larger, generic, non-government organisations (NGO) such as Salvation Army, Anglicare, Centrecare, and Relationships Australia – primarily urban based – who have the resources and are therefore often more skilled to secure government tenders <sup>41 42</sup>. Lack of financial resources appears to be endemic to the area of volunteering, but it particularly impacts upon the subject of this study – small, grassroots, NGOs, urban-based volunteer in-home support associations – and their ability to extend service provision to rural areas, where competitive, short-term funding grants may be the only means of doing so.

In rural areas, Mowbray <sup>43</sup> argues, support often manifests in large, still government dominated, time-limited projects, with questionable long-term, sustainable outcomes for the communities. Kilpatrick <sup>10 p 39</sup> further raises concern over the possible lack of understanding of local rural context when health initiatives, driven by national and state policies, are implemented in rural settings with potentially restrictive conditions:

Resources from various external 'silos' arrive in rural communities, usually with strings attached.

The increasing influence of government and larger non-government organisations in the volunteer sector and associated managerial complexities, such as compliance with service agreements and the inherent strict reporting, accountability and quality assurance requirements, has contributed to tensions in the sector. Views on the effects of this range from a sense of bedevilment to an enhancement of the status of volunteers <sup>31 38 44</sup>. It has also contributed to a trend towards the 'professionalisation' of volunteers and varying models of volunteer management.

#### Models of volunteer management

An area of particular interest in the field of volunteering concerns new models of volunteer management. Zappala <sup>39</sup> contrasts the traditional charity model with the social enterprise model, with an emphasis on partnerships between non-profit organisations, business and government, and the management challenge of applying human resource management techniques. The social enterprise model is linked with the increasing need for the professionalism of the volunteer management role <sup>39</sup>.

It is in the rural setting (though not exclusively) that the trend towards professionalisation of volunteer service delivery, often associated with more stringent management, is more keenly felt as having the negative impact of "bureaucratic interference" <sup>45 p</sup> <sup>133</sup> <sup>46-48</sup>. Support for volunteers often correlates with management issues, which for rural volunteers in particular, is frequently concerned with overformalisation, exacerbated by the head-office of volunteer organisations being located out-of-area <sup>44 46 49</sup>. Warnings abound in the literature of the potential for intentionally positive bureaucratic instruments, such as accreditation and administrative compliance activities, to have unintentional negative effects on volunteers and volunteer organisations, such as "feeling weighed down by bureaucratic red tape" <sup>45 47 p 91</sup>. Onyx, Leonard and Hayward-Brown <sup>45 p 137</sup> describe the increasing levels of frustration, especially in rural areas:

The emphasis on greater bureaucratic control, coupled with greater requirements for training, increased fear of litigation, and centralised surveillance of volunteer activity is having a serious negative impact on the sense of worth and value of this activity, and growing resentment of government intervention, particularly in rural areas.

Of particular note to this research are the findings of Warne and Dietrich's <sup>46</sup> volunteer research project in rural Victoria <sup>46</sup>. The study highlighted volunteers' concerns about deficiencies in communication, comprehension of rural issues and volunteer participation in management, when involved with volunteer organisations with headquarters outside the region. Similarly, the rural volunteers in this study are managed by coordinators based outside their region, in this instance, in the capital city. Creyton <sup>50</sup> advocates for exploring innovative means of involving volunteers in management through collaborative leadership. Metzer et al. <sup>51 p 13</sup> contend there is a "dearth of research" on volunteering and quality of work life in areas such as organisational support, autonomy, job satisfaction, and stress, which may directly impact on the recruitment and retention of volunteers. This research will aim to contribute further understanding to this area of interest.

In regard to the issue of partnerships, Lehane and Lambert <sup>52 p 92</sup> note that as partnerships between the private, public and community sectors rapidly grow, so too has cynicism concerning these partnerships, based on concerns that governments may use volunteers instead of providing public services. Nevertheless, they are encouraging of partnerships with their "joined-up approach that may strengthen our communities". Yates <sup>42 p 4</sup> also

points out the increase in partnerships, and notes that they may prove more cost effective. However, she cautions that "partnership-working skills are underdeveloped in rural areas" and further that "organisations are frequently sceptical of the benefit of a shared voice".

Partnerships can be a means of developing a powerful force for change in a community, but inherent in this are issues of control and influence as to whose interests are best being served. Mowbray <sup>43 p 260</sup> cites an example from a Victorian Government Community Capacity Building Initiative (CCBI) program targeted at small rural towns or groups of towns, which highlights the potentially negative effects of partnerships:

One CCBI facilitator complained [to me] that funding in her area 'went to an already powerful group, which used the programme to become even more powerful at the expense of the rest of the community'.

Lehane and Lambert <sup>52 p 92</sup> argue strongly in favour of partnerships, stating "the other option is to waste time, money and effort in an unfruitful debate about power and control". Far from being "unfruitful", debate could be a vital necessity in this area to help ensure all voices are heard and it may productively contribute to addressing the issues of cynicism and scepticism. Volunteering, like any other sphere of influence, is a political act. Recognition of this fact and exploration of partnerships, power and influence in this study may provide useful insights into rural volunteer in-home support.

Creyton <sup>50 p 2</sup> offers another view of volunteer management, describing a 'capacity approach' model, recognising that working with volunteers is in part about building community, with a central feature of "working with rather than managing" volunteers. This model may have particular appeal to rural communities, with its strong sense of ownership and self-determination, and has the hallmarks of community development and social capital. This will be explored further under the next heading.

#### Social capital, community capacity building and volunteering

Social capital theory is a burgeoning area of interest in the volunteering literature and the nature of the relationship between social capital and volunteering is keenly contested, from volunteering being "a core component of social capital" <sup>53 p 1</sup> to claims "that there is no universal relationship" between the two (Cox, 1997, cited in <sup>44 p 7</sup>). However, a Smith Family report refers to Zappala, Parker and Green (2001, p 2) and Wilkinson and Bittman (2002, p 33) when it claims social capital "has become the dominant framework for interpreting volunteering within Australia" <sup>54 p 10</sup>. While researchers such as Esmond <sup>49</sup>; Bailey, Savage and O'Connell <sup>55</sup>; and Onyx, Leonard and Hayward-Brown <sup>45</sup> consistently report more similarities than differences between urban/metropolitan and rural/regional volunteers, nevertheless, social capital appears to play a particularly significant role in rural communities. Lynch <sup>56 p 8</sup> in her comprehensive literature review entitled 'Sustainable Volunteerism in Rural Communities', emphasises the importance of the connection between building social capital and volunteering in rural communities when she states:

It is important for community organisations to find ways of building social capital, which is dependent on trust and relationships of reciprocity and cooperation, for volunteering to prosper.

Yates and Jochum <sup>57 p 1</sup> offer a succinct definition of social capital and its link to volunteering:

Put simply, the idea behind social capital is that social networks, and the mutual trust they promote, have a value, both to the individual and society at large. Because voluntary action engages and connects people there is an implicit assumption that it contributes to the development of social capital.

Whether the proliferation of time-limited Australian and state government funded rural programs in partnership with large non-government organisations are effective in building social capital is debatable. Mowbray <sup>43</sup> argues for sustained funding of universal programs to empower rural and regional communities. Taggart, Short and Barclay <sup>34 p 7</sup>, in their study of volunteer home visiting support for mothers, warn that totally government funded programs may "change the focus and philosophy of the programmes away from community participation, toward more bureaucratic agencies". Notably, research by Leonard and Burns <sup>58 p 40</sup> on women's volunteering, found that "the highest level of [personal] agency was shown by those who actually set up community groups themselves". These studies indicate the importance of the building of respectful, close working relationships between urban-based coordinators of volunteer in-home support services and rural volunteers, service providers and the rural community, when they seek to extend services to rural settings. This represents an area of interest to be explored in this study.

The linking of social capital and volunteering requires critical analysis of the potential negative effects of social capital itself, such as social exclusion, and vigilance against possible abuse by government, which may use it as a means of rescinding its responsibility for service provision. This is particularly important in the rural setting, which has greater socioeconomic disadvantage <sup>32</sup>. It may be a challenge to facilitate rural volunteer in-home support in a way that allays people's fears that volunteers are replacing paid work that is the responsibility of the government (at its various levels) to provide. The literature suggests various means of achieving this. Demarcating the roles of volunteers in relation to paid workers may avoid the increase in the blurring of boundaries <sup>31 46</sup>. Highlighting the benefits of volunteering to volunteers and the community they work with in terms of increasing social capital, while demonstrating a commitment to ensuring inclusive practices to avoid the potential for volunteering to reinforce social exclusion, is another strategy promoted in the literature <sup>46 59-61</sup>.

Creyton's <sup>50</sup> capacity approach to working with volunteers emphasises the significance of addressing the area of inclusion and recommends an organisational commitment to diversity. Social inclusion/exclusion or "social polarisation" <sup>32 p 41</sup> appears to be of particular relevance to rural communities and hence to this study. Onyx, Leonard and

Hayward-Brown <sup>45 p 136</sup> found evidence of exclusion in their regional volunteering study, an important reminder that "bondedness" can potentially have negative effects also. As Yates and Jochum <sup>57 p 3</sup> point out, "powerful [rural] communities can have disadvantages – lack of privacy, social claustrophobia, cliquiness and hostility to newcomers". Throughout the literature, being invited accounted for the single most important method of recruitment <sup>46 62</sup>. This being the case, an important issue in this research will concern the inclusion of people on the margins of society who are less likely to be connected to the networks that "do the asking" <sup>60 p 33</sup>.

#### Links with motivation and types of volunteering

A repeated finding in the research literature is that the rate of volunteering is higher in rural/regional Australia than in the urban/metropolitan areas <sup>49 56 62 63</sup>. Many argue that the higher propensity for volunteering in rural areas may be "shaped by the logic of necessity" <sup>64 p 53</sup>, stemming from a comparative lack of services with their capital city counterparts <sup>63</sup>, rather than driven by more traditional altruistic motives, more commonly associated with charity models of volunteering.

Warne and Dietrich's <sup>46 pp 22, 27, 5</sup> study in rural Victoria reinforces this, with volunteers' responses to why they volunteer being about "survival of the community", highlighting the importance of "commitment to the local people" and "loyalty to the paid workers", particularly in the face of adversity. These factors are reinforced by the responses for why they would stop, which centre on incapacity – "illness, death, moving, having to care for other family members" – that is, changes in personal circumstances, rather than a rejection of volunteering per se.

In a similar but slightly different vein, Onyx, Leonard and Hayward-Brown <sup>45</sup> in their research comparing the rural and urban experience of volunteers in the provision of human services in New South Wales, note the significance of individual client contact for the urban volunteers as opposed to the more collective nature of rural volunteering. This often manifested in the establishment of a "necessary service" <sup>45 p 133</sup>, for example the creation of a dialysis unit, involving activism as opposed to service delivery. These findings suggest the importance of urban-based volunteer in-home support services engaging with the rural communities sufficiently to develop a commitment to the philosophy and practice of volunteer in-home support, one-to-one service delivery, so that services are driven by the rural communities and viewed as relevant and necessary, rather than imposed.

#### Links with education and training

With the expansion of volunteering from charity model to social enterprise and the linking with social capital, the focus in the literature on motivation, which traditionally centred on altruism, has extended significantly to include self-interest factors such as social contact; skill development (personal and work related); and emphasising reciprocal benefits between the volunteers, recipients of the service and the organisations <sup>44</sup>. A corollary of this appears to be a shift from the 'traditional' training of

volunteers to encouraging a culture of education and learning. This shift entails a movement away from simply matching and skilling volunteers to set roles and tasks, towards focussing on volunteer capacity building and the potential beneficial flow-on effects which might be engendered for the organisation and the community <sup>50 65 66</sup>.

The trend towards the 'professionalisation' of the voluntary sector has had mixed impacts on the areas of management and training. Formalisation of the volunteer role can improve the quality of work for volunteers with its emphasis on training (including accreditation) as an important component of organisational support. Concerns are raised in the literature, however, that training spurred by governmental and organisational demands, based on a drive for professionalism as a reaction to fears of litigation, rather than emanating from the needs of the community and the volunteers, could possibly result in the alienation of volunteers <sup>45 48 49</sup>. The Australia Street Company and Phibbs <sup>62</sup> p2 found that "management and administrative matters" dominated information and training activity, with "volunteer rights and responsibilities" as the most frequently mentioned training topic by volunteering support organisations. Creyton <sup>50 p 6</sup> cautions that "too often the management systems, documentation and standards become the central focus of those who work with volunteers". Esmond <sup>49</sup> p <sup>23</sup> further suggests that education and learning "needs to be based upon opportunities to develop one's full potential rather than about control and regulation and a fear of litigation". Striking a balance between the needs of the volunteers and the requirements of the organisation – noting that "these are not necessarily always compatible". 66 p 3 – may be an important aspect of this research.

The question of balance also relates to the amount of training. While generally considered beneficial, it can have a deleterious effect depending upon whether there is too much: being overly demanding <sup>46 67</sup>; or insufficient: causing stress through ill preparedness (Bennett, Ross and Sutherland, 1996, cited in <sup>51</sup>). The NHMRC and VA <sup>31 p</sup> suggest that volunteers in health care "may require more formal training before being equipped to do their designated work". Arguably, the need for training may be heightened in the rural setting, given the potentially stressful nature of the more socially and physically isolated environment that rural health volunteers may encounter, when supporting people facing challenging issues such as depression, anxiety, grief, and loss. Volunteers need to feel well prepared, and high quality learning experiences may be a significant means of achieving this.

It is of interest to note, however, that despite the research findings by the Australia Street Company and Phibbs <sup>62</sup> of regional and rural volunteers ranking training as the most important kind of support, there was a reluctance of volunteers to commit extra volunteer hours to being trained, even when the usual barriers of cost and distance involving travelling to urban areas to undertake training were removed by presenting locally. Yates <sup>42 p 3</sup> similarly commented on what she referred to as "the rural sector's lack of training culture" and calls for further research into the area, beyond the traditional barriers such as cost, time and distance. Perhaps the cautions from Warne and Dietrich's <sup>46</sup> study and Action with Communities in Rural England <sup>68</sup> against the risk of less rural-focussed organisations possibly failing to understand the local context or

issues, are relevant here. In regard to urban and rural working relationships, MacLean and Kelly <sup>69</sup> in their study of palliative care in rural Canada, emphasise respecting the uniqueness of the rural community by building on existing strengths. This study aims to explore the area of training and education and contribute to informing how it may hinder or facilitate rural volunteer in-home support.

#### Links with sustainability

The lack of critical mass in rural communities has a major impact on the demand for human, physical and financial resources associated with volunteering, with increased interreliance highlighting the merits of a more community development approach <sup>68</sup>. The added burden of isolation and longer travelling distances in rural areas, coupled with higher fuel costs, places a higher financial burden on the provision of services both for the volunteers and the volunteer organisations <sup>38 44 46 62</sup>. These matters are compounded by the fact that rural volunteers are often members of multiple voluntary organisations <sup>49 70</sup>. The literature on volunteering points out the inefficiencies of the duplication of volunteer-related activities such as training, recruitment, retention, and recognition across volunteering organisations <sup>46 49 71</sup>.

Of further concern is the issue of generalist and specialist health practice. The nature of more 'generalist' as opposed to 'specialist' practice in rural areas amongst health professionals <sup>69</sup> – predicated upon the lack of specialist services and the variable and intermittent incidence of exposure to specific health needs – could arguably be a similar reality for rural in-home support volunteers, and contribute to the understanding of the possible benefits of multiskilling or a generic model of rural health volunteering. These matters combined have led to calls in the literature for more 'collaborative', 'joint', 'cooperative' volunteering efforts, with consideration of 'merging', 'pooling' and 'umbrella' measures as a means of fostering more sustainable rural volunteering, with an emphasis on an action research approach <sup>31 32 46 49</sup>. Esmond <sup>66 p 8</sup> poses the challenge to volunteer organisations when she urges:

Discover the power of networking and develop joint projects to enrich the volunteer experience so volunteers may experience a range of volunteer activities across a number of organisations. Competition can be a barrier that results in duplication of services and often creates confusion for potential volunteers. Lower the drawbridge and invite creative collaboration in.

If Lyons and Hockings' <sup>64 p 55</sup> prediction that "civil society will be increasingly carried on the backs of a small troupe of dedicated, well-educated and older Australians" is correct, then the concept of broadly training the few, through multiskilling or a generic model of volunteering in the rural setting, could prove burdensome. The volunteers would need to be particularly well supported, which might necessitate the close cooperation of both local and urban workers, the use of mentors and other innovative means. Without the concerted support of referral sources such as health professionals and other service providers, the opportunities for enthusiastic, multiskilled rural in-home visiting volunteers to apply their skills could be restricted, and the vitality and

momentum created by the training could be dissipated and even lost by the inability to regularly experience theory in practice. This study aims to explore and inform on these issues when examining the experience of rural volunteer in-home support.

#### Orientation to rural health

Prior to focussing the attention more specifically on rural volunteer in-home support literature in the chosen fields of hospice palliative care and supporting families with children, a brief consideration of the literature in the field of rural health is required. The aim is to provide an orientation to some of the issues arising in the rural health literature, given the nature of this study, whereby, urban-based volunteer in-home support services strive to provide a service in rural communities through the training and coordination of locally based rural in-home support volunteers. While there may be commonalities in the rural and urban experience of living with an eventually fatal condition or parenting, it may be the case that the rural context presents certain challenges and benefits both to the rural population and rural health practice, knowledge of which may assist in providing relevant, community specific, rural volunteer in-home home support services.

#### **Rural context and rural practice**

There is an increasing interest in the health of rural communities stemming from disparities in rural and urban health outcomes, with poorer health figures for rural people overall <sup>72</sup>. The contributory factors influencing rural health, urban/rural health inequities and the best means of addressing them, generate considerable diverse views and opinions in the rural health literature, as evidenced in the papers delivered at the Inaugural Rural and Remote Health Scientific Symposium (<a href="http://nrha.ruralhealth.org.au">http://nrha.ruralhealth.org.au</a> accessed 3.7.08). Significant attention focused on issues such as the influence of socioeconomic and cultural factors on rural health <sup>9</sup> and environmental determinants <sup>37</sup>, and their impact on service delivery and practice.

Beard et al.'s paper <sup>9 p 6</sup> raises pertinent questions when their table 'Some rural socioeconomic and cultural factors influencing health' is applied to how the factors might influence rural volunteer in-home support. The table attempts to outline some central, rural-related factors that may influence health: individual (including family) level factors such as stoic behaviours; neighbourhood population and social characteristics, such as movement to cities of young families, and close knit communities with high collective efficacy; and neighbourhood-level physical characteristics, such as access to health services. Consideration of how some of these factors may impact on the areas of interest in this study – living with an eventually fatal condition, and parenting in the rural environment – and how rural volunteer in-home support services with urban-based management might best support individuals, families and communities in light of these factors, may be a useful exercise for this study.

Veitch's  $^{37\,p\,65}$  paper focuses on the impact of environmental determinants on rural health and healthcare delivery in Australia. He refers to the "ABC of rural health" which shape health and well-being in rural areas:

Access (to and availability of health services, choices and options), behaviour (beliefs and attitudes to health and well-being) and context (in which rural people live and work).

He also draws attention to the fact that such determinants can have both positive and negative effects. For example, exposure and connectedness to 'nature' can be experienced negatively with challenging physical conditions, or positively with reducing stress through communion with the natural environment.

In addition, Veitch <sup>37 p 67</sup> points out possible impacts on health service delivery and practice, knowledge of which may have relevance not only to health professionals in rural areas but to rural in-home support volunteers also. Referring to Strasser et al. (2000) and Hays, Evans and Veitch (2005), he contends that rural health professionals will work with:

...access to fewer resources, fewer personnel, and with greater personal awareness of the impact of their actions and the outcomes on community [and] require a broad set of procedural skills appropriate to both their community's needs and the local environment.

The exploration of such considerations in the study may highlight particular training and support needs for rural in-home support volunteers.

Interestingly, Services for Australian Rural and Remote Allied Health (SARRAH) released an online resource 'SARRAH's Remote and Rural Transition Toolkit' <sup>73</sup> in 2009, aimed at allied health professionals or students commencing work in such areas, and the managers supporting them, in recognition of what they propose on the online promotion page is the need to "build the unique knowledge and skills required for remote and rural practice". They emphasise the importance of developing an understanding of the contextual factors impacting the health of clients, and the ways in which services are delivered. It is a resource that may be valuable for urban-based volunteer in-home support services seeking to extend to rural areas, helping to raise awareness of how rural contextual factors may facilitate or hinder the delivery of their service. This study of the experience of rural volunteer in-home support aims to explore these concerns, considering if there are 'unique' knowledge and skills required for the development of rural in-home support services.

Munn and Munn <sup>74</sup> in their paper 'Rural Practice' aimed at rural social workers, highlight some rural context and practice factors which may also be of direct relevance to rural in-home support volunteers. They discuss factors such as centralised policies and managerialist approaches, with assumptions of similarity of needs and interests throughout Australia; increased visibility of both worker and client and its impact on ethics and confidentiality, labelling and constraints to seeking assistance from local networks; importance of the credibility of the rural worker; and impetus for rural workers to be specialist/generalists. These and other ethical considerations such as

privacy, stigmatisation, dual and overlapping relationships between work and personal life explored in the rural literature <sup>75-77</sup>, appear yet to be fully explored in the domain of rural volunteer in-home support. This study seeks to consider such factors as they may arise when exploring the experience of rural volunteer in-home support.

Rural volunteer in-home support services aim to support rural individuals and their families in their caring role, however, there are claims that the role of the family in maintaining and promoting the health of rural Australians is a neglected area of rural health research <sup>78</sup>. Of importance to this study is Humphreys' findings that rural families play a significant role as healthcare providers and carers, as they deal with such issues as vulnerability resulting from lack of access to healthcare services; caring for elderly relatives and friends; and dealing with confidentiality and privacy concerns. Humphreys <sup>78 pp 167, 181</sup> strongly urges a primary healthcare approach, with the principles of community development and participation, as a means of ensuring appropriate healthcare services in small rural and remote communities and recognition of the role of families:

...the need to adopt a primary health care approach as the basis for rural health service provision is vital and urgent...In this way families will remain the cornerstone of healthy rural communities.

How this applies to the delivery of rural volunteer in-home support is an area of interest that this study aims to examine and contribute knowledge and understanding, through the exploration of how urban-based volunteer in-home support services engage with rural individuals and families to ensure services are relevant to their needs.

## Volunteer in-home support: hospice palliative care and supporting families with children

As stated in Chapter One, despite the limited nature of the literature on volunteer inhome support in the domains of hospice palliative care and supporting families with children – and further still in the rural context – nevertheless, there is sufficient evidence to indicate that volunteer in-home support can be potentially beneficial <sup>12</sup>. A dominating feature in the literature for the success of volunteer in-home support in both domains is the importance of a community development approach – building community capacity, and a stance of flexibility and responsiveness to clients' needs <sup>6 16 79-81</sup>. However, gaps in the knowledge of the rural context and its impact on the experience of living with an eventually fatal condition; the experience of parenting; and service delivery and utilisation, may influence urban-based volunteer in-home support services' ability to work with community development approaches, whilst highlighting the very need for them. This section will commence with a discussion of the place of volunteer in-home support, followed by rurality and a community development approach.

#### The place of rural volunteer in-home support

Volunteer in-home support in the domains which are the focus of this study, is generally perceived in the literature to have a place within the broader picture of healthcare services, with individuals and families and the volunteers themselves benefiting from the experience of providing primarily emotional and practical support, and linking with other services <sup>1 2 34 82 83</sup>. It could be argued that there may be an increased need for such support in rural communities. In regard to hospice palliative care, Gomes and Higginson <sup>84 p 9</sup> point out the increased likelihood of patients living in rural areas dying at home, questionably whether from preference or limited resources and lack of alternatives, given the paradox of rural patients' increased difficulties in accessing health care and palliative care. Evans, Stone and Elwyn <sup>85 p 309</sup> claim there is evidence of primary care professionals and families and carers in rural areas "feeling either unsupported or overwhelmed" in regard to palliative care. Wilson et al. <sup>2 p 254</sup> support the increased need for rural hospice palliative care volunteers when they clearly state:

Efforts to increase volunteerism in rural and remote communities may be particularly needed, given greater scarcity of specialized EOL [end-of-life] care programmes and EOL care specialists in these regions.

Similarly, there may be increased need for volunteer in-home support for families with children in rural communities, particularly given the reduced services available to them. But there is a paradox here too if Weiss <sup>14 p 113</sup> is correct in suggesting that home visiting program effectiveness partially depends on "the availability and quality within the community of other services for families as well as on the capacity of the families to connect with such services". The provision of rural volunteer in-home support may prove particularly challenging due to the non-existence or lack of other supportive services for families in rural communities. As previously mentioned in Chapter One, Black and Kemp <sup>1</sup> found that rural communities are confronted with distinctive challenges in regard to the delivery of home visiting programs. They refer to Elix and Lambert's <sup>18</sup> study of volunteers in a small rural community program and their examples of challenges associated with confidentiality and its impact of greater reliance on interaction with the program coordinator; and misunderstanding of the role of the program by other agencies stemming from the reduced services available in these communities. These areas of concern may have direct relevance to this study, especially given the urban location of the coordinators.

#### Rurality and community development approaches

Of particular note in the literature, and especially so in the domain of hospice palliative care where it appears there is more rural-focused research <sup>69 79-81 86-88</sup>, the importance of a community capacity approach to devise community specific services is promoted as vital. It is well known that building community capacity takes time, especially to establish trust in new services <sup>6 88</sup>. However, the reliance on time-limited grants to develop services in rural communities does not necessarily allow for this, and may be a challenge for urban-based volunteer in-home support services expanding to rural

communities. Jenkins <sup>6 p 40</sup> warns that if services are withdrawn before being firmly in place in the community, then "rather than building community capacity, this can contribute to a lack of trust, effectively undermining community capacity".

Taggart, Short and Barclay <sup>34 p 7</sup> in their evaluation of an urban volunteer home visiting project for mothers, emphasise the value of developing a service according to the needs of the community it aims to service, when they contend that "'grafting on' a project to a community because it was successful in another is not productive". McKee, Kelley and Guirguis-Younger's <sup>86 p 171</sup> study of hospice volunteering with rural seniors suggests that there may be differences between urban and rural volunteering, and they caution the automatic implementation of policies and practices devised in the urban context. The study highlighted the special palliative care needs of ageing rural seniors and the importance of acknowledging informal networks of care. This study of rural hospice palliative care volunteers may give rise to similar concerns for the elderly in their rural communities.

There are calls in the literature that capacities cannot be generated or delivered from "outside" <sup>81 p 310</sup> rural communities, and neither should programs be developed from such a position <sup>89</sup>. In Dorgan et al.'s <sup>89 p 2</sup> essay on cancer and rural Appalachia, they contend that:

- 1) visible and credible partnerships must be developed within the communities;
- 2) existing personal networks must be tapped into; and 3) cultural values, resources and beliefs must be considered.

This study aims to help inform the relevance of these matters and how they might be addressed in the context of rural volunteer in-home support. There may be hazards associated with volunteer in-home support models designed in urban contexts, being implemented in rural communities without reference to the rural context.

#### Implications of the literature review findings for this study

This study of the experience of rural volunteer in-home support in the domains of hospice palliative care and supporting families with children, as viewed by rural volunteers, rural and urban specialist service providers, and the urban-based volunteer in-home support service coordinators, seeks to determine: What are the factors that facilitate and/or hinder rural volunteer in-home support in rural areas through urban-based management of rural-based volunteers?

In doing so, it will explore concerns emanating from the literature review such as the possible influence of 'big picture' issues, namely economic rationalism, models of volunteer management, and the linking of social capital, capacity building and volunteering. Particular attention will be paid to the consideration of the possible influence of the rural context through exploration of rural socioeconomic and cultural factors, and environmental determinants, and the potential impacts on health service delivery and practice in terms of rural volunteer in-home support. Consideration will

also be given to how a community development approach is influencing or might influence rural volunteer in-home support.

The findings from this study aim to enhance the knowledge of the development and delivery of rural volunteer in-home support, so that rural communities may enjoy the benefits of services tailored to the needs of rural people living with an eventually fatal condition, and those fulfilling a parenting role.

#### **CHAPTER THREE**

#### **METHODOLOGY**

The literature review provides a contextual framework for this study of the experience of rural volunteer in-home support. It reveals that there are gaps in the literature concerning the nature of the rural provision of such services in the domains which are the focus of this study, hospice palliative care and supporting families with children. This chapter focuses on a discussion of the qualitative research conducted to address this gap. Its purpose is to explain the rationale for the chosen research approach. Further, the rationale for, and detailed discussion of, the methods and techniques of data collection and data analysis.

The chapter commences with a discussion of the context of the study, the precursor to the generation of the statement of the aim of the study and question arising from it, and subsequent direction of the study. It requires discussion of the position of the researcher in relation to the professional association with the research cohort, and its influence on the researcher's perspective. This direction is taken in agreement with Greenhalgh and Taylor's <sup>90 p 4</sup> suggestion, that while it is impossible for a researcher not to possess any views, ideological or cultural perspectives when conducting interviews or focus groups, "the most that can be required of the researchers is that they describe in detail where they are coming from so that the results can be interpreted accordingly".

#### Background to the study and position of the researcher

At the commencement of the study, the researcher was employed as a Community Health Social Worker, providing outreach stationed at a rural/remote Multi-Purpose Centre; and a Specialist Community Palliative Care Social Worker, based in the capital city and providing services as required to the region's rural/remote areas (pertinent demographic details will be provided below).

In these professional capacities, the researcher came into contact with clients who might benefit from referral to volunteer in-home support services in the domains of hospice palliative care, and supporting families with children. The researcher's professional social work experience was that upon contacting the urban-based volunteer coordinators with a referral for an urban-based client, more often than not a suitable volunteer was readily available, and she witnessed the benefits clients experienced from volunteer in-home support.

However, the availability of such rural volunteers was mixed. Frequently the response to a request was, "We would like to help you, but we don't have volunteers in your area", often purported to stem, in part, from resourcing constraints to extend services to rural areas. Further, it appeared that in rural areas where rural in-home support volunteers were available, there were perceptions of varying degrees of utilisation: often underutilisation, associated with concerns that there was a need for volunteers but they were not being sufficiently utilised, or that the number of clients requiring the services

were few; at times optimal utilisation, where the demand for volunteers and their availability appeared evenly balanced; and, on occasions, overutilisation, associated with not being able to meet the demand for volunteers. There was a sense that rural clients were, to some extent, missing out on the benefits of volunteer in-home support. In addition, there appeared to be uncertainty as to the factors which might aid or inhibit rural volunteer in-home support. These experiences lead to the genesis of the study of the experience of rural volunteer in-home support.

The researcher had a professional, collegial association with the research cohort of volunteer coordinators and service providers, all of whom were known to the researcher apart from one then newly appointed volunteer coordinator, and one service provider. The volunteer focus group participants were known to the researcher through both informal and formal links in the rural community in the researcher's capacity as Community Health Social Worker. Of the volunteers participating in individual interviews, only one was known to the researcher.

The researcher's professional, collegial relationship with the research cohort may have contributed to "responsiveness to social context" <sup>91 p 724</sup>, therefore possibly adding to methodological rigour in the qualitative research study. Simultaneously, the researcher consciously sought to maintain as neutral a stance as possible to ensure the privileging of participants' knowledge, encompassing varying views in order to not only enhance the learning from the research <sup>91</sup>, but also the rigour, with the systematic description and analysis of opposing views as they emerged.

#### Qualitative research study design

The aim of this study was to explore the experience of rural volunteer in-home support through urban-based management of rural-based volunteers, in order to further the understanding of the nature of this form of intervention strategy in rural communities. The specific research question thus arising from this aim was:

What are the factors that facilitate and/or hinder rural volunteer in-home support through urban-based management of rural-based volunteers?

The nature of the research aim and question led the researcher to employ a qualitative research study design. The purpose of the study was to gain a deeper understanding of rural volunteer in-home support, which is consistent with the goal of qualitative research:

The goal of qualitative research is the development of concepts which help us to understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences, and views of all the participants. <sup>92</sup> p <sup>43</sup>

Qualitative research methods of data collection and analysis were chosen as they allow for exploration of the potential complexity of factors to be heard through the voices of the participants <sup>92</sup>.

#### Measures undertaken in conducting the study

The following measures were undertaken in conducting the study: the selection and recruitment of research participants; interviews and focus group followed by transcription of the recordings and compilation of volunteer demographic data; and thematic analysis of transcriptions. The final outcome of these actions led to the development of Table 5.1 'Flags of the experience of rural volunteer in-home support health care' (adapted Dorgan et al. <sup>89</sup>), which forms the basis for the Discussion Chapter. The 'flags' represent reference points which may be useful for urban-based volunteer in-home support services to consider when they seek to provide a service in rural settings. The measures undertaken are discussed in turn.

#### Selection and recruitment of research participants

Selection of rural volunteer in-home support services

In an effort to explore the experience of rural volunteer in-home support health care, the researcher chose to focus on the experience of two small, grassroots <sup>93</sup> organisations based in the capital city which were known to provide services to rural communities through urban-based management of rural-based volunteers, in the domains of hospice palliative care, and supporting families with children. Apart from the fact that the two organisations were known to provide services in rural areas, the researcher chose to focus on these two services for the following reasons. Firstly, it was anticipated, through the researcher's professional knowledge and experience, that the number of both rural volunteers and rural areas serviced would be limited. Focusing on the two services would potentially provide a larger cohort of participants, and assist with the gathering of sufficient depth and breadth of information to explore the subject area <sup>91</sup>. Secondly, it was anticipated that there could be learnings from the study which could apply to either or both services through the commonality of the two services engaging in rural volunteer in-home support. Thirdly, as previously discussed in the literature review, there are calls for more collaborative action amongst volunteer services <sup>31 32 46 49</sup> and an exploration of the views of two services, one of which was known to have been involved in a rural collaborative venture, could potentially provide further knowledge in this area of interest to this study.

Description of the volunteer in-home support services

Both of the incorporated, urban-based volunteer in-home support services have a history of operation of over twenty years. Their services originated in the urban areas, with a reliance on government funding for a paid coordinator position and reimbursement of volunteer expenses. Extension of services to rural areas through the training, support and management of rurally based volunteers, has been dependent upon various means such

as stretching existing resources; project 'one-off' funding, often in collaboration with other services; and in the case of hospice palliative care, the addition of fund raising efforts and individual donations.

Volunteers provide varying degrees of emotional and practical supportive care for clients in their own homes, and in the case of hospice palliative care, in medical and some nursing home settings also. In addition, supporting families with children volunteers can provide information and assist families in accessing relevant services and resources, while hospice palliative care volunteers can provide respite for family carers and hand and foot massage. Volunteers provide an undertaking to be available to support clients. Flexibility within defined boundaries of what, how and when support is provided to suit the needs of the client, is a feature of both services. Clients can self-refer or others, such as family or health professionals, can do so (with permission) on their behalf.

#### Recruitment of participants

A purposive sampling strategy was undertaken in order to gain an in-depth understanding of the experience of rural volunteer in-home support through the representation of a range of perspectives <sup>90 91</sup>, namely those of: volunteer coordinators, service providers and volunteers. The intention of the use of triangulation through the exploration of multiple points of view, and data collection techniques (in-depth semi-structured interviews and focus group) was to attain a more complete picture and complex understanding of the subject area <sup>90 91 94</sup>.

An important voice absent from the picture was that of the people who, if offered a volunteer, chose to accept or decline the offer. While an understanding from this perspective would make a significant contribution to the study, it was the researcher's view that the complexity of this area of enquiry warranted a separate study, such as that undertaken by Barnes, MacPherson and Senior <sup>95</sup>. The study compared the characteristics of families with a new baby who did not take up the offer of home visiting support from a community volunteer with those families receiving support, in order to investigate the factors influencing the acceptance of volunteer home visiting support. The potential volunteer recipients in this study were a vulnerable population group, especially in the instance of hospice palliative care. Their inclusion was considered an extension beyond the scope and capacity of this study. The perceptions of the volunteer recipients' experiences from the viewpoint of the other participants in the study – indirect or second-hand – may contribute some valuable understanding to the study.

Full committee approval of the study was gained from the Tasmania Social Sciences Human Research Ethics Committee, University of Tasmania. The researcher then met individually with the volunteer coordinators and the following documentation was provided to inform the discussion of the details of the study: Information Sheets, Outlines for Data Gathering and Consent Forms for volunteer coordinators, service providers and volunteers (for an example of a Volunteer Information Sheet and Consent

Form refer to Appendix 1. The Volunteer Demographic Information form and Outlines for Data Gathering/Interview Guides/Outline of Questions are provided below in Tables 3.1 and 3.2). Discussion focused on discerning the rural areas where the services were able to provide a volunteer service. As anticipated, the number of areas and volunteers were limited. Available approximate figures indicated that of 120 hospice palliative care volunteers registered at that time, 11 were in four rural/remote areas. Of approximately 22 supporting families with children volunteers, seven were in three rural/remote areas.

Volunteers were recruited to the study by the following means according to the methods of least impost as suggested by the volunteer coordinators, and within the university ethics guidelines. Rural hospice palliative care volunteers were contacted by mail by the volunteer coordinator, a copy of the Volunteer Information Sheet was included with the contact details of the researcher. The researcher was invited to attend two meetings (one rural, one urban) of the supporting families with children volunteers, to inform them of the study and invite their participation. Information sheets were distributed with contact details of the researcher. Volunteer participants contacted the volunteer coordinators or the researcher directly either by telephone or email. Through discussion with the researcher, participants chose to attend either individual interviews in the location of their choice (home or researcher's workplace), or a focus group in one rural/remote area where there were sufficient numbers.

The volunteer coordinators informed the researcher of common service provider referral sources. Service providers in the rural areas where volunteers were available, and urban-based service providers who provided outreach to the rural areas, were contacted by email with an invitation to participate and Information Sheets were attached. Some service providers with whom the researcher worked alongside were approached directly. Through discussion with the researcher, service providers chose to either participate in face-to-face interviews in their workplace, or telephone interviews.

#### Information pertaining to the research cohort

The Tasmanian health services landscape is undergoing major restructuring. In describing the areas in which the rural in-home volunteers participating in this study operated, the researcher has referred to the document 'Tasmania's Health Plan, Primary Health Services Plan May 2007' <sup>36</sup> available at www.health.tas.gov.au (accessed 3.6.08).

Thirteen **Rural Volunteers** (consisting of four supporting families with children volunteers and nine hospice palliative care volunteers) who participated in the study were located across six Local Government Areas (LGA): Derwent Valley (one), Southern Midlands (six), Glamorgan Spring Bay (one), Tasman (one), Huon Valley (three), and Kingborough (one). All the LGAs are classified in the above document as rural/remote, bar Derwent Valley and Kingborough which are classified urban/adjacent urban area. However, both of these areas are a base for the delivery of services to rural areas which attract Australian Government Regional Health Service funding – Bruny Island and Central Highlands – so the volunteers delivering services in these areas were included as rural volunteers for the purposes of this study. All of the rural volunteers

lived in and delivered services in their LGA, with the exception of two volunteers who lived in one urban/adjacent urban area classified LGA and delivered services to a bordering rural/remote LGA.

Eleven **Service Providers** participated in the study. One rural service provider contacted the researcher, but was excluded from the study on the grounds that there had been no experience with the volunteer services, volunteers or members of the community who might benefit from referral to the services. Nine of the rural service providers were located across five of the LGAs: Southern Midlands (three), Glamorgan Spring Bay (three), Tasman (two), and Huon Valley (one). Two participants were urban-based specialist service providers in the domains of interest who provided rural outreach: one to Derwent Valley and one across the region. The service providers by profession included three rural Community Health Nurses; four rural Community Health Social Workers; one Clinical Nurse Manager of a rural Multi-Purpose Health Centre; one rural Family and Child Health Nurse; one rural General Practitioner; one Palliative Care Clinical Nurse Specialist based at an urban specialist palliative care service; and one Family and Child Health Nurse based at an urban specialist parenting service.

Three **Volunteer Coordinators** participated in the study. One was an urban-based coordinator of urban- and rural-based hospice palliative care volunteers. One, at that time, was a recently appointed urban-based coordinator of urban- and rural-based supporting families with children volunteers. One was a recently retired coordinator of the aforementioned volunteers, who after being approached by the then new coordinator, kindly agreed to be interviewed.

In summation, there were twenty-two individual interviews and one focus group consisting of five rural hospice palliative care volunteers, a total of twenty-seven participants interviewed for the study.

#### Tasmanian socio-demographic information

To aid with the provision of context to this study, bearing in mind the focus on rural volunteering in the domains of hospice palliative care and supporting families with children, a brief socio-demographic account will be provided of the rural areas covered in this study, with reference to Tasmania's Health Plan 2007 <sup>36</sup> noted above, and the Tasmanian 'State of Public Health Report 2008' <sup>96</sup> available at <a href="www.dhhs.tas.gov.au">www.dhhs.tas.gov.au</a> (accessed 12.11.09).

Population ageing, high incidence of cancer associated with increasing age and growing chronic disease are particular issues for Tasmania, presenting challenges to the delivery of health care and meeting service demands across a dispersed, highly rural population <sup>36</sup>. These factors join together to possibly increase demands for rural hospice palliative care volunteers, providing services not just to elderly patients, but across all age groups and eventually fatal conditions, both malignant and non-malignant.

In relation to the possible demand for supporting families with children volunteers, it is noteworthy that after the Northern Territory, Tasmania has the greatest teenage pregnancy rate at 26.6 births per 1,000 women aged 19 years and under, compared with the national average figure of 15.4 <sup>96 p 22</sup>.

The LGAs and area specific localities covered by this study range in population from one as low as approximately 600, to three between 2,000 and 5,000, and two between 11,000 and 14,000 people. The availability and range of health services vary, being organised around different configurations of Multi-Purpose Centre, District Hospital, Community Health Centre, Child Health Centre, Regional Health Service, and Tasmanian and Volunteer Ambulance Services. All are facing projected increases in the ageing population and health services sustainability issues <sup>36</sup>.

### Interviews and focus group; transcription of recordings and compilation of volunteer demographic data.

Semi-structured, in-depth interviews using an interview guide was a chosen method of data gathering for this study, as they are an effective means of facilitating a focused, yet flexible, detailed exploration of the participants' experience <sup>91 92</sup>. A focus group of five rural hospice palliative care volunteers in one LGA was another method chosen for its qualities of being a facilitated group discussion, potentially enabling data to be enhanced by group dynamics which can assist with recall, elaboration and exploration of complementary and differing opinions <sup>91 92 97</sup>. With the participants' permission, interviews and the focus group were recorded and the researcher undertook verbatim transcription in order "to privilege their [the participants] voices in the analysis and interpretation" <sup>91 p 728</sup>. In addition, permission was also sought for volunteers to complete a re-identifiable demographic information sheet to further enrich the level of knowledge on the subject of the study.

Three separate interview guides, informed by the research question and the literature review, were devised by the researcher for the participants representing three perspectives on the subject: volunteers, service providers and volunteer coordinators. The questions were grouped in themes: organisational and management concerns; training, education and support; and ethical considerations and rural notions. An additional theme heading for volunteers was the impact of volunteering on relationships with clients, family and personal life. The questions were ordered in a manner to progress from a general to a more specific level of questioning, known as the funnelling approach, with the use of both descriptive and probing questions <sup>98</sup>. The interview guides, while providing some structure to the interview/focus group, nevertheless were used in a manner which was flexible and responsive to the participants' concerns, consistent with the exploratory goals of the study <sup>91</sup>. The Volunteer Demographic Information form is shown in Table 3.1 and the three interview guides or "Outlines of Questions" are listed in Table 3.2.

# Table 3.1 Volunteer demographic information form

# **Volunteer Demographic Information**

Please tick your volunteer organisation:

Name

Age

Gender

Number of years lived in the community

Number of formal organisations with which you volunteer

Length of time volunteering with this organisation (months or years)

Average hours per week volunteered with this organisation

If applicable, average hours per week volunteered informally (i.e. not as part of a formal organisation e.g. helping neighbour with shopping)

# **Table 3.2 Interview guides/outline of questions**

# **Outline of Questions for Volunteer Interview/Focus Group**

Areas of questioning will cover:

# Organisational and management concerns

Views will be sought on the effects of organisational and management concerns such as:

- volunteer duties, roles
- referral system
- hours of work
- urban-based location of volunteer coordinator
- levels of utilisation of volunteer service
- working relationships with paid staff
- impact of "professionalisation" or "formalisation" of volunteering
- perceived levels of satisfaction with volunteering

# Training, education and support

Views will be sought on the effects of training, education and support concerns such as:

- qualities related to training access, location, quantity and quality, relevance of content to rural context
- opportunities for ongoing education after the initial training/induction
- opportunities for ongoing support e.g. regular meetings

#### **Ethical considerations and rural notions**

Views will be sought on the effects of ethical considerations and rural notions in the rural volunteering context, such as:

- privacy and confidentiality
- multiple and overlapping relationships
- rural notions such as self-sufficiency, mistrust of strangers

# Impact of volunteering on relationships with clients, family and personal life Views will be sought on:

- the perceived outcomes of volunteering for the client, the community, the volunteers
- positive and negative aspects of volunteering

# **Outline of Questions for Volunteer Coordinators**

Areas of questioning will cover:

#### Organisational and management concerns

Views will be sought on the effects of organisational and management concerns such as:

- funding arrangements and sources of income support, and their impact on the ability to provide rural outreach
- models of management, urban/rural differences
- impact of urban-based management
- impact of "professionalisation" or "formalisation" of volunteering
- level of utilisation of volunteer service
- perceived level of satisfaction of the rural volunteers with their work
- relationship of volunteers with paid staff

# Training, education and support

Views will be sought on the effects of training, education and support concerns such as:

- nature of training provided by whom, access, contents covered, initial training, and ongoing education
- support opportunities
- experience of uptake of training by rural volunteers, exploration of factors which contribute to this
- explore any specific training needs for rural volunteers

#### **Ethical considerations and rural notions**

Views will be sought on the effects of ethical considerations and rural notions in the rural volunteering context, such as:

- privacy and confidentiality
- multiple and overlapping relationships

• rural notions such as self-sufficiency, mistrust of strangers

# **Outline of Questions for Service Providers**

Areas of questioning will cover:

#### Organisational and management concerns

Views will be sought on the effects of organisational and management concerns such as:

- referral system
- volunteer duties, roles
- hours of work
- urban-based location of volunteer coordinator
- levels of utilisation of volunteer service
- working relationship with volunteer coordinators and rural volunteers

#### Training, education and support

Views will be sought on the effects of training, education and support concerns such as:

- understanding of training, education and support provided
- significance of training, education and support and their importance when discussing referral with potential client
- participation or contribution to training, education of rural volunteers
- other important qualities about volunteers

#### **Ethical considerations and rural notions**

Views will be sought on the effects of ethical considerations and rural notions in the rural volunteering context, such as:

- privacy and confidentiality
- multiple and overlapping relationships
- rural notions such as self-sufficiency, mistrust of strangers

Participants were offered interviews at a time and place of their convenience. Volunteers were offered home visits, or if they preferred to maintain the privacy of their own home, interviews were also offered at their local health facility or at the researcher's urban workplace, should the interview coincide with a 'trip to town'. The researcher took the position that the onus was on the researcher to engage with participants in their social context if that was the participants' preferred option, in order to gain insights into their social context <sup>91</sup>. The researcher did however, through her extensive professional experience involving home visiting, already have familiarity with working in all the rural areas covered by the study. Five rural volunteers chose to be interviewed face-to-face at the researcher's urban workplace, fitting the interview in with other appointments or activities in town. The interviews, mostly of around 30 minutes duration, were held in an informal, relaxed, conversational manner, in an interview room with a lounge seating

and coffee table setting. One home visit to a distant LGA, had a considerably longer duration of 80 minutes. A focus group of around 30 minutes duration was held at a rural health facility, as were two individual interviews of similar length.

All three volunteer coordinators chose to be interviewed face-to-face at the researcher's urban workplace (the services were located at the same worksite). The interviews ranged from approximately 40 to 60 minutes duration. Three service providers chose to be interviewed face-to-face in their rural health facility and three chose to be interviewed at the researcher's workplace, most ranged from approximately 20 to 40 minutes. Six choose to be interviewed by phone ranged from approximately 10 to 30 minutes.

The participants' experiences with rural volunteer in-home support varied in their extent, intensity and period of time elapsed between their experiences and the time of the interview. Some participants were relying on their memories of events which had occurred some months or even years previously. Frequently, enquiries from participants about partaking in the research centred on concerns that their experience in the area of rural volunteer in-home support was limited. The researcher emphasised that participation was welcomed, no matter how extensive or limited their experience might be. Subsequent findings demonstrated to the researcher that the depth of insight on the subject, and level of contribution to the study, was not necessarily dependent on the amount of practical experience in the area of rural volunteer in-home support. A comment in an email correspondence from a volunteer summed up the sentiment of many participants when a statement was made about the importance of getting "the grassroots of volunteering into the realm of academia".

#### **Transcriptions**

The interviews were transcribed by the researcher verbatim, and stored electronically with a code file name and job number. Hand notes were written during the lengthy, meticulous process to capture initial ideas as they emerged and links between transcriptions and the literature. The transcriptions were printed, and read and checked against the recordings several times for optimal accuracy. The researcher consequently became fully immersed in the data, with multiple readings contributing to richer insights into and deeper understanding of the interviewees' experiences.

#### Volunteer demographic profile

The collection of volunteer demographic data was chosen as a means to enable the researcher to develop a deeper, richer picture of the rural in-home support volunteer profile than a reliance on interviews alone could provide. The volunteers, consisting of eleven women and two men, tended to be older, ranging in ages from 43 to 72 years. The majority, nine, were aged in their 60s to 70s. Four were aged in their 40s to 50s.

The rural volunteers predominantly had a long, if not lifetime, experience of living in their rural communities. Two had lived their entire life in the same rural community they serviced (70 and 57 years), and one had lived there all of the 72 years other than one

year. Most (seven) had lived between 26 and 71 years in the rural community in which they volunteered (two of whom had lived 30 years each in a bordering urban area). The remaining six had lived between three and fourteen years in their rural communities.

With the exception of two volunteers, all had a history of volunteering with their respective volunteer in-home support service since the inception of the service in their rural communities. One volunteer had an outstandingly long history of 19 years with the service. Others ranged from two to seven years since the inception of the service in their rural communities.

The average hours per week volunteered with the in-home support service was difficult for most participants to gauge and the question provoked some discussion. None of the rural hospice palliative care volunteers had regular weekly hours to record. Referrals were described as few in number and intermittent. The numbers were based on the average hours dedicated to in-home support in the event of having one client or family a week to visit. One hospice palliative care volunteer who nominated 20 hours per week noted that the amount of time was exceptional, but it was the volunteer's stated preferred intensive mode of support. Another volunteer nominated ten hours per week, while two others nominated three and four hours per week. Focus group hospice palliative care volunteers in a rural community where the volunteer service had been established for two years, recorded zero hours per week as there had been no opportunities to volunteer. One volunteer from the same area interviewed individually, had one experience of volunteering an average of four hours a week.

The rural supporting families with children volunteers reported having an average of between two to four hours a week volunteering. The incidence in one of the two LGAs was generally described as variable but reasonably sufficient in number for the volunteers to obtain regular hours. In another more remote LGA, the incidence was described as exceptionally limited and intermittent.

With the exception of one volunteer, all were actively involved in mostly multiple other volunteer services in their communities. Nine volunteers were volunteering with one to three other volunteer services, while three were volunteering with three to seven other volunteer services. Only one volunteer, living in an urban/adjacent urban LGA, was involved with another similar home visiting service. The others were involved with a variety of rural community service related volunteering activities such as Community Transport, Meals on Wheels, Volunteer Ambulance, SES, Health/Hospital Advisory Committees, Hall Committee, Visitor Information/Tourism Centres, Church and Community operated Opportunity Shops, and Parish Councils. In addition to this, nine of the thirteen volunteers were involved in informal volunteering (as defined by Onyx and Leonard <sup>53 p 1</sup> as "the provision of the unpaid work of caring and informal neighbourly support"). The informal volunteering ranged between one to six hours per week, with one exception of 20 hours a week.

There are aspects of the participant profile which are commensurate with some issues noted in the literature review. The older aged rural volunteers' involvement in numerous

community volunteering activities and informal volunteering reflects Lyons and Hockings' <sup>64</sup> prediction, and also concern, that the responsibility of volunteering may be falling on the shoulders of too few a number of dedicated, older volunteers. The intermittent and limited opportunities for many rural in-home support volunteers to apply their skills may be problematic in terms of contributing to a sense of frustration with underutilisation, as noted previously in Claxton-Oldfield and Claxton-Oldfield's study <sup>99</sup>. The more collective nature of rural volunteering as opposed to individual client contact more familiar with urban volunteering, as noted previously in research by Onyx, Leonard and Hayward-Brown <sup>45</sup>, is also evident in this profile. The rural communities' unfamiliarity with the individual client contact form of volunteering, as is the nature of in-home support volunteering, may impact on its existence in rural settings. These and other issues are explored further in the Findings and Analysis and Discussion Chapters.

#### Thematic analysis of transcriptions

Thematic analysis characteristically entails developing themes derived inductively from the data through the iterative processes of gathering, reviewing and coding or labelling segments of data to facilitate systematic description <sup>91</sup>. Taft <sup>100</sup> describes qualitative analysis as simultaneously consisting of both mechanical, data management tasks and conceptual, analytic activities. Being a novice both to research and the use of a computer, the writer chose to manually manage data (using individually titled word documents on a computer, paper filing, butchers' paper) without the aid of a computer-assisted software program. Iterative processes involved 'practical' tasks such as classifying, comparing, grouping and refining groupings of text segments, and labelling them to identify themes <sup>91</sup>. Concurrently, the researcher developed conceptual level processes which Fossey et al. <sup>91 p 729</sup> describe as "exploring the meanings, patterns or connections among data that involve the researcher's own thought, reflection and intuition". The researcher's learning experience related to that observed by Agar (1991, cited in Taft <sup>100 p 381</sup>):

That critical way of seeing...comes out of numerous cycles through a little bit of data, massive amounts of thinking about that data, and slippery things like intuition and serendipity.

Attention to certain aspects in the data emanated from the researcher's focus on the research question, connections inspired by the reading on the subject, participation in the interviews and focus group, links made with the volunteer demographic data, and openness to surprise involving the seeking out of challenging and competing views as well as agreement. Examples of descriptors developed from highlighting key words or phrases within and across transcriptions included: local knowledge, privacy and confidentiality, loyalty, communication difficulties, professionalisation, awareness of service, generic verus specialist, confidence, training, utilisation, intermittent, and funding.

Descriptors were grouped into themes. This process was assisted at one point by the development of a diagrammatical representation of the study. It consisted of three

overarching themes impacting on the experience of rural volunteer in-home support health care depicted in three concentric circles with associated elements:

- 1. big picture for example, political context, health systems and culture;
- 2. organisational: urban-based management of rural-based in-home support volunteers for example, fundamental elements of recruitment, training; impact of urban-centric model, community development approach; and
- 3. rural context for example, intermittent need, lack of services, privacy, influence of family.

This process helped with the further clarification and refinement of themes, which resulted in the development of four salient themes or sections which formed the basis of the Findings and Analysis Chapter:

Section One: Adaptation of volunteer in-home support service delivery according to local rural context.

Section Two: Local rural context and heightened ethical issues.

Section Three: Coordination at a local level. Section Four: Beyond formal volunteering.

It culminated in the Discussion Chapter which synthesised the outcomes of the Findings and Analysis Chapter to develop Table 5.1 'Flags of the experience of rural volunteer inhome support health care' (adapted from Dorgan et al. <sup>89</sup>). The 'flags' represent reference points which may be useful for urban-based volunteer in-home support services to consider when they seek to provide a service in rural settings. They provide a means of coherently describing the findings that make sense of the data as a whole, answering the research question: What are the factors that facilitate and/or hinder rural volunteer in-home support through urban-based management of rural-based volunteers?

Throughout the study, the researcher sought to authentically represent the views of the participants in an effort to enhance its validity. The use of a wide range of verbatim quotations in tandem with the researcher's interpretations and discussion aimed to provide a sense of transparency and coherency between the data and the findings <sup>91</sup>. The confidentiality of the participants was paramount throughout the study. Normally, the researcher would identify the participants by using some protective means. However, the small, interconnected nature of rural Tasmania exacerbated the need for caution to ensure that as much as possible no participant would be identifiable in the reporting of the findings. The researcher, therefore, deliberately chose not to identify participants, and was circumspect when referring to a participant to use the least identifiable description, even if that meant that the richness of the data may have been compromised in the effort to protect the identity of the participant.

#### **CHAPTER FOUR**

#### FINDINGS AND ANALYSIS

The crux of the findings from this study is the need for a commitment to the permeation of the 'local' context into all aspects of the establishment and implementation of rural volunteer in-home support, and some form of locally based coordination by urban-based organisations seeking to provide a service in rural areas.

The chapter will proceed with an examination of the findings and analysis through the lenses of four salient points emanating from the data, which serve to illuminate the significance of this fundamental issue. The chapter is divided into four sections:

Section One: Adaptation of volunteer in-home support service delivery according to local rural context.

Section Two: Local rural context and heightened ethical issues.

Section Three: Coordination at a local level. Section Four: Beyond formal volunteering.

The study focuses on the experience of rural volunteer in-home support in the domains of hospice palliative care and supporting families with children, as heard through the voices of the rural volunteers, urban-based volunteer coordinators, and rural- and urban-based service providers. Substantially, findings may be relevant in varying degrees to both domains. They are therefore not considered separately, unless an issue warrants singling out as having specific application to that domain.

The matters arising under each point are not mutually exclusive to that heading, nor are they ordered according to their weight of significance. However, ordering the points in this manner may facilitate the progression towards a richer understanding of the significance of the permeation of the 'local' context in the delivery of volunteer in-home support in rural areas.

# Section One: Adaptation of volunteer in-home support service delivery according to local rural context

The findings suggest that flexible and innovative approaches may be required of urbanbased services seeking to deliver volunteer in-home support services in rural areas. This need could arise from some of the forces at play in the rural environment, discussed in this section under the subheadings of:

- Access to services;
- Intermittent need and utilisation; and
- Resourcing and resourcefulness.

Volunteer in-home support services defined within an urban-centric context may need to adapt their services to suit the particular local rural context.

A seminal statement made by a volunteer coordinator, serves to highlight the significance of the adaptation of volunteer in-home support service delivery according to the local context. Reflecting upon experiences initiating volunteer in-home support services for families with children in rural areas, the coordinator commented on a sense of difference working within rural environments. This led the coordinator to question the veracity of simply transplanting a service system devised in an urban environment, and to consider what other approaches and adjustments might be required to better suit operating in the particular rural environments:

But it is different the rural, it is different. I sort of thought that you could just transfer what you did in the core program, just transfer it out. But it didn't quite work like that. There did have to be sort of changes. And it does have to come from a, I think for it to really work...I think...for the [rural community] it probably felt to people like it was a top-down thing "well who said we needed this in the community?" (Volunteer Coordinator)

The coordinator's comments reflect concerns raised in research by Warne and Dietrich <sup>46</sup> and Taggart, Short and Barclay<sup>34 p7</sup> whom stress the importance of "individualised" approaches to volunteer service delivery, and warn against the "grafting on" of projects from one community to another. It may be the case that there are aspects related to operating in rural environments (along the lines of what Humphreys <sup>78 p 180</sup> refers to as "'rural' risk factors") which impact on volunteer in-home support services devised in urban environments, and that their success may vary according to their readiness and ability to adapt to working in the particular rural environment. This study explores some of these aspects, their implications and the participants' views and responses to them, commencing with the issue of access to services.

#### Access to services

A recurring theme revealed by the analysis of the interviews is the lack of local services and access to services in rural areas, an issue which is well documented in the literature on rural health <sup>7 78</sup>. The impact on volunteer in-home support in rural areas revealed in this study may include increased complexity of referrals, and limited ability to support the volunteers and promote the service.

Several participants commented on the challenging nature of volunteer in-home support in rural areas, and the need therefore for services to be more flexible and inventive:

...I feel really strongly that in rural areas there needs to be volunteer home visiting. I think it is under-represented...ironically, people who live in rural areas, can't – unlike in the city – they can't make a choice about what family support service to access. I mean there aren't the choices there...So I think it's sort of crucial, but it is fraught with difficulties...you just had to sort of be that bit more flexible. (Volunteer Coordinator)

[Rural] areas like this are difficult, but we can't give up. It is needed, it is necessary, and we just have to be more inventive. (Volunteer)

The paucity of services in rural areas may mean that rural in-home support volunteers can struggle at times, despite thorough training and concerted efforts to support them, with the independent nature of the practice of home visiting. Rural in-home support volunteers comment on breaking the rules endeavouring to meet the often complex needs of rural clients, arising from the dire lack of services in rural areas, as people grapple with the brunt of isolation, both geographic and personal:

...I think that because we don't have a lot of services here, possibly the referrals that we were getting were quite full on...They were so desperate, that I think probably eighty percent of the people that I saw felt some sense of disappointment that I wasn't the super-woman that was going to walk in and say "oh let's see what we can do". And the twenty percent that didn't feel disappointment were the ones that needed someone to come and hold their baby while they had a shower. The ones that [Volunteer Coordinator] had the vision to begin with...I've broken rules all the time...we lack so many of the basic services that people in larger communities take for granted...I get really frustrated because you're trying your best as a volunteer with the basic skills you've got...And then there's no service there to back me up...[the Volunteer Coordinator] was always really good at debriefing...how do you debrief that fact that you can do nothing other than just show up? (Volunteer)

...there are a lot of isolated families...they've just moved from the mainland and they have got absolutely no-one...Very often they're one car families and the breadwinner takes the car to work and so they're sort of fairly isolated without knowing anybody...And not being able to get out and go anywhere. (Volunteer)

The sentiments are echoed in the comments from service providers, who further highlight the possible stress on the volunteers, and pressures that might arise for dedicated rural volunteers struggling to meet the challenging demands of their rural

clients and urban-based volunteer coordinators, charged with ensuring the volunteers' well being:

And we've had some great volunteers in this area...and they do tend to end up going, you know, 'beyond the mile' sort of thing. But, they've got to be careful...from their perspective, for being able to keep going...they've been apologetic about it practically...they're not meant to do shopping, or they're not meant to do this or that, and they just said "well I don't know how I'd manage if I didn't have somebody to do it, so I just do it"...And people in cities don't always realise that's it hard to do your shopping, if you haven't got a car or you haven't got money to put the petrol in it, so along they go...it's easier for them to negotiate with the client than negotiate with the organisation, I think. So they just do it. (Rural Service Provider)

They [the volunteers] feel more responsible, even though they're, you know, can have a good training, very good training, they've got the coordinator to talk to, and also the worker...but it's still very hard. (Rural Service Provider)

They might have support through [the coordinator] or through myself, but, you know, often they were left thinking where were they going to get that support from when you're not there?...it's not like you're in town and you can say "well look, how about you go into COS [Community Options Service] and see whether you can get bond assistance"...that just complete lack of services in rural communities. (Rural Service Provider)

The findings in this study reflect those in the supporting families with children literature of Weiss <sup>14</sup> and Vangelista <sup>16</sup>, which emphasise the importance of home visiting as being viewed as a part of a wider system of support for families, requiring working relationships with other service providers and support and supervision. The rural environment of fewer services may, in some measure, accentuate the importance of these issues, whilst at the same time pose a challenge for their implementation. The ability of urban-based volunteer home visiting volunteer services to support the volunteers and promote the service may be constrained, and require flexible adaptations. A volunteer coordinator commented:

...I think in the urban program, it just goes along anyway. But I think you have to put a lot more into the rural ones, to be making sure that the volunteers aren't feeling isolated, they can't just drop into the office and see you, say how are things, and little things like that. And working to promote the service, through the limited services that are in the region. (Volunteer Coordinator)

A volunteer service devised innovative practices to meet some of the challenges associated with access to services in rural areas, including urban-based coordinators' limited ability to travel long distances to rural areas to undertake initial home visit assessments and to support rural volunteers. The adaptations simultaneously contributed towards enhancing service delivery through increasing response time to referrals; and

supporting, upskilling and potentially increasing the retention of rural volunteers. A volunteer coordinator described the innovations:

I've formed teams from the volunteers who are actually doing part of my job...One of them is an Assessment Team...with an Assessment Training Program, they then go and become Assessors. So they actually do a lot of the outreach work...So...we're actually responding to service providers...we have someone go and see them within that week...upskilling and...acknowledging the volunteers, their capabilities...I'm aware of the big thing of retaining volunteers...I've just trained up two people who are Peer Support Volunteers...we phone volunteers between us...either they come to the volunteer meeting or they get a phone call once a month...So they are people from their own groups who will say "hi, how are things going?". Two innovative things and I think that the two of them are really important. (Volunteer Coordinator)

The innovations reflect Creyton's <sup>50 p 1</sup> "capacity approach to working with volunteers" enabling volunteers to extend their roles and develop new skills, while progressing new ways for the organisation to achieve its goals, and have particular relevance to the rural conditions. The Peer Support Team importantly provides rural volunteers working in isolated conditions with what Weiss <sup>14 p 122</sup> terms "intra-program backup".

#### Intermittent need and utilisation

Lack of critical mass in rural environments may, in part, influence the demand on rural volunteer in-home support services, resulting in intermittent need, and impacting on levels of utilisation. There are implications concerning awareness, understanding and promotion of services; role delineation; education and support; and volunteer retention. The perceived lack of utilisation of rural volunteer in-home support was a recurring theme throughout many interviews in both domains. It presented as a perplexing issue for volunteer coordinators, rural volunteers and service providers alike, which could only partially be understood in the context of the smaller population mass to draw upon. Views as to the possible contributory factors for the perceived lack of utilisation, their degrees of influence and the means of addressing them, varied amongst the participants. Experiences described revealed a complex synergy of influencing factors.

The perception of lack of utilisation was exceptionally strong in the domain of hospice palliative care volunteering. Therefore, in this section, the study participants' endeavours to understand and respond in the context of intermittent need and its ramifications, will centre on the experience of rural hospice palliative care volunteering. Unlike in the domain of supporting families with children, a referral to hospice palliative care volunteers is dependent on a medical diagnosis. This factor appears to play a central role in coming to an understanding of the conundrum. Determination of the palliative status of living with an eventually fatal or life limiting illness which involves connections between primary, secondary, acute and tertiary sectors, may be a complicating concern. While the focus of the study is primarily on the provision of rural volunteer in-home support, the experience of rural hospice palliative care volunteering in rural health

facilities will also be explored. The insights from this section, though focused on hospice palliative care, may also have relevance to some aspects in the domain of supporting families with children.

Gaining referrals for rural hospice and palliative care volunteers presented as a vexed issue. The small and intermittent nature of the number of palliative care clients in rural areas posed a challenge as how to best promote and maintain awareness and understanding of the volunteer service to service providers and the rural community. The urban location of the volunteer coordinator added a further complexity to doing so, limiting opportunities to maintain a high profile of the service in the rural areas. Smaller numbers of palliative clients also possibly limited rural service providers' opportunities to skill themselves in the art of engaging conversations with palliative care clients about the acceptance of volunteers. For rural volunteers, limited opportunities to volunteer made it difficult for them to maintain their skill level and influenced their decision to attend meetings and further training, and may have impacted on their retention. The volunteer coordinator commented on the state of rural volunteer utilisation and referral rate, and the rural volunteers' sense of frustration:

[Utilisation is] very poor, very poor. The services [rural volunteers], they've had very little, very few referrals...for the volunteers, who are in the rural areas, and who see people around who they know are sick, and who they know aren't being referred to the service, I think there's a level of frustration in that for them... what they see is their local community, they see the needs in their local community and they see those needs not, as they see it, not being met. Now they may be being met, but they are not necessarily privy to how those services are being met...you can have a little cluster, and then nothing for months, or weeks, or months or years even, before you get another little cluster maybe. The trouble is, when you get those little clusters, have you got the volunteers in situ? (Volunteer Coordinator)

A volunteer, while praising the calibre of training and support, confirmed the observation of the sense of frustration of rural volunteers:

I'm happy with the organisation in Hobart, I think that's excellent, the training, the information that comes out, the care and the concern that comes out is fabulous. But where it fails is that simply nothing happens in [rural area], it's not followed through...No referrals, there is simply nothing. Nothing happens. (Volunteer)

There was a keen perception amongst volunteers that – after taking into account that "perhaps families have opted not to use us" – a significant reason for the lack of referrals hinged on the local service providers not referring clients to the volunteer service, either through choosing not to do so, or stemming from the service providers' and communities' lack of knowledge of the service and the extent of what it could offer. A volunteer described an experience with a community member known to service providers:

I know [a person] was just so desperate, but didn't know we existed, and was nursing day and night, and said... "oh, if only I had known"....It just seems to get to, we're here, they [local service providers] don't want to know we're here, and it just hits a blank wall. (Volunteer)

Another volunteer also commented on perceived tensions between volunteers and service providers as a possible barrier to referrals, and recommended training to help resolve them:

It has to be ongoing training for the staff to learn to trust, and they are trained not to see it as threatening. I mean most staff do, but you do get that barrier. (Volunteer)

There was uncertainty expressed about eligibility for referral to the service. Discussion at the focus group focussed on the experience of the death of an ageing, "not well" community member who lived alone, whom the volunteers felt could have benefited from the service. Whilst the volunteers felt the persons' needs justified referral to the service, what was not clear was whether the community member would have been diagnosed as 'palliative' by service providers, and thereby rendered eligible for referral to the service. It raised the question, at what point is a community member considered to be 'dying'?:

[He/she] would have had a lonely, lonely time of it. And I just think, well, if someone could have gone down, even stayed over...What do you do? You know, you feel like saying "you know we've got someone here who could go", or are you imposing? Or they probably didn't even know we were there? Or, it's just so puzzling. (Volunteer)

Volunteers' comments highlighted the importance of keeping local service providers and the community informed about the service, and there was a suggestion of devising a "local" means of describing and promoting palliative care, in a manner that emphasised a broader understanding of palliative care than just offering assistance at the dying phase:

Perhaps the palliative care name, perhaps that puts them off. If you could say they'll come and sit with you while your wife goes, or mother goes shopping, or do things like that. Do they think that we only sit with them, like in the hospital, when they're on their last moments sort of thing? Because I got that impression from talking round the town. "Now how could you sit with them when they're nearly dying?" I said to them "That's not the only thing you know". (Volunteer)

*I think we need a local way of describing it.* (Volunteer)

Further, volunteers suggested a locally tailored publication to promote the volunteer service in the community, emphasising that it should not be officious:

Maybe you could make it local-applicable, like not a formal thing. (Volunteer)

Just have it nice. And they can just stick it up, take it home and read it at their leisure, and think "oh, that might suit Aunty Mary" or whoever. (Volunteer)

From local rural service providers' perspectives, there was also a sense of concern that perhaps the hospice palliative care volunteers were not being sufficiently utilised, and that intermittent need played a part:

...It just seems such a waste because these people were trained and then haven't really been utilised...I mean if we really needed them and they [palliative clients] didn't have anyone, they'd be wonderful, absolutely wonderful. But it might be once every three or five years. (Service Provider)

They're probably underutilised at this point...it's been such a long time and so few instances of their being used. (Service Provider)

For some, the need for raised awareness of the volunteer service was not an issue:

...as far as the organisation and management, it was well set up and we know [the Volunteer Coordinator] exists and we know all we've got to do is get on the phone and that would be arranged. (Service Provider)

whilst for others, promotion of the volunteer service to local service providers was of particular concern:

I think it's a matter of keeping that group of volunteers in your radar, within your radar, so that you are, when you come across a situation where they might be used well, you could access the service...Maybe they could just send out an email every now and again that keeps you in touch with what they're up to elsewhere? Even if there were other good stories happening from other similar centres to our own, that might keep it within the radar. (Service Provider)

This official structure that has been created, how often do they make contact with the [specific local service providers]? In town, do they ever speak to us about it? Do they? Not very likely, you know what I mean? A lot of these things, you'll gather momentum with greater communication between the two resources...We get so bogged down with work...you just haven't got time to think "now who's that on the, who works with carers [volunteers]?"...And part of that is like an awareness thing, and the profile of this organisation. (Service Provider)

The findings suggest that the conceptions of the role of the volunteers may have varied amongst the service providers, particularly concerning the timing of offering support – on occasions focusing on the dying phase:

I haven't come across a situation for a while because we haven't had anybody who's been palliative and **imminently about to die...**I think it would be good just to discuss it with the RNs within the facility itself, so that they are aware that there are people who can come and sit with people who may be dying [emphasis added]. (Service Provider)

as opposed to earlier in the progression of the illness (in line with the views expressed by volunteers):

...perhaps the patient might think that it's a last resort sort of thing? You know, once the family's worn out, then we get a volunteer. Rather than, it should be the other way around...it's the support that they can give to the patient and to the family...I think the people must get to know the volunteers early, so that they're not presumed to be coming to visit right at the end. They should know them as a person before they get really bad. (Service Provider)

Again, the ambiguous nature of defining who is palliative and at what point is a referral to the volunteer service warranted, may be influencing the utilisation of volunteers. A particularly interesting finding is that there were contrasting views as to where the focus of promoting the volunteer service and influencing referral rates should lie. While, as noted above, a number of the rural volunteers spoke of the need to promote the service locally, and some local service providers spoke of the importance of improved communication between themselves and the urban-based volunteer service, the volunteer coordinator expressed a different view. This was based partly on the intermittent nature of palliative care clients in rural areas; the urban location of the volunteer coordinator; and also notably on the location of the main source of referrals – predominantly, the urban-based specialist Palliative Care Service. The volunteer coordinator explained the volunteer service's position, describing the link with the urban-based specialist Palliative Care Service as "the critical lynchpin":

Mostly those rural referrals come from the Community Palliative Care Nurses, rather than from the local services and most of the Community Palliative Care Nurses and Social Workers know the sort of information I need and can give me a pretty good referral anyway, because they're use to working with me...It [the urban-based location of the Volunteer Coordinator] may be impacting on the fact that we don't get referrals. Because my experience is very much that if people don't actually clap eyes on you, you know, they forget you're there...So I think that actually eyeballing you is a really, really crucial part of referral, and I don't think it applies only to rural areas, I think it applies to the city as well. But the fact is, that there's only one of me, and I can't possibly be going and seeing those people on anything like a regular basis...So I do rely on Palliative Care Service Nurses and Social Workers being the ones to refer on because they're the ones that...actually, get the referrals from the [rural] nurses because they've seen that there's a need, they've seen the need for palliative care, and then the Palliative Care Nurses have seen that there's a need for hospice, and so that's the link that happens there. (Volunteer Coordinator)

The urban-based volunteer coordinator, therefore, emphasised the importance of directing limited resources for promoting the volunteer service to the urban-based specialist Palliative Care Service through their links with rural service providers, rather than directly with the rural service providers:

So I'm of the view now, I think, that it's probably not a hugely useful use of my time for me to be really working hard at maintaining those connections with the rural nurses and staff, because honestly, I think they forget about you a nanosecond after you've left the room. And I honestly don't think it stays in their memory and they may not see a palliative client for another three or four months, you know, in rural areas where there's not a big population. And so by that time they've absolutely forgotten that we exist, they're getting on with it. (Volunteer Coordinator)

An urban-based specialist palliative care service provider delivering services to both urban and rural populations, expressed similar views to the volunteer coordinator. The service provider elaborated further, questioning the "level of information" rural and urban service providers with limited exposure to palliative clients might require, and suggesting that perhaps the concept of a "central link" for service providers to access services associated with the needs of palliative clients might be an option:

I think...from a GP or a Community Health Nurse perspective, rural or urban, [Volunteer Service] is one of many services that they have contact with. I think their knowledge of (a) what's available from [Volunteer Service] (b) what their selection process is, is probably significantly different from what someone working in the Palliative Care Service understanding is...I'm conscious that palliative care is just a small component of GP and Community Health Nurses' workload...is it important for them to have that knowledge or is it important that they know where a palliative care service is and is willing to access it, in the first instance?...I'm just concerned that even when you give, you ensure that people have the knowledge, if they're not using it regularly, they may not retain it anyway. We're totally focussed on palliative care, but for the GP, he might see three to four clients a year through the Palliative Care. What level of information does he need to know?...Also they may not be terribly comfortable bringing up the concept of a volunteer. And I think yes, just having a central link. And I'm not saying it should be the Palliative Care Service, but...we probably have more exposure to the GPs and Community Health Nurse than the [Volunteer] *Coordinator*. (Urban-based Specialist Service Provider)

Of significance is the finding that the close working relationship between the Volunteer Service and the Palliative Care Service is considered to emanate from the proximity of the services, which assists in fostering both formal and informal links, as the specialist service provider described:

The [Volunteer Service] is an integral part of the Palliative Care Service...

Periodically the Coordinator of [Volunteer Service] does [attend meetings]. I
think the other thing that's quite useful is that because we're co-located [in
Hobart] that often if we have a referral we either hand-deliver it or the
Coordinator periodically stops in. So I think the common locality fosters that
relationship...But I think a lot of the reasons why we work closely are informal
links. It's not necessarily at the moment about the structured meeting links, it's
about I think also the personality of the Coordinator and [his/her] willingness to
come and see us, and we go and see [him/her]. (Urban-based Specialist Service
Provider)

The urban location of the volunteer coordinator constrains the coordinator's ability to formally or informally foster such strong working links with local rural service providers. It is an issue that led the volunteer coordinator to consider how a local coordinating presence might enhance working relationships, which will be explored below under the section 'Coordination at a local level'.

Some rural service providers also highlighted the linking in with palliative services, including volunteers, that appears to mainly occur while rural people are accessing specialist services in the city:

...when somebody becomes terminally ill, usually there's a stronger link to metropolitan services. Like, you know, they might be travelling up for treatment or something on a regular basis. So they're connected to perhaps the [major urban tertiary hospital]. They're probably connected with Palliative Care [Service] and there seems to be a little bit of separation away, like a move away from the MPS [Multi-Purpose Service] a little bit. And if anything the only people that might be connected with, maybe the GP or the Community Nurse. But they might be linked more with specialists in metropolitan, urban areas, or with Hobart. So there's sometimes a little bit of a degree of separation. (Rural Service Provider)

Perhaps talk to the person while they're in [the major urban tertiary] hospital before they come home, or early stages of when they've been diagnosed, find out what family support they have and talk to them about having some volunteer support as well...I think it has to come back to, you know, being linked in with the GP and the Palliative Care [Service] when they're in Hobart or when they're having treatment. (Rural Service Provider)

There were contrasting views about meeting the challenge of the perceived lack of utilisation through possibly extending the role of volunteers beyond solely the needs of palliative care clients. For some, the specialist nature of the hospice palliative care volunteer role was essential, and "refresher" training was proposed as a means to assist with skill maintenance and volunteer retention in the face of limited opportunities to volunteer. For others, broadening the role was considered the means to do so, through expanding opportunities to use some of the skills learnt. A local rural service provider

described concern about lack of utilisation, and promoted role expansion beyond the "guidelines" as a means of addressing the issue:

They had this group of nine people that were really enthusiastic, I mean [the Volunteer Coordinator's] passionate about it and infused that into them as well and then nothing happened. But then we [Service Provider and Volunteer] thought ...maybe we could expand this a bit, not just to palliation, and we could use them at other times...like dementia people that were unsettled and need someone to sit with them, or maybe old people that were...really off the show...until the antibiotics kicked in...And we did try to see if we could get someone to sit with them and [the Volunteer] tried I think to talk to management, but that didn't eventuate. But that's where we would have had a need, to expand it a little bit and keep them skilled up...that was our main point, to try and keep them together and ready...It really wasn't in their guidelines. But when you look at all the training and effort put in to getting those people, and to have them all fired up to do something and then to lose it, it's a pity. It's like Volunteer Ambulance. You know, you can train them up, and then you don't support them enough, or they don't get enough practice, it becomes too scary for them...And I think that's where we went back to maybe using them [Hospice Palliative Care Volunteers] not only for that, trained for that, but broadening it to help rural areas and support people in just acute and chronic little episodes as well. Because otherwise I don't see how we could keep them skilled up, and together and feeling valued and getting some reward out of helping out. (Service Provider)

However, for a volunteer working in a rural area where the volunteer service had been expanded to include the in-patient Aged Care program, the opportunity to do so did not satisfy the volunteer's desire to work with palliative clients. The frustration at the perceived lack of utilisation remained:

In the three, I think it's probably four years now...I have never had a volunteer position down there [rural area] I've had to travel...I had one...and that was it. ...[Volunteer Coordinator] has set up that we can go in and be of assistance to the Aged Care program...It is broadening it absolutely. And I'd prefer not to be involved in that...Because I don't have a relationship with one particular person, and I think that's what I'm after, it's having that one on one relationship, as fulfilling my own self really, that part of it. (Volunteer)

Some service providers expressed the importance of the specialist nature of the hospice palliative care volunteers, which was viewed as "crucial" when working with clients and encouraging their uptake of a referral:

I do think that having a purely palliative care focused volunteer service is crucial. And because I just think that if you were volunteering for Disability Services, I think the skills base is again different, and so that's a huge plus. (Service Provider)

But it was important that it was [the Hospice Palliative Care Volunteer]...there are, sort of like St Johns Visitors and other people from the Church...that could have popped in, but it was someone that she wanted to be sure was comfortable with ...dying...So the fact that they were trained and that they, you know, were able to sit with that fact when lots of people couldn't, was a crucial thing. (Service Provider)

The idea of "refresher" training, to maintain skills in the face of intermittent use, was a recurring theme, especially for those volunteers not operating in other health-related fields such as Volunteer Ambulance or Home Help:

[Some are] honing there skills as well in those other areas. But certainly for people who are not availing themselves of that, I guess they may need refreshers every now and again. And without the opportunity of referrals, you know, we all tend to forget, and if you don't get to practice your skills, they can get quickly depleted. (Volunteer)

I think if someone's been trained to do that particular work it would be really sensible if they were given the opportunity to practice it more, on a more regular basis. But if you haven't got the client need, then they miss out on keeping in touch with their skills, like all of us...what do they have open to them as volunteers to...go back to the coordinator in an organised refresher day? (Service Provider)

Conversely, in response to a volunteer's suggestion of a "refresher course" to assist with the revitalising of skills diminished through lack of opportunity to volunteer, several other volunteers described a sense of futility in pursuing training if there is little or no call on their services:

But we haven't taken up, apart from that once, we haven't taken up the offers of more in-service because it wasn't, not relevant, because we weren't doing anything. We all lead busy lives and so you don't do something that — while it would be enjoyable and valuable — you don't make the sacrifice if you know it's not going to be used. (Volunteer)

Like even the two-day weekend, it's fabulous, but when you're with groups of people who are all involved, and you go down, and you're not, there isn't really very much contact you can make with those people, because you don't belong. (Volunteer)

You feel a bit of a goose, because "oh, no, I haven't had a job in two years". (Volunteer)

This is a particularly significant finding providing some insight into the perceived lack of rural participation in training and volunteer support activities as reported by Yates <sup>42</sup>.

Rather than being foundered on lack of interest or inability to attend due to other commitments, it appears to stem from the frustrations associated with lack of utilisation. Comments from a volunteer coordinator and a volunteer highlight the disparity in views on the subject:

Oh hardly any of them [rural volunteers] come up to town for training, for volunteer support...and I have to say they're not great ones for turning up when I actually go to them either...I guess they're busy? They, perhaps it falls on a day that isn't convenient for them, they've got other things to do. (Volunteer Coordinator)

We don't follow as much training as we could, in fact we know we don't. We don't go down there. If we were active, we'd probably take much more opportunity to attend other training programs. But what's the point? (Volunteer)

The findings from the study highlighted in this section, suggest that one of the core issues concerning utilisation of rural hospice palliative care volunteers where there is intermittent need, is the necessity for a more shared understanding of palliative care. There appears to be a need for increased dialogue across all levels of service delivery and the community, towards consensual understanding of what is palliative care in the local rural community context, and how hospice palliative care volunteering may best be developed, delivered and supported. This may ensure that a volunteer service devised in an urban context may adapt to the particular rural setting <sup>86</sup>.

Claxton-Oldfield and Claxton-Oldfield <sup>99</sup> nominate underutilisation and feeling undervalued by some members of medical staff as common problems confronting hospice palliative care volunteers, as was the case in this study. While the paper serves more to highlight the issues rather than providing direct, proven strategies to address them, it offers some suggestions as how to resolve them, such as more education for service providers about the volunteers and raising community awareness, echoed by some participants in this study. An important part of achieving this is having a shared, common understanding of palliative care, something which O'Connor and Payne <sup>101</sup> however point out, cannot be assumed. As Hudson, Toye and Kristjanson <sup>102</sup> note, there exists a multiplicity of definitions of palliative care, causing some confusion amongst health providers and the community about referrals. This issue surfaced in the study when participants questioned how the needs of the frail and chronically ill elderly might fit within the ambit of referral to palliative care services; and the timing of referral to palliative care, at what point is someone 'dying'?

This study reveals that the rural clients mostly access the hospice palliative care volunteer service once they are connected to the specialist palliative care service, as a consequence of having specialist treatment in the city. This mechanism may be effective for those persons fortunate enough to be accessing specialised services in the city. But what does it mean for the many that do not? As Evans, Stone and Elwyn <sup>85</sup> point out, rural patients have difficulty accessing specialised palliative care services, and do so at a lesser rate than patients in urban areas. Further, Phillips et al. <sup>80 p 372</sup> note that 85% to

90% of the palliative care patient profile is made up of adults with cancer, yet palliative care is also a need for people with non-malignant progressive disorders. How then do these people – like the elderly, with medical conditions associated with advancing age – access the volunteers? Particularly so, if there is contention as to where to direct the efforts for promoting the service – with the urban specialist palliative care service or at the local level?

Much can be learnt perhaps from the study by McKee, Kelley, and Guirguis-Younger 86 p 170 of hospice volunteering with rural seniors in Canada. The volunteers in the study challenged what they considered to be a restrictive view of palliative care as practised in the urban settings, which focused on the more "actively dying palliative clients" to extend the meaning of palliative care to include the "medically frail, slowly dying seniors" which was the need as they experienced it in their communities. In relation to the current study, similar views were expressed by local service providers and volunteers about concerns for the isolated, lonely elderly in their communities, who were unwell at home, or in hospital with an acute episode and requiring support. Rather than possibly being constrained by guidelines developed in an urban setting, perhaps through dialogue with all parties concerned, including the community, a broadened vision of palliative care more in keeping with the needs of the particular community could be developed. The speciality of a palliative care specific volunteer service could in this manner still be retained. It may mean that some form of coordination at the local level would be required to enable this to happen, an area which will be explored below under the section 'Coordination at a local level'.

#### Resourcing and resourcefulness

The expansion of service provision into rural areas by the small grassroots volunteer inhome support services that were the subject of this study appears to be particularly dependent on the goodwill and vision of the services, and especially the dedication of the volunteer coordinators that lead them. While there is acknowledgement by the participants of this study that sufficient funding alone does not ensure success, nevertheless it presents as a resource that has significant bearing on the ability to sustain rural volunteer in-home support. The findings indicate that the political, economic and health environments in which these small services must compete for funding and operate, can be challenging, with the potential to simultaneously inhibit yet necessitate flexibility and adaptability. This section will explore the experiences associated with funding resources as viewed by the volunteer coordinators, service providers and volunteers.

A volunteer coordinator working in the domain of supporting families with children, described the service as emanating from a "very grassroots, very practical approach", which from the outset had to struggle to secure funding and overcome constraints imposed by regulatory conditions. The service was originally founded in 1989 by a group of women working with families in the urban community, who recognised a gap in services, and sought to target families with a baby under twelve months of age, with practical, hands-on support provided through volunteer home visiting. The original

funding application failed, however they were directed to funding under another program (historically Australian/state government tied funding arrangements) which imposed certain conditions, including broadening the support to include dependent children up to eighteen years of age; restrictions on practical support; and declined targeting of families with new babies. Despite the restrictions, the service was able to develop in keeping with its original visionary intentions, as the volunteer coordinator explained:

I did behave myself and I didn't target those families, and yet naturally enough they're the families that automatically came to us...Interestingly enough, now there's a whole push...for families with under threes in particular, and how valuable home visiting is. So my management committee were way ahead of their time, you know, very logical, pragmatic, caring people...We've been a little bit more relaxed in recent years about the real target group...we still managed to be hands-on without doing housework...We started off as one-off funding, but ...we were slotted into ongoing funding, although we still have to do our service agreement and apply for the money...every year. (Volunteer Coordinator)

The volunteer service was funded to support families in the capital city, Hobart, and surrounding suburbs. The demand for local volunteer support in rural areas quickly became apparent, however, endeavours to secure extra funding from existing sources to expand the service to those areas were rejected. It was only as a direct result of the extraordinary commitment of the volunteer coordinator and the management committee, combined with resourceful collaborative efforts with a local rural service provider (not volunteer based) funded under the same program, that the volunteer service was able to extend its service to its first rural setting. With the help of a one-off funding grant, the services jointly developed and delivered a parenting course, with a community capacity building orientation, and parents then had the option of continuing on with the volunteer training (unfunded) provided by the volunteer coordinator. Whilst proving to be a very successful venture, it was not without imposition on the volunteer coordinator, in terms of extra hours of unpaid work; and the service, in terms of the significantly increased levels of reimbursement of travel costs associated with delivering services across great distances in rural areas, as the testament of the volunteer coordinator demonstrated:

Eventually we started training in the [rural] area. We didn't have extra funding to do that, so I did that without extra funding, which, in effect meant that I just worked more unpaid hours...we started off with the core of about eight women based in the [rural] area who wanted to go on and do volunteering...highly skilled, very caring...and it really took off...it [the travel] blew our budget quite badly. That was of quite some concern to the management committee, but we'd started it and we just, we kept on the best way we could. We were committed, but it did knock us around financially...And so what I did learn from that experience too was that, I mean I wanted to expand into other areas, but I knew I couldn't do it without extra funding, I wouldn't do that again. (Volunteer Coordinator)

The volunteer coordinator's next venture into a more isolated rural area involved collaboration with local health services and included one-off funding for an innovative volunteer training partnership with another home visiting volunteer service, also managed from an urban base. Participants were provided with training from both volunteer services, and could choose to volunteer (or not) with either or both services. The model was attractive to the volunteer coordinator because, in addition to being potentially more economically viable through sharing the training costs, it could provide a means of avoiding competition recruiting volunteers from the smaller rural population base in the specific realm of home visiting volunteering with its innate challenge of isolated practice, as was explained:

I quite liked the idea...because in a rural area, there's only so many people who are going to come forward and do volunteering. And only so many again who are prepared to do home visiting. I mean, it seems to me, it's easier to get volunteers to come into a centre-based organisation and help do a newsletter once a month, or do something like that. It's actually, I think, a little bit more difficult to get people to do home visiting, because it's a bit more isolated. They don't have that camaraderie of coming to a centre base with other volunteers and having a cup of coffee and a chat while they do a mail out or that sort of thing. So people who are looking to fill a little gap in their lives, I can see that's more attractive. So in a rural area there's a limit to how many people are going to be interested. (Volunteer Coordinator)

Another volunteer coordinator expressed similar views concerning the less social aspect of home visiting volunteering:

It's not for the social aspect. They don't come to be part of going out once a month or something like that...What I've found is that they want to just go and be with the family, give their all to the family, and go home. (Volunteer Coordinator)

Interestingly, despite the second venture having the potential hallmarks of success with one-off funding for training and promotion in the rural communities, and the emphasis on collaborations, partnerships both between home visiting volunteer services and with rural service providers, it nevertheless failed to achieve its aspirations of establishing a sustainable presence in the rural communities:

We were properly funded this time, and we struggled to get the numbers – even though – the numbers of volunteers. We held a couple of sessions, just information sessions, to gauge...the interest...There weren't many referrals...we had a trickle, just a trickle...even despite promotion in the area and holding a session for the service providers...[volunteers] became just linked in with the core city ones. (Volunteer Coordinator)

While the factors contributing to this situation presented as many and varied, in part, it appears that the under-resourced, fragmented nature of the rural health service system

may have conspired against the best intentions of the collaborative efforts of the people involved. Focussing attention on one particularly important aspect, that of inclusion, Child Health Nurses were described as a primary source of referrals "especially in the rural areas" according to the volunteer coordinator. Their important role is also acknowledged in the literature <sup>103</sup>. Yet this crucial professional link person, in this instance, did not feel included in the vital stage of establishing the service in the rural community, most likely, as the service provider surmised, as a consequence of miscommunication "at a higher level". The service provider considered this omission may have impacted on the outcome of the program:

But I think in the setting up process, that truly Family and Child Health were left off the map and they could have been more involved in that process, which might have been interesting in some of the outcomes...I'd worked there for a number of years and I had a pretty good relationship with the women that were coming to the centre...it might have been more accepted...there didn't seem to be a lot of communication...it might have happened with [urban-based health services] management but it went no further. But I certainly thought that it could have been a bit more successful had people on the ground been involved...But it may have been that it happened at a higher level and meetings weren't on an appropriate day, because you're only working there part-time obviously, and decisions may have been made. (Rural Service Provider)

The value of partnerships and collaborations are the focus of much attention in the literature on health care for both paid and voluntary workers <sup>10 16 71</sup>. However, it is important to be mindful that, as Asthana and Halliday <sup>104 p 464</sup> point out, "the resource constraints facing many rural areas may prohibit the necessary investment required to support such innovation". The concept of developing 'trust' is a vital ingredient in partnerships and collaborations, and Vangelista <sup>16 p19</sup> advocates for volunteer coordinators to devote resources to "face-to-face" education and promotion. Yet for urban-based volunteer coordinators, this poses a daunting task. Not only are they hamstrung by the considerable distances involved endeavouring to deliver a service in a rural area, but they, like the rural service providers themselves and community members, are facing the additional challenges associated with communicating in a working environment thwart with: part-time positions where colleagues may never meet, turn over of staff managed from urban centres, and gaps in service provision between replacements. Some comments from the participants serve to illustrate this point:

You know it's possible sometimes in these positions that become maybe vacant for a period of time, before they're filled. It's possible that [information] could not be passed on very well because of the gap. And I'm aware some of the rural positions have been a bit like that...We [Child Health Nurse and Service Provider] came on different days, so we didn't really meet. Occasionally we might have had a chat over the phone but we never really met each other. (Service Provider)

You see a lot of things have broken down and changed [in the health system]. ...little things like our Child Nurse used to be a local lady, and she prided herself on knowing all the kids names. And somebody obviously in an office somewhere has gone "oh, this is insular" and they've swapped her around...[the Service Provider] would have been really good at referring people, because she'd know the background...there'd be people falling through the cracks just because of that. (Volunteer)

The resourcing constraints for the volunteer coordinator to be there "on the ground" and engaging with local rural service providers and the community – not only in terms of the financial resources for that particular venture, but in the broader context of dealing with the under-resourced rural health system – may have contributed to the volunteer coordinator's sense that for that particular rural community:

..it probably felt to people like it was a top-down thing, "well who said we needed this in the community?" (Volunteer Coordinator)

A matter of concern expressed by participants in the study went beyond the issue of the more obvious element of the poor level of funding, to issues regarding the nature of the funding itself, as one volunteer coordinator succinctly stated:

...I think a lot of it comes back to how things are funded, I don't think it's a lack of willingness in the communities' part at all. (Volunteer Coordinator)

Of particular concern were the seemingly arduous, bureaucratic burdens associated with Australian Government (also referred to as Commonwealth, Federal or National) funding applications and service agreement implementations; the perceived politically driven, short-term, fragmented nature of funding projects; and the apparent favouring of larger, not-for-profit organisations at the expense of the smaller, grassroots organisations, at the centre of this study. Any rural expansion aided by short-term grants or projects ultimately lead to the volunteer services having to grapple with how to meet ongoing costs from the non-expanding core funding sources.

A volunteer coordinator strongly expressed views concerning the unsupportive nature of Australian Government grants:

Commonwealth grants are a nightmare and I very rarely go there because the reporting requirements for the Commonwealth are just horrendous and I mean jumping through so many hoops, it's just not worth it. For the amount of money that we will likely get for anything. They're just not interested in supporting small organisations like us really. It's too big a burden, of admin burden. (Volunteer Coordinator)

The sentiments expressed by the volunteer coordinator are strongly reflected in the volunteering literature <sup>2 44-46 105</sup>. Economic rationalism, it has been argued, has led to the devolution of what is often perceived to be state responsibility for health and welfare

services to private organisations, non-government organisations (NGOs), including increased usage of, or reliance on, volunteers. It has made for a more complex, convoluted health environment with an increased emphasis on partnerships, collaborations, bureaucratisation, and administrative scrutiny. It has contributed to the rise of larger NGOs such as Salvation Army, Anglicare and a proliferation of Australian Government funded projects. The impact on existing, smaller, grassroots volunteer inhome support organisations and their efforts to provide a service to rural communities has been mixed. Wilson, Spoehr and McLean 41 p 3 state that:

...contracting out has most likely favoured the interests of larger not-for-profit organisations who have the resources to win government tenders.

Frustrations were voiced by participants concerning the fragmenting effects of short-term, time-limited project funding:

Like there's a lot of this pilot and short-term funding...all these little tiny bits of money that come in for a short amount of time and something rises from the ashes and then the money runs out and it stops...there's a lot of fragmentation. (Volunteer Coordinator)

Expanding on this, a volunteer spoke directly of the negative impact of a new, larger, Australian Government funded service using volunteers, with a similar brief to the smaller home visiting volunteer service, entering the arena. Being better resourced to promote its service, it was able to dwarf the existing home visiting volunteer service, so that when the new service ceased to operate in the rural area, the smaller service's profile had suffered as a consequence:

[The Australian Government funded project] has got a huge foot in. I think we're more versatile...we're much smaller...we are more flexible on what we will do. ...[The Volunteer Home Visiting Service] has been around for a long time, but a lot of the services that are put in on government grants for a couple of years, you [Service Provider] just get used to thinking "oh that's good, that's where I need to refer this – monies gone, service's gone". So, you know that's really hard, hard to know that you [Volunteer Home Visiting Service] are still there. (Volunteer)

There was also a sense of cynicism expressed about funding initiatives being driven by imperatives for political gain, rather than the genuine needs of the community:

Well, I can be very, very cynical. It's – the funds – are given regarding political shifts. That's always been the case. (Volunteer Coordinator)

That's the trouble, so much political decision-making is made about short-term, flashy, looks nice, you can publish lots of nice looking brochures and things, and that's the end of it. (Volunteer Coordinator)

The views expressed by the participants resonate with those particularly espoused by Mowbray <sup>43</sup> and Menadue <sup>106</sup>. Mowbray <sup>43 p 263</sup> argues that if government was genuine in its desire to "empower localities" it would:

Move beyond the dubious use of pilot, demonstration or trial projects and commit substantial resources on a long-term basis to universal (rather then selectively targeted) programmes.

Both authors share similar concerns with the study participants, about what they term as "boosterist"  $^{43 p 264}$  and "announcement-driven"  $^{106 p 1}$  programs.

A volunteer used an analogy of a wheel and its broken cogs, when describing the importance of a concerted, joint effort amongst service providers in the small rural setting to provide for the community, and their shared experience of feeling unsupported:

It's not just volunteering, and it's not just our GPs, and it's not just the nursing fraternity, or social workers, it's the whole thing. I just don't think any of us are getting the back-up...I also figure that if the cog breaks, that wheel's going to have trouble turning, no matter which cog's fallen off...it doesn't mean how good the volunteers are. (Volunteer)

The opinion is in unison with that of Weiss <sup>14</sup> in her seminal paper on home visiting services supporting families and young children entitled 'Home visits: necessary but not sufficient'. Weiss <sup>14 p 113</sup> stresses the effectiveness of home visiting as being, in part, dependent on:

...the availability and quality within the community of other services for families as well as on the capacity of the families to connect with such services.

The rural environment may, therefore, present as a more challenging environment for urban-based volunteer in-home support services to deliver their services, given the operational realities of being services that "run(s) on the smell of an oily rag" (Service Provider) and the added burden of the fragmented, under-resourced rural services environment in which they seek to operate.

# Section Two: Local rural context and heightened ethical issues

The need for an understanding of potentially heightened ethical issues and perceived rural notions in the local context was a pervasive theme throughout the findings of the study. Exploration of such concerns may be grouped under the following subheadings:

- Resilience: self-reliance and the increased influence of family and friends network;
- Multiple Relationships: increased potential for complex relationship dynamics;
- Stigma: challenging demands on privacy.

There are particular concerns raised in regard to privacy, confidentiality and anonymity, which have great potential to affect the utilisation of rural in-home support volunteers, impacting on the uptake by clients and their families, and the willingness of service providers to refer. They also have implications for volunteer services' processes such as the selection, training and assignment of volunteers.

# Resilience: self-reliance and the increased influence of family and friends network

The notion of resilience at the level of rural individuals, families and communities to support themselves, presented as a recurrent theme throughout the study. For some participants, it possibly negated the need for rural in-home support volunteers, especially for life-long and long-term residents of the community, with supportive family nearby and well-established networks. Changing demographics, however, were viewed as impacting on the nature of familial and network support mechanisms. Resilience characterised by independent, self-contained individuals and families was not always perceived to be of positive value – strong family ties at times were viewed to stymie efforts to access volunteer support outside the family system. The rural experience of having to rely on one's own resources, was viewed as possibly impacting on the receptiveness of the utilisation of volunteers.

There was a strong sense amongst service providers that life-long and long-term rural residents, in particular, were most likely to prefer to use their own familial and network support systems rather than access volunteer support:

Most people with terminal illness...normally feel more comfortable with family or friends...Not to say that there's not a very real place for what this organisation is doing. But I think the majority would, by preference, have family and friends. (Service Provider)

The notion of rural resilience and a linking to reticence to accept volunteer support was seen by some to stem, in part, from the rural experience of limited access to support services:

Well lots of people in country areas try to use their own social networks before they get people that they don't know...Because overall, the people I see are used to doing most things themselves...And some would rather go without than have somebody come...they don't really have the experience of things being there for them. (Service Provider)

#### Another service provider elaborated further:

There are more services in the city and you can almost get instant gratification because you can go to the Doctor, or you can go to the Social Worker or you can go to the Nurse. Whereas in the country, you haven't got those options, so you have to be more resilient and develop skills around, if something does happen, what am I going to do, because there's not a hospital, or there's not someone here immediately, have to think about how am I going to problem solve and how I'm going to manage. So whether, you know, country people are just simply better at doing that, because they've had to. I think that's probably true. (Service Provider)

The notion of rural resilience, with a reliance on self and kinship ties, and independence are matters of interest in the literature concerning rural health <sup>76</sup> <sup>107</sup> <sup>108</sup>. Hughes et al. <sup>108</sup> p question whether self-reliance and informal networks are indeed preferred by rural dwellers, or are a "product of necessity rather than an active choice". For a hospice palliative care volunteer, the particular isolation of the rural community accentuated the need for resilience, but simultaneously did not obviate the need for services, and motivated the volunteer to ensure that such a service existed in the community, offering support:

Funnily enough, because we have such a concise boundary, we've got water all around us, people tend to be more caring of other people on the island, they tend to also know that they've got to look after themselves, and be a little bit more independent than most, because they can't access other things quite as readily. So there is somewhat of a different mindset on the island, and so therefore I think people do – as I think I would like to do – spend as much time as I could in my home surrounds. And I think therefore the support for those people who choose to do so, should be there, should be there. (Volunteer)

For many participants of the study, the primacy of the family in the carer role was a paramount feature of rural dwellers. While mostly portrayed in a positive light, one service provider spoke of the possible negative effects of close family ties in rural communities, pointing out its potential to impact on receptiveness to volunteer in-home support, in this instance, in the domain of supporting families with children:

...there's more of an influence of, from that perspective that "you don't need a volunteer, because we're here, we'll support you"...there seems to be that family, generational stuff, has more impact on the parent...it does seem to be a stronger influence from what mum or grandmother says. (Service Provider)

The service provider spoke of examples where young mothers were always accompanied by their mothers to appointments, which could be interpreted as "supportive" or "interfering":

So if there were a lot of issues that they needed support with, that, maybe mum would say "oh no, you don't need that". So that could impact on their receptiveness towards a volunteer. (Service Provider)

There was a sense of not wanting "outside the family involvement" (Service Provider). Humphreys <sup>78 p 177</sup> in his study of 'Rural Families and Rural Health' also noted the reluctance to seek support outside the family for the impact of stress on families, stating that "it was accepted as something to live through and be dealt with by the family".

There was recognition by the participants in the study that the changing demographics in rural communities might impact on peoples' resilience, and could lead to an increased need for volunteer in-home support. In particular, this related to the movement of new people into the community who may not have family or established networks of support; and the movement of young people away from the community, with the weakening of family support mechanisms for those that remained. The following quotes illustrate the point:

Some haven't got family members, and they haven't got a very good network of friends, particularly ones that have moved here more recently. (Service Provider)

...we're getting people moving here from the mainland, retiring...and not necessarily having family. So in the future it won't be as it was, where everyone had these family networks...And a lot of the young people, more and more...they're moving away. (Service Provider)

One of the things that perhaps is a difficulty is ageing parents, and the children having grown up and for the want of work and/or a relationship they are going off island. (Volunteer)

A volunteer pointed out the need for support not only for people deemed "outsiders" because of their status as newcomers to the community, but also for local people who may be out of step with their informal support network due to the timing of life events, such as being an older mother:

There are still people that have come to this town that aren't from here and I can see them struggling. Because we don't have any support networks for people like that...people have their own little cliques...there's going to be...people that don't have roots here, and yeah, could be a bit stuck. Even people like me who do have roots, because I was an older mum. (Volunteer)

The volunteer pointed out the hardships newcomers could face in their efforts to build networks of support, the reality challenging their expectations of the 'idyllic' rural life:

[The client] decided to move to the country because she thought country people were nice...It's really hard to get into a community like this...if you just move in it takes years. And so it's really isolating. You think you're moving into this lovely little country town where everyone smiles and they all talk. Yeah, they do, they say "hello", but ask them to help and they run a mile. (Volunteer)

It is important for rural volunteer in-home support services managed from an urban base to consider the impact of changing demographics in rural areas, and the effects it may have on peoples' resilience, with the potential weakening of family and network supports. Baker et al. <sup>109 p 6</sup> emphasise the increased likelihood of a "mix" of demographics, including established residents and various "outsiders", with a diversity of needs that heighten the need for health systems to be "flexible and responsive to local needs". Beard et al. <sup>9</sup>, like the participants in this study, also draw attention to the circumstances of older adults in rural communities, who in addition to geographical isolation, may have a reduction in social and family networks associated with the movement of young families to cities. This could potentially lessen their resilience.

Yates and Jochum <sup>57 p 3</sup> confirm the views expressed above by the volunteer, pointing out the potential for "cliquiness and hostility to newcomers" for those rural residents who are not part of the established strong social networks, and who therefore may struggle to form connections. While for those rural residents who are part of strong family networks, but whose needs may still not be met (as described by the service provider above), seeking support outside the family in the form of volunteers may be viewed as non-conformist <sup>9</sup>, acting against the social norm of reliance on self-independence and family. These matters may have a bearing on the willingness or reticence of rural people to seek volunteer in-home visiting support.

# Multiple Relationships: increased potential for complex relationship dynamics

The experience of multiple and overlapping relationships, commonly associated with rural health practice <sup>76</sup> <sup>77</sup> <sup>88</sup> <sup>107</sup> <sup>110</sup> <sup>111</sup>, presented as a significant issue in the study, and was described by participants as having both positive and negative consequences. For some, there was a sense of an increased potential for complex relationship dynamics, eliciting ethical considerations which may not adequately be addressed by organisational processes devised in urban contexts. The concerns particularly focussed on matters of privacy, confidentiality, trust, and the precedence of the role of local knowledge.

Experiences described by volunteers in the study revealed that they invariably knew or knew of clients, and for most, the prior knowledge – particularly if any dealings had been positive ones – enhanced their ability to facilitate constructive working relationships. Further, volunteers credited quality training in building 'professional' practice skills, coupled with volunteer service processes which assisted with the assignment of volunteers and any issues which might arise from that, as contributing to the success of the program, as the following examples demonstrate:

In a rural community people...learn to trust you, as being one of their own. If you stick to the guidelines...and you are professional in your approach and they know they build their trust in you – and you have to earn it –...you can remove yourself to the point, yes, that is professional, I do know them, but I know I can trust her not to say anything. Yes, and they're more likely to open up with someone from their community than with someone who comes up from Hobart. ...The only minus is, is you don't become involved in family feuds, which is very easy. You've just got to shut up, say nothing, and take it as a professional. (Volunteer)

Sometimes it helps [knowing the client] because invariably we do know them...I understand the protocols before a carer [Volunteer] goes in, is that the patient themselves is asked if they would be comfortable to have this particular person there...But certainly in a small community there's a fair chance that we will know them. And if your association with them has been honest and friendly outside this situation, the chances are that they're going to welcome you rather than not...you don't have to break the ice...because of knowing some of their background. (Volunteer)

But you do have to be very careful how you speak and to whom you say what. Because half the people are related to somebody and if they're not they know them. So you tend to always say positive things about people when you're speaking, because it's deadly...when I got to know all these old people [when in the workforce] and then you come back as a volunteer, it's lovely, because they know you. (Volunteer)

Nevertheless, there was acknowledgement amongst participants in the study that the issue of prospective clients knowing, or not knowing, the volunteer could potentially facilitate or hinder the utilisation of volunteers in the rural environment, more so than in the urban setting, where there was less likelihood of multiple or overlapping relationships. A volunteer coordinator spoke of the potentially negative aspects of what was described as "country networks":

They have a country network, I believe that's quite strong. But it also can act against them. Knowing the people who might come to help you could be quite a deterrent. Whereas you've got your critical mass in Hobart, the actual city of Hobart and its suburbs, there's less likelihood that you will know that person if they come to volunteer. (Volunteer Coordinator)

An urban-based specialist service provider, when engaging in conversations with rural clients about the use of locally based volunteers, described the concept as:

...either a selling point or a stumbling point for some people. (Service Provider)

For those people who would prefer not to have a locally based volunteer, foundered on concern that "someone locally is going to know my business", the service provider felt

there was the flexibility within the volunteer service to either try and find a local person that the client did not know, or failing that, utilising a volunteer from another area. There were however logistical concerns with using out-of-area volunteers that would curtail that option.

Local service providers commented on the challenges for both rural volunteers and clients, associated with adapting to the multiple roles played in small communities. Developing skills in maintaining clarity of "boundaries" was viewed as a means for rural volunteers to successfully address the issue:

Small town, mostly people who've lived here for most of their life would know everybody in town. I think perhaps if they knew them too well in a different position, whether they were a shop keeper or whatever, that they wouldn't imagine them as a visitor [volunteer]. I'm sure they are very competent people. (Service Provider)

...[the volunteer] was also her friend, so here we are crossing the boundaries almost, being a small community. And that went quite well. For the worker herself, she's normally very good with her own boundaries, when I have seen her working within the community as a Carer and Home Helper. (Service Provider)

Volunteers' experiences revealed mixed outcomes concerning the nature of the relationship with the client, post the volunteering period. For one volunteer, there were positive, affirming experiences:

I'll see them at the school fair or down the shops or something like that. And it's nice to say "How's everything going?" and they tell me "Oh look it's great now, thanks for your help" and that sort of reinforces what I'm doing too, which is good for me as well. (Volunteer)

For another volunteer, lack of anonymity in the small community and fears associated with being perceived as someone in need of support, meant that meeting clients in other social contexts could be awkward:

I always felt that I had to sneak up to stop people realising that I was sort of helping her. And I think that sort of thing was stopping people instantly, because it was very hard to remain anonymous in such a small community...I run into people that I've been into their homes as a [volunteer] and I'm standing right next to them in the shop, and we don't acknowledge each other, because the only way we could possibly know each other would be through that. So I certainly wouldn't acknowledge them, and they don't acknowledge me, so I feel well that must be the way that they want it to be. So there's this huge thing of not wanting to be identified as somebody who needs help. (Volunteer)

This issue of being perceived as someone in need of support will be explored further below under the heading 'Stigma: challenging demands on privacy'.

Matters concerning the selection, assignment and revealing the identity of volunteers in rural areas presented as a contentious issue for some service providers and a volunteer coordinator. For the service providers, local knowledge of inter- and intragenerational family dynamics held paramount importance. This was in order to manage the potentially complex relationship dynamics associated with providing a volunteer service in small rural communities. A service provider described the difficult nature of selecting a volunteer in a community where families have lived for three or four generations, and where some people are known to not speak to each other:

*I imagine it would be like picking a jury.* (Service Provider)

Another service provider was more forthright in posing rhetorical questions which challenged how an urban-based volunteer coordinator could be sufficiently knowledgeable of complex family dynamics inherent in small communities, without possibly engaging with local service providers in the selection and assignment of rural volunteers:

Where does she get her local knowledge? Because I think that's also part of the selection criteria...But is there any local input into the selection? Without wanting to corrupt the objective process...because in a close knit community...you've got to be aware of some of the dynamics, it's not like we're in the middle of Hobart...But also the capability of the carers [Volunteers]. So I guess there's probably local feedback through the domiciliary sisters [Community Nurses] maybe when they make a selection of who's going to be a carer? (Service Provider)

The issues associated with multiple and overlapping relationships may apply not only to the relationship between volunteer and client but also volunteer and service provider. Unlike in an urban setting, in a rural context the service providers, upon whom the volunteer service is reliant for referrals, are more likely to know the volunteers, and hold views as to their suitability to the role of volunteer. This knowledge could impact on the service providers' willingness to refer to the volunteer service. For the service provider referred to above, confidence in referring to the volunteer service hinged on a preference for some local input into the selection and assignment of volunteers, and also an awareness of the identity of the local volunteers:

I don't know whether a list of the carers [volunteers] has been promulgated...but in the first instance I'd be very interested to see whose names are down, because I certainly have the knowledge of most people in the district...I don't think there would be many [Health Professionals] who wish to refer...without even knowing who they were...And I'm sure if there's a list of ten volunteers I'm sure they would be exceptional, but I'd like to see them. (Service Provider)

For a specialist service provider co-located with the volunteer service in the city, a well-informed knowledge of the selection and education processes was crucial for

establishing confidence in referring to the service. Knowing the identity of the volunteers was not raised as an issue, which could be expected given the less likelihood that the urban-based service provider would have prior knowledge of the volunteers:

I think that having confidence in the selection process of the volunteer service is crucial. Because if I'm going to turn around and suggest another service then I want to have confidence in how they select their...volunteers...I think having had exposure to the education program and selection criteria that they do undertake...is a huge plus...I have no qualms about referring clients to that service. (Service Provider)

There was an acknowledgement by the urban specialist service provider that rural service providers' knowledge of such processes is "probably significantly different". A rural service provider who was only able to attend some partial volunteer training, nevertheless, was exposed to some of the training and consequently the rural volunteers in attendance, which perhaps contributed to a sense of confidence in the volunteers:

I sat in on a couple of part talks that [the Volunteer Coordinator] gave to the volunteers here, but because of my workload I wasn't able to go for the entire one...I have confidence in the people who trained. (Service Provider)

For a volunteer coordinator, there was concern that local service providers might be wary of some volunteers, that their knowledge of volunteers might impact on relationships between volunteers and service providers:

...in some places I think there's a bit of suspicion about volunteers, about the motives and so on...because rural community people do know one another, there are some volunteers that I know that they wouldn't want to have to go see some of their clients...because they know something about the volunteer that perhaps I don't know. And so I guess that might be a barrier too, it might be a problem in terms of relationships. (Volunteer Coordinator)

The volunteer coordinator strongly advocated for the protection of the privacy of the rural volunteers, and for this reason was against a list of volunteers and their details being available to local service providers:

...some rural services said they want a list of the volunteers and their phone numbers and address and I said "No"...I don't give that information to third parties...because I'm protecting the privacy of the volunteers...not all volunteers want everybody in their community to know that they volunteer. Some people like to do it just on the quiet. Not that they're being sneaky, they just don't want to make a big hullabaloo about it. (Volunteer Coordinator)

The findings from this study reveal that the rural experience of multiple and overlapping relationships can serve to be both a hindrance and a support for rural volunteer in-home support, in terms of working with clients and also service providers. The nature of dense

social networks in rural settings means that, as with rural health professionals, the boundaries between personal and volunteer roles are not as distinct as in urban settings <sup>112</sup>. Notions of privacy, therefore, may be more challenging in the rural context, not only for clients but for volunteers also. Rural service providers, because of their more intimate knowledge of community dynamics than their urban counterparts <sup>111</sup>, may prefer to have more direct input into the selection and assignment of volunteers. Such opportunities may enable them to have increased confidence in referring to the volunteer services with urban-based management, and thus help overcome "suspicion" of volunteers. If this were the case, however, care would need to be taken to ensure diversity amongst the volunteers to avoid social exclusion <sup>60 61</sup>.

The literature encourages the use of local service providers in training and support services for volunteers<sup>87</sup> and the offering of education sessions for other health professionals about the roles of volunteers <sup>31 99</sup>, as a means of fostering and promoting healthy relationships between volunteers and service providers. However, as previously discussed, the opportunities for the small urban-based volunteer in-home support services to reach out to workers in small rural communities, in any sustainable form of partnerships and collaborations, are exceedingly rare under current conditions despite their concerted efforts.

Meeting clients in social situations outside the volunteer role need not be an issue, but can be awkward for some. Green, Gregory and Mason <sup>112 p 457</sup> refer to "active negotiation" as a common rural social work practice. As in the example described by the volunteer, the practice refers to negotiating with clients about how to deal with meeting in social contexts outside the formal role, such as not acknowledging clients until they have initiated acknowledgement. Such ethical dilemmas are more likely to occur in rural practice. Information about dealing with such dilemmas, however, is often urban biased, therefore education and training on this subject delivered by the urban-based volunteer in-home support services may need to be expanded to incorporate a more rural focus, such as developing strategies in concert with clients (Epstein, Overstreet and Frick, 1997, cited in <sup>110</sup>).

#### Stigma: challenging demands on privacy

A recurring theme revealed by the analysis of the interviews was the impact of stigma. The concept of stigma centred on the perception by participants of clients' fears of being identified as someone needing support, thereby contravening the rural 'cultural norm' of self and family reliance, as discussed in a previous segment. Volunteer in-home support in the small rural community context, presents enormous challenges for upholding the notions of privacy, anonymity, confidentiality, and trust when rural volunteers are literally seen to be visiting clients' homes. This may heavily impact on rural clients' preparedness to accept a rural volunteer into the 'privacy' of their own homes, a condition which rural clients may guard more keenly. Stigma may also impact on rural volunteers themselves, with overlapping relationships with service providers having the potential for rural volunteers being cast more as a person in need themselves rather than as someone suitably credentialed to be a provider of support to others. There may be

links with the move towards the 'professionalisation' of volunteers (Warburton and Mutch, 2000, cited in <sup>61</sup>). While such a move may be beneficial for assisting the credibility of volunteers in formal health care <sup>113</sup>, it potentially may also have the detrimental effect of marginalising some people <sup>61</sup>. Rural in-home support volunteers may find themselves being co-opted into the biomedical model of health care, with an overemphasis on 'professional skills' and less on the human relationship aspects of caring, for which the small grassroots volunteer in-home support services are renowned <sup>113</sup>

#### Increased exposure to community scrutiny

Experiences described by volunteers vividly illustrate the perceived stigma associated with seeking support as a sign of weakness in their rural communities. The provision of support through the mechanism of visits in the home potentially adds to the complexity of the issue. The oft described experience of residing in small rural communities as like living in "fishbowls" <sup>110 p 500</sup> means that rural clients are more readily identified as recipients of support when in-home support volunteers are seen to be visiting their homes. The following volunteer's experiences illustrate these points:

There's the stigma of reaching out for help...people knew I was involved, even though I hadn't actually told anyone, it wasn't hard to work out...whoever was fronting up at the Medical Centre on Monday morning obviously was involved with these organisations...There was a lady I went to visit, and people in the community knew that I mustn't have known her any other way, so therefore this woman must have been experiencing problems...you can be character assassinated in a town like this for showing weakness. (Volunteer)

## Other volunteers shared similar experiences:

...I think some people in a small community are a bit worried that people will think "What will other people think if they know I need help?", you know, it's an admission of failure or something on my part...I could see that could be a barrier for some people...that would stop clients coming forward and asking for help...And the fact this is a small community and everybody knows everybody... "What are you doing with her at her place?" kind of thing. A couple of times I've had to sort of say [when asked] "Who are you, what are you doing here?" and I've said "oh, I'm just a friend, I'm just visiting" that sort of thing. (Volunteer)

I've had a lady...who was very aware of not asking for help because...she felt that she couldn't ask for it, because people, well, they can be pretty hard really, because they see it as she can't manage. (Volunteer)

Service providers' observations contributed further to exploring the issue of stigma. In particular, the role that the increased visibility of rural clients might play in potentially rendering them more prone to the stigma of being labelled as not coping. It was not

necessarily an issue of volunteers intentionally breaching confidentially, but a negative consequence of the lack of privacy in rural communities:

...everyone's very aware in these small communities about who people connect with...questions rising up in the ether about why was this person connecting with this person, and then this person knowing that this is a volunteer and so then this family becomes kind of labelled as a family with high needs, and not coping, a not coping family. Not concerned about the volunteer gossiping...but I think it's problematic in a rural community, that people are going to cross paths, it's just the nature of them. (Service Provider)

Other service providers shared these concerns, and commented on the primacy of the privacy of the home in rural communities, which might contribute towards a reluctance of rural people accepting volunteer in-home support:

...there's this thing about having a problem and needing support. But sometimes for rural people they're very conscious of the fact that they don't want to be seen to be struggling...You may not get the formal referrals in a rural community... because of some of that stuff around...the relationships...it's about obviously saying that you need support, and everybody knows "this is somebody who is probably one of those volunteers going into somebody's home". (Service Provider)

Another service provider also commented on the heightened need for privacy of the home, borne perhaps from the general lack of privacy in rural communities. The service provider described the importance of rural people "paying their respects" to dying rural residents. The service provider suggested that this may be something that is more conducive to a formal care environment, whereby, the privacy of the home can be maintained and staff can assist with the monitoring of the number of visitors to suit the patients' and families' needs:

...it's just been my experience that up here everyone's very private. Like they know everything that's going on before you do, out in the town, but everyone's very private about their own homes. So I think it's something that they protect more and more by living so closely together. But we see someone here [in the rural in-patient facility] that might be in the hospital part, and palliative care or the nursing home or hostel, and visitors will come and go all the time. So they allow that...and you're sort of trying to strike a balance, between too many visitors, but it's so important for [the patient] to have them and feel that support for [the patient's] family. But they are cobbers or they are farmers that have lived in the district, you know, old gentlemen paying their respects. And even though they're not close, they need to do that. And [the patient] feels good about that. (Service Provider)

Some service providers emphasised the importance of a strengths approach <sup>114</sup> as a means of assisting people overcome stigma associated with accepting help. Such an

approach focuses on empowerment, through recognition of peoples' strengths and resources and the structural and cultural impediments which may hinder them. A specialist urban-based service provider urged caution with the choice of language when engaging in conversation with potential rural clients about the concept of a volunteer. There was a recommendation for individually targeted, positive framing of the suggestion, in a manner which did not diminish the sense of resilience:

It's a personalised approach, not a stock response...I think...a huge hurdle for a lot of people [is] that we should be able to cope with this, we should be looking after them...I think the language is very important, how we actually even broach the concept of a volunteer. And I tend to use words like 'supplementing'... emphasising that this is just to help out rather than take over, replace...it's almost like it's more of a positive thing...it also doesn't have to be something that's permanent...like with all aspects of palliative care, the ultimate decision is the clients' and the carers' and they can change that position at any point. (Service Provider)

In addition, another service provider spoke of the need for creative responses to the utilisation of volunteer in-home support in rural communities where home visits may be perceived as intrusive. In this instance, a volunteer in-home support service other than the two identified in this study (an Australian Government funded project) which also focused on supporting families with children, chose to incorporate home visiting volunteers into existing peer group activities for families, after attempts at home visiting failed:

...we had all these volunteers all ready, trained, ready to go. We just didn't get the referrals. People were not interested in somebody that was from this local area...coming in to provide support, and also around the fact that they didn't want to be perceived as needing support and having a problem...they weren't keen to actually have somebody come into their home...What was anticipated didn't [happen] it shrivelled...So we've had to be a little bit creative about how they've been able to utilise some of these trained up volunteers...like in a strength-based model...it's the last thing you want to do as a parent is to be seen as not being able to cope. (Service Provider)

In an effort to support rural clients with avoiding the stigma of literally being seen to have a home visiting volunteer come to the home, and to ensure that the volunteers could be active and valued, the volunteers were invited to participate in existing community support groups for parents and children:

...volunteers [were] invited to those [group] sessions where they could just connect, informally, like in a relaxed manner. Sitting on a couch having a cuppa and talking about, you know, some of the trials of parenting. So that they would still be developing the connections and feel like their training was valued in some way. (Service Provider)

The service provider emphasised the importance of the informal nature of the group setting as a means of avoiding the stigma of being individually labelled as someone needing help, and taking a more whole-of-population, primary health, education approach:

So it's around us getting more creative about how we can get the message across without making people feel like they're, they've got a problem, a label or whatever...if you ran any particular groups that...had any sort of stigma attached to it, you just wouldn't get the participants...what initially started out as a volunteer project around training up volunteers and linking families to them has now developed into utilising those volunteers in some of those [groups] but also getting a parenting resource library up and running...stepping out of the square about how you can actually get your message across around education, around parenting, without pointing the finger at anybody. (Service Provider)

Weiss <sup>14 p119</sup> referred to the possible experience of intrusion as the "down side" of home visiting, and pointed out the use of peer groups as a means of addressing it or further adding support. However, as a volunteer coordinator in this study described, broadening the service to include community education in a group setting, in this instance on the sensitive issue of suicide prevention, does not necessarily resolve issues of confidentially and stigma in small rural communities:

I got one-off funding and opened it up to the whole...community, as well as the volunteers...and they stayed away in droves. And...when I discussed it with the volunteers, they thought it was probably about confidentiality again. "If I go to this, someone, she lives over my back fence, and she might think that my son's thinking, is suicidal"...Which you don't think about when you're doing the urban stuff. (Volunteer Coordinator)

Of particular note, was the volunteer coordinator's observation that while volunteering appeared to flourish in the rural areas, it was more likely to occur in the larger, organised community services arena than one-to-one home visiting volunteering. Where one-to-one volunteering did occur, it tended to be in a structured setting such as an aged care facility rather than in rural peoples' homes:

I think...in rural areas...a lot of people are very active in the volunteering community, as in sort of Fire Brigade, Ambulance, Red Cross and that. But not in the, like it seems to me, that a lot of rural people do a lot of volunteer work, but not the home visiting...Because I know...a lot of volunteers were already doing stuff at the Old People's Home, things like that. But the actual home visiting is where there doesn't seem to be too much happening at all. (Volunteer Coordinator)

The findings from Onyx, Leonard and Hayward-Brown's <sup>45 p 131</sup> study of volunteers' experiences in the provision of human services in regional New South Wales support the volunteer coordinator's observations. They noted that there is a:

...stronger picture of individual, one to one connection with clients within urban volunteering as opposed to the more collective nature of rural volunteering.

It was claimed that rural volunteering was characterised by:

...the creation of a necessary service for the community as a whole...a great deal of volunteering was oriented towards the public realm of the wider community <sup>45</sup> p 131, 135

The types of other volunteer activities that the participants in this study were engaged in would support this view, for example Meals on Wheels, Volunteer Ambulance, SES, Hospital Advisory Committee. It may be the case that there is more community acceptance in rural communities of the need for individual or family support in times of crisis, or at particular life-stages such as the frail elderly requiring assistance with meals, than with the general pressures associated with transitions in life experiences such as commencing parenthood and facing the end of life. The findings from this study suggest that concerns around stigma stemming from literally being seen in small rural communities to have a volunteer visit the home, and thereby being identified as being a person or family in need, may be hindering the development of rural volunteer in-home support services. A volunteer's perceptions would appear to support this view:

...when there's a real crisis the community will really help, but it's only sort of like for a week or two though. It will be intense help you'll get at the time if your house burns down or...if your partner dies...and then it just drops off. And I think it's because we just...lack the know-how of how to carry it on...and it's this country "oh, we can't be weak, just sort of get on with it". (Volunteer)

The results of this study would support the views expressed in the rural health literature that stigma and fears about confidentiality may act as a barrier to health care, in this instance, rural volunteer in-home support <sup>77</sup> 104. The results from a study by Warner at al. <sup>77</sup> p <sup>32</sup> resonate with this study, when they conclude:

...small communities possess distinct features, clinically and ethically, and... constructive adaptations in smaller communities need to be better understood.

Rural volunteers "too well known" (Volunteer)

It has been argued that volunteering "has always shown signs of marginalisation especially with regard to the paid workforce" <sup>61 p 34</sup>. It may also be the case that in some instances "stigma and its corollary, social exclusion" <sup>115 Chapter Two p 17</sup> applies not only to potential rural clients, but to rural volunteers themselves. The solitary, independent nature of the practice of providing volunteer in-home support necessitates a high level of functioning of the volunteers, even more so in the isolated rural environment. Overlapping, multiple relationships characteristic of rural communities, means that volunteers may be known to service providers both as clients and as volunteers. This

more intimate knowledge of rural volunteers has the potential for some volunteers to be judged by local service providers as suitable or unsuitable for the volunteering role. If some volunteers are deemed unsuitable, it may hinder the referral of clients by service providers to the volunteer in-home support services. A volunteer coordinator believed that in a particular rural area where an outreach service provider encouraged some local clients to train as in-home support volunteers, the inclusion of such clients may have been a contributory factor to the perceived lack of success of the volunteer in-home support service:

...the [Service Providers] thought that it would be good [if] some of their clients could become volunteers. They had clients who they could see would benefit from being involved in something. And philosophically I agree with that and embrace that. However, it didn't work...and I think...that possibly, that's why we didn't go so well. Because, quite a few of the volunteers were, had very high needs themselves, and to put them in the position of home visiting to support other families, well just didn't work. They would have been far better to have had a centre-based volunteering organisation situation where they could have been monitored closely, I mean, and feel they've done something worthwhile and not be isolated...And some of the other people were very capable and highly competent and could have and would have done great work had we had sort of the referrals. (Volunteer Coordinator)

The volunteer coordinator sensed that in this instance, there may have been a lack of confidence in the volunteers amongst some local service providers. This may have been due in part to the volunteers' dual identities as both volunteers and service recipients of support; and their possible lack of discretion with openly identifying themselves in the community as volunteers, as the volunteer coordinator explained:

...I think what happened is that service providers got to know who some of the volunteers were, and thought "oh well, I'm not going to refer anyone there, because if that's the calibre of volunteer"...I suspect that some of the people ...were very quick to be telling everyone "I'm a volunteer with..." some of the people doing the course didn't have the capacity to really understand about that...it's fine to say you're a...volunteer, but there's an appropriateness around it. (Volunteer Coordinator)

A service provider commented further, querying the possible tensions associated with the changing roles and status of the rural in-home support volunteers in relation to their dealings with local service providers:

...the service providers in those [rural] communities are usually people living in those communities, like nurses...I was wondering how those relationships then were going to sort of crossover with these volunteers and how these volunteers saw themselves, as whether they then saw themselves as service providers or clients, you know, there's a whole lot of role stuff. (Service Provider)

The service provider questioned whether rural in-home support volunteers would be afforded equality with other paid service providers, or whether they might be perceived as having a lesser position in a "hierarchy":

...whether there's a hierarchy, you know. Like I think the nurses, by living in the community and within these smaller Community Health Centres that are rurally based, that they play a major role, and they take their status, their status is really important to them, and just how they were going to crossover with these volunteers, who would start to see their role as important...like what equality? (Service Provider)

A volunteer declared a "breakdown" in the relationship between paid staff and volunteers as a contributory factor for the apparent lack of success of the rural volunteer in-home support service. Educating paid staff about volunteers, with an emphasis on the 'professional' skill of the volunteers, was proposed as a remedy:

...ongoing training for staff to acknowledge that the volunteer can be trusted, is professional enough to know what they're doing and that they are not threatening. The staff, not the client, that's our breakdown here. (Volunteer)

For another volunteer, service providers' knowledge of his/her personal health status was perceived to be a possible barrier to being called upon to volunteer:

...I feel that I'm too well known. Because I feel that if there was something, like one of the sisters say... "she's not well, no we'll get somebody else"...not that they've said anything...because they know, I'm in and out [of hospital] quite often. (Volunteer)

The findings from this study suggest that the possible stigma at times directed at individual rural in-home support volunteers, or indeed volunteering in general, may in part stem from fundamental tensions about the place of volunteers in the formal healthcare system. This study does not seek to focus on the debate concerning the justification for professional, para-professional and volunteer home visitors, but does acknowledge that some tensions exist (Simpson, 1996, cited in Taggart, Short and Barclay <sup>34</sup>), and that the findings in this study suggest that such tensions may play a part in hindering rural volunteer in-home support.

Volunteer in-home support as a strategy for delivering a support service, whether in the arena of hospice palliative care or supporting families with children, recognises the primacy of the relationship of the volunteer with the client as a major component of the experience <sup>103 113</sup>. Volunteering provides a means for the community to "reach into the formal care system" <sup>113 p 144</sup>. In doing so however, volunteer services may find themselves at odds with the 'professional', 'expert' dominance of the biomedical model of health care. The shift to the 'professionalisation' of volunteer practice as a means of affording more equal status with health professionals, may jeopardise the ability of volunteers to focus on the paramount importance of forming meaningful relationships

with clients <sup>113</sup>. Moreover, Warburton, Oppenheimer and Zappala <sup>61 p 37</sup> argue it may potentially impact on the marginalisation of certain groups in the community:

...the old, the young, those from a low socio-economic background, the culturally and linguistically diverse, the unemployed.

The experience of the volunteer in this study of the perceived breakdown of the relationship with staff, is similarly reflected in a study of palliative care volunteers by Claxton-Oldfield and Claxton-Oldfield 99, where volunteers felt most valued by the patients and families, and least by professional staff. There is a focus in some of the literature on volunteering of raising the status of volunteering through the improvement of management processes akin with professionalisation, with caution to simultaneously ensure inclusive practices <sup>61</sup>. The volunteer in this study also emphasised the promotion of the "professional" aspects of the volunteers to build improved relationships with service providers. However, perhaps the elevation of the significance of the supportive interpersonal relationships afforded by well-trained and supervised volunteers dedicated to contributing to their community could be equally – or more — important a focus than on the 'professional' attributes <sup>113</sup>. An over-emphasis on the 'professional' qualities of the volunteers may only add to the tensions where volunteers' contributions, as 'lay' persons, risk being viewed by service providers as merely operating with "watered down versions of proper professional medical knowledge" (Stainton Rogers, 1991, cited in <sup>115</sup> Introduction p 5), rather than being valued and appreciated in their own right. More discussion, transparency and possibly joint partnerships involving selection processes and organisational support mechanisms between volunteer coordinators and service providers could perhaps assist with ensuring a diversity of volunteers, and assuage concerns that might otherwise stigmatise certain volunteers. This is of particular concern in small rural communities where the volunteer coordinators are based in the city and most likely do not know the local volunteers, as opposed to the local service providers whom most likely know, or know of, them.

#### Section Three: Coordination at a local level

The establishment of some manner of locally based coordinating presence for the rural volunteer in-home support services was a theme repeated by many participants across the spectrum. The need for such a strategy and the various forms proposed, stemmed from experiences related to:

- Fostering connection to the local community and volunteer service;
- Fostering increased visibility of volunteer in-home support services in the local communities; and
- Fostering a comprehensive response to rural needs.

A local coordinating presence was also espoused as a means to foster a better understanding of local, rural circumstances by volunteer in-home support services managed from an urban setting.

#### Fostering connection to the local community and volunteer service

A strong feature of the study was the high level of connection and commitment of the rural volunteers to their respective volunteer in-home support service, and to their communities. This, in some cases, included a willingness to extend their roles beyond those established in the urban environment, to include some promotion and initial home visits/assessments. The time and financial constraints imposed upon urban-based volunteer coordinators associated with the provision of rural services also contributed towards the innovations, as a volunteer coordinator's comments demonstrated:

At the ongoing monthly meetings there would be a full contingency, everyone would turn up...I never had that in the city, they were so committed and were so happy to take brochures around for me or do any of those extra things...because we were so busy down there, what I did do was ask who would be prepared to do initial home visits for me, because I couldn't just do them when I was down once a month...So we did have someone...she knew the group, so she could actually even go ahead and link up and I gave a lot of support to her. (Volunteer Coordinator)

...there's obviously a lot of real energy and commitment to a community in [the rural community]...they have something really quite valuable in terms of a community sort of spirit there. (Volunteer Coordinator)

A volunteer coordinator reflected on the impact of urban-based management upon rural in-home support volunteers. It was suggested that such an arrangement could contribute to an uneasy sense of "divided loyalty" which could perhaps be remedied by creating some form of local coordinating presence, to foster a sense of belonging:

...I think in rural areas where you run a service like I do – that's based in the city but operates in the country – their loyalties are a bit divided. That they're

loyal to [the Volunteer Service] but they're also loyal to their community. And it's kind of when the two don't quite meet, quite match, they don't quite know where they should be...if you could locate it [the local coordinating presence] in their community, there wouldn't be that sense of divided loyalty. There would be that sense of they belong here, they belong to this, they belong to this organisation. (Volunteer Coordinator)

The sentiments expressed above were a considered response to dealing with tensions which were highlighted by the volunteer coordinator in relation to concerns about perceived "gate-keeping" by rural service providers. It was speculated that this may have been a reaction to a perceived lack of understanding by the urban-based service of the rural context:

I think there is a level of gate-keeping by rural staff. They see [the Volunteer Service] as a city-based organisation because I'm in the city and so they want to keep things kind of in their area. Despite the fact that volunteers are in their area, you know, they still see that it's an external organisation coming in from outside, because it's me, you know, or it's [the Volunteer Service]...but maybe therefore I don't have an understanding for what's going on for these people. (Volunteer Coordinator)

A volunteer's comments reflected the volunteer coordinator's concerns about perceived lack of understanding, and repeated the call for a form of locally based coordination:

It's very hard in the fact that our organisational management comes from Hobart. There is a big breakdown between Hobart and our area...I guess that the organisation has to refocus...and acknowledge that they may have to change to accommodate [the rural area]. Specific areas have specific needs, and I don't think that they can manage it from Hobart and give people the same empathy and feeling they had if they had someone here. (Volunteer)

A statement in the report by the organisation Action with Communities in Rural England <sup>68 p 6</sup> may be particularly relevant to this analysis, highlighting the importance of the role of empathy, and a reminder that remoteness cannot solely be measured by kilometres:

...perceptions of remoteness can be a result of lack of empathy with potential user groups as well as physical distance.

This is especially significant in the island state of Tasmania, where distances measured by kilometres travelled or time taken may be markedly less than by mainland standards. It is not just a matter of a coordinator being based in an urban centre distanced by a certain number of kilometres or time taken to travel, but also the possible distance resulting from a sense of cultural divergence. There may be different perceptions in rural and urban settings of the meaning of relationships with family, with the community, and the offering and acceptance of support.

Warne and Dietrich's <sup>46 p 26</sup> project on volunteerism in rural communities similarly found that volunteers with headquarters outside the region were also concerned about:

...lack of meaningful communication, lack of understanding of issues and lack of control and involvement.

In the reported instances, there had once been local ownership, which may have exacerbated their concerns. The commitment and loyalty of rural volunteers were also a feature of the study.

## Fostering increased visibility of volunteer in-home support services in the local communities

A local coordinating presence in rural communities was promoted by some participants in the study as a means to increase the visibility of the volunteer in-home support services, for the benefits of keeping the community and service providers informed, building relationships with them, and strengthening support for rural volunteers. The intention was not necessarily to replace the urban-based volunteer coordinator role, but to engage a locally based person in an ancillary, intermediary role and infuse local relevance. Others encouraged a more active role for volunteers in the coordinating role of service promotion.

A volunteer coordinator considered rural volunteers to be disadvantaged by the lack of a local coordinating presence visible to service providers, and contended that funding for such a role was necessary to ensure the service was "viable" in rural areas if the service were to expand into other rural areas:

I think that our volunteers in rural areas definitely have less advantage in the sense of not having somebody there...a presence if you like, in their area...and the service providers seeing that...What we have to look at is the committee making a commitment to broaden the service, making it more viable in rural areas...I think because of a lack of funding, there is no doubt in my mind that's why...people don't have access to it in [some] rural areas...They're [the local coordinating presence] on hand, we're not talking big dollars here, I think two days a week would be all right for the rural area. (Volunteer Coordinator)

A volunteer described the position of a local coordinator as assisting with the provision of a "satellite" service to enhance working relationships between volunteers and service providers, yet still managed by the volunteer coordinator in Hobart:

If we had a coordinator in the area...someone trained by the staff in Hobart, who is in the area, who can keep that circle of understanding between the volunteers and the paid staff...and it can still be managed from the greater Hobart, but we're a satellite off it...a person from the local area could be a great asset. (Volunteer)

A service provider suggested that local awareness of the volunteer in-home support service could be improved if there was a volunteer with the ability to be "taking a little ownership of it and promoting it" through such avenues as the local community radio, gazette or addressing service coordination meetings. However, a volunteer in that area expressed concerns about taking on such an active role of promoting the service, beyond arranging material displays when requested by the volunteer coordinator. Promotion was viewed as the volunteer coordinator's role. Whilst the volunteer felt capable of more actively promoting the service – if given the training – the absence of that aspect in the training schedule meant that the volunteer felt it was not part of the volunteers' brief:

...I didn't see that as part of my job description...to promote [the service] as a volunteer...to actually speak about our role...make contact with various agencies there...it wasn't in the training, I can do it, but it wasn't in the training as a volunteer, so I haven't. (Volunteer)

The more high level promotional activities of the volunteer in-home support services, such as meetings with service providers, public speaking and addressing the media, appear to be the domain of the urban-based volunteer coordinators. In the urban setting, this role is more readily achievable, however, the isolated rural environments pose more of a challenge for urban-based volunteer coordinators to successfully do so. It may be the case that through adopting a capacity approach to working with volunteers as promoted by Creyton <sup>50 p 6</sup>, rural volunteers with an aptitude for the task could be provided with additional training to undertake a more active promotional role:

By focusing on the capacity of individuals and exploring how they can assist, we can identify a range of additional ways the organisation can achieve its goal.

## Fostering a comprehensive response to rural needs

A volunteer coordinator's concluding remarks intently focussed on an ideal model of a centralised, rural-based volunteer coordinating presence. It was envisioned that a centralised, coordinating presence in the rural community could transcend the likely fragmentation and multiplicity of volunteer in-home support service delivery which could arise if individual services were to consider each having its own rural coordinating presence. It could also potentially provide more comprehensive assessment and access to volunteer in-home support and other volunteer services to meet the often multiple and changing needs of the members of rural communities, in a manner which would be specific to the particular rural community. A commitment to permanent, ongoing funding for a locally based volunteer coordinating position was considered essential to ensure the sustainability of rural volunteer in-home support. There is much support in the literature for united action for integrated and coordinated health care <sup>7</sup>, arguably applicable to both paid and voluntary workers, with consideration for multiskilling, generic training and collaborative partnerships <sup>31 66 68 71</sup>.

A volunteer coordinator promoted the concept of rural-based volunteer coordinators, providing a model of a centralised, locally managed group of rural volunteers which potentially included the following key features:

(i) a "consolidated place" for the support of a broad range of rural volunteering services:

if...they could employ somebody...as a community liaison officer who could... genuinely support core volunteer groups...across the whole spectrum field, whether that's community arts...health promotion...hospice volunteering...early support for parents, whatever it is, that there is somehow a more kind of consolidated place that that can happen from. (Volunteer Coordinator)

(ii) a sense of "loyalty" to the rural community and service with organised access to specialist training in the rural localities by urban-based volunteer services:

They [the rural-based Volunteer Coordinators] could manage those volunteers in that area. But [the urban-based Volunteer Coordinator] goes and gives them specialist training about hospice...and maybe somebody else goes and gives specialist training about working with people with Alzheimer's or whatever it is. But that there's a core group of volunteers who have a loyalty to that area and that central person who is there or the central organisation that runs that, and that's where their loyalties lie, and that's where their loyalties will lie. (Volunteer Coordinator)

(iii) avoidance of "fragmentation" of services caused by a series of short-term funded programs which risk collapse at the cessation of the program, and promotion of "sustainability":

There's a lot of fragmentation... if those things could be drawn in...centralised in the area, in the community...funded in a way that...has some sustainability about it...some long-term commitment to providing ongoing funding. (Volunteer Coordinator)

(iv) a central point of contact for local and external service providers, and the community, providing increased visibility and avoiding confusion and uncertainty:

I don't know who I should contact in [the rural community] and if the rural areas are contacting people in the city to organise volunteers that might be rural volunteers but are managed from the city, they don't always have tabs on who the person is...to contact...so the community nurses know that they ring 'Sue' because she's the coordinator of volunteers for this area. (Volunteer Coordinator)

(v) notably, ensuring a more holistic assessment and individualised attention to rural peoples' complex needs; with an ability to transcend organisational borders and avoid

multiple assessments through access to a "pool" of volunteers; and operate in a community specific manner:

[The rural-based Volunteer Coordinator] can get a volunteer appropriate for this family...you've got somebody who's got that kind of pool of people, they can then assess. They can talk to the person, they can do what I can't do, which is to go and sit in somebody's living room and say "what can we do that's going to be the most helpful for you?"...So there's somebody who can engage with that family and find out what their needs are, because peoples' needs are seldom one thing...it can provide a community with what they need. (Volunteer Coordinator)

At the centre of much of the findings and analysis from this section, and flowing on from the antecedent sections, is the importance of the consideration of the local rural context when urban-based volunteer in-home support services seek to provide a service in rural areas. Some form of locally based coordination can be a significant means of achieving this. Caution is called for in the literature when applying policies and practices devised in urban settings to rural situations <sup>86</sup>. Martens <sup>75 p 5</sup> contends that "the overarching bias of urban views [is the] flaw of design that assumes transferability". Local participation in the development, implementation and delivery of rural volunteer in-home support services is crucial, and may best be achieved where there is coordination at the local level, as Alston <sup>116 p 199</sup> cogently asserts:

...rural needs are different, and in developing new models of care that empower communities, planning and coordination of rural health service delivery should occur as close to the ground as possible.

The findings in this study of the importance of some manner of local coordination or management with strong links to urban 'specialist' volunteer in-home support services are in unison with those of the Hume Regional Palliative Care Caring Communities project <sup>79 p 3</sup> which found that:

**Local** ownership, recruitment, training and management of palliative care volunteers strengthen the capacity of rural communities to provide an accessible service of which local communities are proud. To sustain rural palliative care volunteer services they need **funded** management and coordination...**linkage** into palliative care services [emphasis added].

The findings from Warne and Dietrich's project <sup>46 p 6, 7</sup> similarly posed options for the future in line with the suggestions made by some participants in this study, notably the concepts of a possible "central pool of volunteers" and a "Volunteer Resource Centre – a 'one stop shop' for volunteers and volunteer organisations". There are repeated calls in the literature for more 'collaborative', 'joint', 'cooperative' volunteering efforts, with consideration of 'merging', 'pooling' and 'umbrella' measures as a means of fostering more sustainable rural volunteering, including generic training <sup>31 48 49 71</sup>. Volunteer services such as Wimmera Volunteers and the Lyell McEwin Regional Volunteers Association <sup>31 p 42</sup> coordinate multiple volunteer services and enable volunteers to

expand their experiences through "sharing volunteers' between organisations". The possible benefits of a coordinated, central pool of rural in-home support volunteers, with the option of multiskilling, means that rural clients could potentially avoid having to accommodate visits from multiple volunteer in-home support services, thereby perhaps going some way towards allaying concerns about community exposure and intrusion into the privacy of the home. For example, if a rural community member with a history of mental illness is also diagnosed with a palliative illness, he or she may benefit from an in-home support volunteer who has accessed specialist training with the Red Cross Mates <sup>117</sup> program and hospice palliative care. In addition, multiskilling could potentially extend opportunities to volunteer, with in-home support volunteering in the rural setting being hampered by the variable, intermittent incidence of demands for specific areas of interest.

## **Section Four: Beyond formal volunteering**

The findings strongly suggest that the success and benefits of the establishment of the rural volunteer in-home support services go beyond those merely measured by the level of uptake of the formal volunteer in-home support services. Exploration of this premise are analysed under the following headings:

- Significance of building on 'informal volunteering' in the community dissemination of knowledge and capacity throughout the local community;
- Significance of personal development; and
- Significance of 'safety net' role.

The development of formal rural volunteer in-home support services are perhaps best built on an understanding and awareness of 'informal volunteering' or caring in the community, which supports the enhancement of both <sup>86</sup>.

For the purposes of this analysis, the definitions of volunteering as described by Onyx and Leonard <sup>53 p 1</sup> will be used, where they refer to volunteering as "the willing provision of unpaid labour"; formal volunteering as occurring "within the context of a formal organisation"; and 'informal volunteering' as "the provision of the unpaid work of caring and informal neighbourly support".

# Significance of building on 'informal volunteering' in the community – dissemination of knowledge and capacity throughout the local community

The findings reveal the dedication and commitment that many of the rural volunteers have to 'informal volunteering' or caring for members of their communities, pre-existing the formation of the volunteer in-home support services. The education, training and support derived from the volunteer in-home support services were viewed as building on their capacity to support members of the community, whether through the formal channels in league with the services, or through their continued 'informal volunteering' enhanced by their learnings. Volunteers were keen to advance both the formal and informal volunteering in their communities. They valued what they perceived as the added benefits to the community that the volunteer in-home support services could contribute, albeit frustrated at times with the lack of opportunities to formally volunteer.

A volunteer made the distinction between supporting a community member in the usual informal manner as a "visitor" and being able to expand on that support through the provision of added support mechanisms available as a formal in-home support volunteer:

Oh most people we know them and we visit them as visitors. But whereas we could be utilised – they're having a bad night, would someone like to come and sit with them – that's not being observed at all. (Volunteer)

Another volunteer emphasised the importance of the dissemination of knowledge and skills throughout the community, achieved through the training which was provided in a

community health promotion mode. Members of the community were invited to participate in the joint volunteer in-home support services training, regardless of whether they ultimately chose to volunteer with one, or both or neither service. Despite the service no longer formally operating in the rural area, the volunteer still regarded the exercise as a success, increasing peoples' capacity to support each other:

It was wonderful and...even though it's not a formal group here any more, and we didn't get a lot of referrals, we've all had the training and that's still in our heads. And it's probably the best approach in a town like this for it to be totally informal like that, just to have people trained. I'm more aware if one of my neighbours or someone in the community's got a problem...to use the skills like listening and just being there and more attentive and looking out for warning signs, if somebody's really floundering. And that way hopefully it'll filter through the community. (Volunteer)

Further, the volunteer's involvement with the volunteer in-home support service was perceived as increasing the level of informal volunteering provided, through the connections within the community. However, the volunteer strongly supported the revival of the volunteer in-home support service, especially for those people in the community whose circumstances, for whatever reason, rendered them as "outsiders":

I have noticed that people will come and ask me more...I think it's a combination of knowing that I went through that [related personal experience] and they know that I was involved with [the volunteer in-home support service]...But I'd really like to see some way of making it work formally as well...There are still people that have come to this town that aren't from here and I can see them struggling, because we don't have any sort of support networks for people like that...for people who were 'outsiders'...so there is still a need for formal things for those sorts of people. (Volunteer)

A local service provider similarly praised the value of the education and training provided by the volunteer in-home support services in building community capacity to support each other. There was an accentuation of the merits of the "investment in rural communities" achieved through the betterment of formal and informal volunteering, despite what might be perceived as poor levels of formal referrals:

...it's really fantastic that people have been trained...in some way all their knowledge and their skills...are passed on through the community...whether it's just as a friend or they go in specifically as a hospice carer or whether it's to support somebody else who might be supporting somebody. So it's just that whole connectedness and networking...And I think that's what I see the investment in rural communities is. So it's really valuable to train people...around hospice care or parenting...And it may not formally be enacted, but it will informally, it will be just travelling throughout the community...You may not get the formal referrals in a rural community...like high rate of referrals...but I do think that it's a really good investment and it would be

utilised, [there would] be heaps of benefits in many other ways in the community. (Service Provider)

The findings from this study reflect those of Onyx and Leonard <sup>53 p 7</sup> where the benefits of formal volunteering were perceived by volunteers to have a flow-on effect on their informal volunteering or caring in the community arising from the "increased networks of contacts and specialist knowledge". The findings from McKee, Kelley and Guirguis-Younger's <sup>86 p 171</sup> study of hospice volunteering with rural seniors would appear to be of significance to this study, emphasising the importance of considering existing formal and informal networks of support, and working closely with volunteers in the planning of volunteer services to ensure local relevance and the continuation of informal caring:

Strategies to address the end-of-life care needs of seniors living in rural communities will succeed to the extent that they take into account the pre-existing formal and informal networks of care supporting seniors, and work with them to develop policies and practices reflecting local realities and aspirations [which] should be community-driven and adapted to the unique needs of each community, in order to preserve the natural caring networks which have always been the foundation of healthy communities.

Mary Lou Kelley's <sup>88</sup> study of healthcare professionals and hospice volunteers who provided palliative care in rural communities in Canada, offers a model for developing rural palliative care using the perspective of community capacity development, which resonates with the findings from this study. Establishing rural volunteer in-home support services based on this perspective, be it hospice palliative care or supporting families with children, may aid in providing a framework which ensures building on the strengths of existing community resources in a manner which accords with local conditions. Rural in-home support volunteers, as members of the community and through their informal caring networks, can help inform service providers and urban-based volunteer coordinators of the specific needs of the community, while simultaneously acting as a conduit of information flow amongst all parties. Ajemian <sup>118 p 20</sup> highlights the bridging and informing roles that health volunteers may play between the health institution and the community:

There is often a major gulf between the professional world of the institution or health care programme, and the community it serves. Volunteers bridge this gulf, bringing a special dimension of community support to the programme, and reminding health-care professionals of the particular needs of that community.

### Significance of personal development

The findings from participants across the spectrum highlight the significance of personal development derived from participation in the training of rural in-home support volunteers. This was considered valuable, regardless of whether the community participant continued on, post-training, to be a volunteer, or had the opportunity to

formally engage the skills through acting upon referrals. The personal skills acquired and benefits included literacy skills, social networking, sense of achievement, raising political awareness, and advocacy. Volunteers perceived volunteering to have reciprocal benefits. The findings in this study of the significance of personal skill development through training and the reciprocal benefits of volunteering are reflected in the literature  $^{44\,46\,50}$ 

For a service provider involved with the establishment of rural volunteer in-home support services in a rural community, the broader community education aspect of the training was important. The training was viewed as serving a "dual" function of not only providing participants with the education and skills required for volunteering, but also the opportunity to develop "personally":

It was put really clearly to these volunteers that if they didn't go on and be volunteers that that was ok. So it had that function of, as well, of providing them with a course that they could personally develop from...apart from learning some skills, it was just socialising, and it was confidence building, and it was getting out of the house...maybe they were going to make friends with someone...that it had that capacity, so it was a dual sort of thing, extraordinary. (Service Provider)

A volunteer coordinator found that the opportunity to improve some participants' literacy skills was an added bonus to the training. While it was not the original intention, it was nevertheless a significant achievement:

...it was interesting to watch some of those people who came on board as volunteers, a couple whom were really almost illiterate, and they got so much out of the training. And so that was valuable in itself. So that's not what we were there for, but you can't dismiss that side of it. (Volunteer Coordinator)

For another service provider, the personal benefits for the volunteers and community could still be enjoyed even though the volunteers might have limited opportunities to use the skills due to few referrals:

Everybody, you open up, provide an opportunity for people to actually develop these skills. And even though you mightn't get the referrals...but the fact that they have those skills where they're going to be utilising them in lots of ways in daily life. (Service Provider)

Comments from the volunteers were in line with those expressed by the volunteer coordinators and service providers. One volunteer expressed appreciation of the personal benefits of the training, but nevertheless the lack of opportunity to volunteer was disappointing:

We've had all this wonderful training, which we can take as life skills, and I've only had the one chance of using it. (Volunteer)

A raising of social awareness of those struggling in the community and consequently developing advocacy skills to promote the needs of the community was an outcome for a volunteer:

It's changed my whole perception of everything...because now I'm much more aware...that we have people that are struggling just to get out the front door or to put food on the table for their kids or pay the electricity bill. And it's a good thing now that I'm aware of it, because I'm much more vocal these days if I get any politician's ear. (Volunteer)

Other volunteers emphasised the social networking aspects of in-home support volunteering for isolated rural residents, and also the reciprocal nature of the benefits:

...those social contacts too, which are important in a rural community I think, because a lot of people are isolated...they don't get to meet other people with children or similar interests...so it brings you together in sort of a social network ...clients say to me "oh how wonderful you come, and you're such a big help"...but I actually think it's benefited me personally as well, because it's given me something useful to do. (Volunteer)

As in this study, the social benefit of networking was a factor which predominated in Warne and Dietrich's <sup>46</sup> rural study, and perhaps could be related to the increased isolation of rural residents. It is a factor which Creyton <sup>50 p 4</sup> emphasises in his capacity approach to volunteering. The reciprocal nature of volunteering is well established in the literature, as Flick, Bittman and Doyle <sup>44 p iv</sup> state, "All the research shows that volunteers indirectly benefit from assisting others". The findings from this study appear to demonstrate that the success of a rural volunteer in-home support service should not be predicated on the number of referrals alone, as there are significant personal benefits also for the volunteers and the community, particularly through the community training offered and opportunities for networking. Nevertheless, the sense of frustration and disappointment for many volunteers with limited opportunities to formally volunteer is evident and requires attention.

## Significance of 'safety net' role "a sense of security, and acknowledgement and acceptance". (Service Provider)

The value of rural communities having well-informed knowledge and awareness of the volunteer in-home support services is potentially an important asset to rural communities. Widespread promotion of the services may play an educative and supportive role in addressing the perceived stigma that may be attached to struggling and reaching out for help in rural communities. Developing and promoting the services in a capacity development, health promotion manner simultaneously informs the rural communities of the availability of the services, whilst encouraging understanding of the offering and acceptance of support as a natural extension of the caring in rural communities at times when people face challenging life circumstances. The mere

presence of the volunteer in-home support services may play an important 'safety net' role in supporting members of the community, even if ultimately some do not formally access the support of volunteers in the home.

A service provider spoke of the value of volunteer in-home support services in rural communities "just because they're there". The presence of hospice palliative care volunteers was viewed to be supportive of community residents coming to terms with their needs, in a manner which did not accentuate feelings of moral judgement:

I think that it's one of those really valuable services that are of value, just because they're there too...even just to mention it, you can see people sort of relax into themselves a bit, to know that they're there and to know that that sort of thing is valued, that somebody would bother doing it...it sort of gives them permission in itself, to have that sort of need, even to themselves, even if they're not, you know "oh yes, well, if I get up to that I'll let you know" sort of thing, but they're really pleased that it's there, so I think it's really valuable. It gives them a sense of security and acknowledgement and acceptance. (Service Provider)

A volunteer emphasised the universality of struggle that can accompany parenting, as a means of assisting rural residents to overcome concerns associated with the stigma of being seen to need support in a rural community:

...I think some people in a small community are a bit worried that people will think. "What will other people think if they know I need help?" You know, it's an admission of failure or something on my part, which it isn't, we all struggle with small children, so you have to get past that. (Volunteer)

The findings suggest that engaging with rural communities using a community capacity development perspective may be a means of facilitating the development of rural volunteer in-home support services. Kelley <sup>88 p 144</sup> points out that central to this perspective is the contention that:

The method for change is to enhance existing capacities and not impose solutions from outside. The approach is strengths-based rather than needs- or deficit-oriented.

Working with local rural service providers, volunteers and the community, engaging with them for their ideas and strategies and building their capacity through training may assist in keeping the volunteer in-home support services focused on the particular sensitivities of the rural communities. Rural volunteer in-home support services may also benefit from emphasising a model of practice which moves away from the "expert-professional tradition", through using approaches based on citizenship and partnership, anti-oppressive and anti-discriminatory practice models which "work to create equal relationships and demystify processes involved in helping" 112 p 453, which are more in tune with the community-based, volunteer support ethos.

#### **CHAPTER FIVE**

## **DISCUSSION**

The Findings and Analysis Chapter commenced with a statement from a volunteer coordinator, questioning the automatic transferability to the rural setting of a volunteer in-home support program devised in an urban setting, and the need for the service to be community driven. The findings from this study strongly support these concerns. They suggest that consideration of the rural context by urban-based volunteer in-home support services and some form of locally based coordination, may contribute to ensuring the development of rural volunteer in-home support services most suited to the specific rural conditions. The Findings and Analysis Chapter employed the lenses of four salient points emanating from the data to explore the matter: adaptation of volunteer in-home support service delivery according to local rural context; local rural context and heightened ethical issues; coordination at a local level; and beyond formal volunteering. Invariably, there was acclaim for the work of the rural in-home support volunteers and services, with critical observations focusing on the nature of supporting the delivery of such services according to the exigencies of the rural context.

This Discussion Chapter will synthesise the outcomes of the Findings and Analysis Chapter, in order to contribute an understanding of possible answers to the research question: What are the factors that facilitate and/or hinder rural volunteer in-home support through urban-based management of rural-based volunteers? To provide a focus for this discussion, Table 5.1 entitled 'Flags of the experience of rural volunteer in-home support health care' (refer p 95, adapted Dorgan et al. 89) has been developed by the researcher, drawing on the findings from this study. The 'flags' represent reference points which may be useful for urban-based volunteer in-home support services to consider when they seek to provide a service in rural settings, namely: precedence of family support; self-reliance; multiple overlapping relationships; intermittent need; fragmented and under-resourced nature of the rural health system; and rural volunteers' strong sense of connection to their local community and volunteer organisation. The examples provide a brief summative exploration of how the 'flags' may manifest, their implications for the provision of rural volunteer in-home support and may include actual and aspirational responses by participants of this study and diverse possibilities emerging from them.

At the core of the findings is the suggestion that a community capacity development approach by urban-based volunteer in-home support services, which inherently considers the rural context, together with some form of locally based coordinating presence, may contribute to the development of rural volunteer in-home support services suited to the specific rural settings. The discussion will proceed to consider the table in more depth, focussing on each 'flag' in turn.

Table 5.1 Flags of the experience of rural volunteer in-home support health care (adapted Dorgan et al. 2009  $^{\rm 89})$ 

Flags	Examples
Precedence of family support	Strong family ties may mean that relatives and social networks are the primary source of support. Such ties may inhibit access to volunteer support by individuals and family members. Changing demographics are likely to lessen opportunity for family support with family members moving away; 'new' residents without family connections and limited social networking opportunities; life-long/long-term residents 'out of step' with social networks.
Self-reliance	Limited access to services, geographic and personal isolation, may have contributed to stoicism, reliance on self, family and a high degree of complexity of needs. Perceived stigma associated with literally being 'seen' by the community to need help, may be exacerbated by the strategy of home visiting, and elevate the need for privacy of the home. Tendency for rural volunteering to be directed at broader community service level rather than one-to-one addressing of individual needs throughout the life cycle.
Multiple overlapping relationships	Increased potential for complex relationship dynamics. Precedence of local knowledge of community members, inter- and intra-familial relations. May require increased knowledge of or input into selection, training, allocation, support of rural volunteers by local service providers.
Intermittent need	Intermittent need may impact on levels of utilisation and the ability to maintain: a high local profile amongst service providers and the community; volunteer skill level; motivation for volunteers to access further education. Responses may include refresher courses; multiskilling; extended roles beyond those originating in urban setting (intra-service and service delivery).
Fragmented and under-resourced nature of the rural health system	Fragmentation and under-resourcing can impact on the ability to build trusting relationships which form a basis for interdisciplinary and intersectoral collaboration. Such collaborations can foster understanding and appreciation of the positive contribution of volunteers as an extension of informal helping in the community, and help alleviate tensions associated with role ambiguity and blurring between and amongst professional/paid workers and volunteers. They may present as more challenging to achieve in the rural setting, particularly without a local coordinating presence.
Rural volunteers' strong sense of connection to their local community and volunteer organisation	The rural volunteers' strong sense of connection to the their local community and to the volunteer organisation may be harnessed through a community capacity development approach with a strengths perspective. Training offered on a whole-of-community level may facilitate dissemination of knowledge and capacity throughout the community. Increased possibilities for local ownership with strong links to urbanbased specialist volunteer in-home support organisations may help ensure the infusion of local relevance and applicability.

## **Precedence of family support**

The findings suggest that where family and social networks exist in rural settings, support will primarily be garnered from these sources. Their existence was often viewed to mitigate the need for rural volunteer in-home support, however, they did not necessarily preclude the need for such support. Indeed, strong family ties may at times stymie the acceptance of volunteer support by individuals and family members. Changing demographics were more likely to increase the need for rural volunteer in-home support, with the dispersion of family members; 'new' residents without family connections and limited social networking opportunities; and life-long or established residents having needs outside the realm of their usual social networks. The findings suggest the importance of urban-based volunteer in-home support services having an awareness of the particularly strong influence that families may have in the rural setting (often intergenerational) and the impacts of the changing demographics on the population they wish to support.

The findings from this study support those of Humphreys <sup>78</sup> in regard to the significant role of family and friends in small communities in maintaining and promoting the health of the family. Of particular relevance to this study, was Humphreys' finding that while stress presented as a chief health problem for many rural families, rather than seek assistance from health services, it was viewed as something to be endured and remedied within the confines of the family <sup>78</sup>. Similarly, in this study of rural volunteer in-home support aiming to assist rural individuals and families with the potentially stressful experiences associated with parenting and living with an eventually fatal condition, there was a strong sense of caring primarily being the sole responsibility of families and/or close social networks. The ramifications of this were the participants' reported experiences that volunteers, in many cases, were either not considered; sought out as a "last resort" (Service Provider) when capacities were virtually depleted; or the offer of a volunteer aroused tensions as individuals and families struggled with what they perceived as a possible threat to their independence and sense of duty or responsibility.

Service provider participants of this study, sensitive to these concerns, employed a number of strategies to acknowledge and elevate the importance of the family when engaging in conversations with potential rural clients of the volunteer services. For example, there was an emphasis on a shared sense of responsibility between families and volunteers, utilising such terms as "supplementing" and "help out". There was a focus by some on the early intervention of specifically trained volunteers to prevent carer burnout, particularly in the area of hospice palliative care. Hospice palliative care volunteers were promoted as having the benefit of being "comfortable" with death and dying, often in contrast with some family and other social networks.

At the same time, the findings demonstrate recognition amongst study participants of the influence of demographic shifts within the rural communities, similar to those described by Beard et al. <sup>9</sup> and Baker et al. <sup>109</sup>. Notably, the movement of young people out of rural communities, with the concomitant reduction in social and family networks, particularly

for older adults; and 'new' rural residents, both retirees and young families, who may not have family connections and face the added burden of geographical isolation, limited social networking opportunities, and potentially social exclusion associated with being an 'outsider' <sup>57</sup> <sup>109</sup>. These factors were viewed as potentially increasing the demand for rural volunteer in-home support. In addition to this, the findings demonstrate that in the domain of supporting families with children, socio-demographic shifts, such as women parenting later in life, may also increase the need for volunteer support, as older mothers find themselves isolated through not being in synchronisation with the life experiences of their peers. An awareness by urban-based volunteer in-home support services of the diversity of needs of people in rural communities presents as an important issue.

#### **Self-reliance**

The findings from this study suggest a picture of a strong sense of self-reliance at the individual, family and community levels within the rural communities under consideration, which may impede the use of rural volunteer in-home support. Elements such as limited access to services, geographic and personal isolation appear to contribute to a high degree of complexity of needs, and a stance of stoicism when dealing with adversity. The findings indicate that there is a perceived stigma associated with needing help from others, tantamount to a sign of weakness. This perceived stigma may be exacerbated by the strategy of home visiting in rural settings where community members are highly visible, thus presenting a challenge to upholding the notions of privacy, confidentiality and anonymity, and potentially elevating the need for privacy of the home. The findings further suggest a tendency for rural volunteering to be directed at a broader community level, rather than the one-to-one nature of connection with clients, as associated with volunteering in urban settings. The findings indicate that strategies such as volunteer in-home support services providing education at a whole-of-community level and involving volunteers in group health promotion activities, may facilitate the acceptance and use of rural volunteer in-home support in the community.

The findings from this study add to the literature on what is often referred to as rural cultural norms emphasising stoicism, reliance on self, family and community, the value of privacy, and possible avoidance of health care because of perceived stigmatisation <sup>77</sup> <sup>89 111</sup>. In this study, the results suggest that there is a perception that seeking support from rural volunteer in-home support services may stigmatise people: "*There's the stigma of reaching out for help*" (Volunteer). This perceived stigma may act as a barrier to accessing volunteer in-home support in rural communities, where individuals and families fear a risk of being stigmatised by being socially identified as "*weak*" (Volunteer), "*labelled as a family with high needs*" (Service Provider), or "*seen as not being able to cope*" (Service Provider).

Rural residents are highly visible, and as such, notions of privacy, confidentiality and anonymity are severely tested in an environment where the strategy of home visiting means that volunteers may literally be seen to be visiting and thus the recipients of the service can be readily identified as being in need of the services. Beard et al. <sup>9</sup> refers to the high collective efficacy often associated with rural communities, and the negative

consequences. In this instance, the ability of a community to informally enforce the social norm of self and family reliance, building resilience, may have the negative effect of stymieing efforts to seek external support of volunteers at times of additional stress when resilience may be challenged.

The findings from this study reflect those of Reutter et al.'s <sup>120 p 309</sup> study of poverty stigma when they urge:

Professionals in health and social sectors need to be sensitive to low-income people's understandings of their social identity and their need to maintain a positive self-concept amidst the threat of stigmatization.

Applied to this study, it appears that professionals and volunteers may require sensitivity to rural people's understanding of their social identity in regard to self and family reliance, and work in ways which can support them without arousing fears associated with perceived stigmatisation through the acceptance of external support. Several approaches were considered in the study. Working with a strengths approach with individuals and families was promoted by some participants as an effective means. Education at a whole-of-community level was also promoted, whilst primarily for building community capacity, it also potentially provides a forum to explore concerns associated with stigma. To this end, it could be a mutual learning experience between the urban-based volunteer in-home support services and the rural communities they engage with, simultaneously building resilience while providing a forum to explore the challenge of the provision and acceptance of volunteer support as an extension of informal caring in the community.

Calls in this study for more "creative" (Service Provider), "inventive" (Volunteer) and "flexible" (Volunteer Coordinator) means of working in rural settings to address these (amongst other) concerns, included considerations beyond the strategy of home visiting. As Sweet and Appelbaum 82 p 1449 point out:

...home visiting is a **strategy** for delivering a service and **is not a service in and of itself** [emphasis added].

Additional support through access to peer group activities was noted in Weiss's <sup>14</sup> study of home visits supporting families with children. Similarly in this study, the inclusion of rural in-home support volunteers in parenting group activities was a means of utilising volunteers where the home visiting strategy appeared to be struggling, in this instance, possibly due to concerns related to perceived stigma. It could be similarly argued, that providing group support for rural carers in the hospice palliative care domain, may be an additional means of utilising volunteers and supporting individuals and families, where the strategy of home visiting might exacerbate perceived stigmatisation. It may be an effective means of introducing the concept of volunteers and could potentially lead to more acceptance of the strategy of home visiting volunteer support. This study supports Hughes et al.'s <sup>108</sup> concerns that there could be a greater reliance on informal networks in rural areas and burden on caregivers in palliative situations, which could heighten the

need for education. Involving rural in-home support hospice palliative care volunteers in group education activities might be a valuable means of utilising the rural volunteers and supporting rural communities.

The findings from this study support those of Onyx, Leonard and Hayward-Brown <sup>45 p 135</sup> that in rural communities "volunteering was oriented towards the public realm of the wider community" as opposed to individual, one-to-one client connection, more common in urban settings. This study suggests that this may be related to self and family reliance, the privacy of the home and perceived stigma of seeking support, which could be exacerbated by the strategy of home visiting, where rural people may feel more exposed to public scrutiny. Utilisation of the volunteers at a broader community level through engaging with group and community education initiatives aimed at strengthening individuals and families in the areas of parenting and palliative care, rather than only individually targeting them in their homes, may dissipate some of these concerns. It may provide a mechanism for building trust with the volunteers and volunteer services which may then lead to people opening up their homes.

## Multiple overlapping relationships

The findings from this study suggest that the increased nature of multiple, overlapping relationships in rural areas potentially has both favourable and disadvantageous consequences for the provision of rural volunteer in-home support. While positive prior knowledge or experience of individual volunteers may be a supportive aspect influencing the uptake of volunteers, negative perceptions or experiences, and adapting to peoples' changed identity as a volunteer, may be a hindrance to their use. The findings suggest that the potential for complex relationship dynamics highlights the precedence of local knowledge of community members, and inter- and intra-familial relations. This may have ramifications for some of the volunteer service processes such as the selection, training and allocation of volunteers, with the need for more inclusive local service provider participation in or knowledge of them. There may need to be a raised awareness of the potential for social exclusion.

There is a focus in the literature on some of the ethical dilemmas health professionals face associated with multiple and overlapping relationships with rural clients, commonly experienced in small communities <sup>76 77 107 111</sup>. The findings from this study suggest that rural in-home support volunteers, as volunteer 'service providers' similarly face such concerns in their dealings with rural clients, challenges associated with boundaries, confidentiality and privacy. It is argued that "rural cultural norms encourage people to seek help from people they know and trust' <sup>107 p 302</sup>, and the findings from this study appear to support that contention. The findings indicate that as a consequence of this, a more intimate knowledge of social relations in rural communities may be required of urban-based volunteer service coordinators when considerations are made for the selection, training and allocation of rural in-home support volunteers. Rural service providers, through the nature of dense social networks in rural settings <sup>111 112</sup>, are more likely to know, or know of ,volunteer candidates and how they may 'fit' within such networks. The findings suggest that there may, therefore, be a heightened need for more

involvement with, or increased knowledge of, such processes with local service providers.

The findings suggest that there are additional complexities concerning the recruitment and allocation of rural in-home support volunteers, in part associated with the multiple overlapping relationships inherent in small communities. Local service providers' more intimate knowledge of potential rural volunteers, stemming possibly from experience of them as recipients of their service as well as general knowledge of them as community members, may influence their perceptions of the suitability of certain volunteers, and consequently the trust they place in the volunteer in-home support organisation. The study revealed some tensions concerning this, with a local service provider emphasising the importance of "local knowledge" and "local input" in regard to the selection and allocation of volunteers. While an urban-based volunteer coordinator acknowledged that such concerns could be a barrier to relationships between local service providers and the volunteer service, concerns for "protecting the privacy of the volunteers" were raised in regard to the disclosure of volunteer identifying information to local service providers. It may be the case that notions of privacy take on different dimensions in small rural communities, and that the urban-based organisations may not fully appreciate the intricacies of the local rural context and the impact that multiple overlapping relationships may have in this regard. As a local service provider exclaimed, "you've got to be aware of some of the dynamics, it's not like we're in the middle of Hobart".

The findings from this study support those of Vangelista <sup>16</sup> and Freeman et al. <sup>87</sup> who encourage paid staff participation in the selection, training and/or supervision of volunteers as a means of building familiarity of paid staff with volunteer workers, and assisting suitable matching of families with volunteers. The findings suggest that the more intimate nature of rural service providers' knowledge of prospective rural volunteers, may have implications for greater awareness of the potential for social exclusion in the selection and allocation processes. More joint efforts may be required to explore this important issue between local service providers and urban-based volunteer coordinators at the point of discussions leading to the introduction of the volunteer program in rural settings, to help ensure a diversity of volunteers in the community; avoid elements which might "corrupt the objective process" (Local Service Provider), whilst ensuring a high "calibre" (Volunteer Coordinator) of rural in-home support volunteers.

#### Intermittent need

Findings of this study indicate that the perception of intermittent need of rural volunteer in-home support, borne from a lack of critical mass, is a flag which may play a significant role in their utilisation. Intermittent need was often linked with a perception of underutilisation of the volunteers, but the relationship presented as a complex one. In the domain of hospice palliative care in particular, participants' views were often at variance in regards to the contributory factors and consequently the possible responses. The findings suggest that the meaning of palliative care may vary in rural communities depending on their specific needs and that the role of the volunteers, therefore, may also

show cause to vary accordingly. There were implications affecting both domains of volunteering for the ability to maintain a high profile amongst local service providers and the community; volunteer skill level and motivation for rural volunteers to access further education. Responses included the suggestion of refresher courses, multiskilling, and extended roles.

In regards to the domain of hospice palliative care, the findings of this study are consistent with the literature concerning rural palliative care which describes palliative care service providers in rural and remote communities as generalists, with infrequent exposure to palliative care type patients <sup>69</sup> <sup>81</sup> <sup>86</sup>. It follows therefore, that rural hospice palliative care volunteers will similarly experience infrequent exposure. The specialist nature of their volunteer training, however, means that unlike their rural generalist service provider counterparts, rural hospice palliative care volunteers will have less opportunity to practice and maintain their skills and interest through non-palliative care experiences. The perception of underutilisation from this perspective of lack of demand due to intermittent need, was raised by Claxton-Oldfield and Claxton-Oldfied <sup>99</sup> as a common problem for many hospice palliative care volunteers in Canada and the United States, and suggestions for addressing the matter included strategies such as raising awareness of periods of inactivity with volunteers during training (also recommended by Freeman et al. <sup>87</sup>), a 'buddy system', keeping interest and involvement through education/training, and non direct patient/family care such as administrative tasks. In this study, suggestions also included a 'refresher course'.

Notably, in this study consideration of causes and remedies for intermittent need and perceived underutilisation went further than just considering practical concerns associated with lack of critical mass to help make rural hospice palliative care volunteering 'fit'. As in McKee, Kelley and Guirguis-Younger <sup>86</sup>, and MacLean and Kelley's <sup>69</sup> rural studies, many participants in this study questioned the applicability of definitions of palliative care and service delivery as conceived within urban conditions. In regard to palliative care, this study similarly called for a "local way of describing it" (Volunteer) and a consideration of other broader views of palliative care, such as support people in just acute and chronic little episodes as well" (Service Provider). There appeared to be some agreement in this study with MacLean and Kelley's <sup>69 p 66</sup> finding concerning the adaptive development of rural palliative care, of which rural volunteer hospice palliative care home visiting may be a part:

The philosophy, definitions and guidelines developed in urban areas could be presented as **a framework to be adapted by rural care providers** based on their circumstances rather than an urban program that must be implemented by rural providers [emphasis added].

Interestingly, the findings from this study in relation to intermittent need may provide insight into the apparent disinterest by rural volunteers in further training and education <sup>42</sup>. The findings suggest that the lack of opportunities to apply the skills through direct volunteering in both domains may act as a deterrent to their participation. As Claxton-

Oldfield and Claxton-Oldfied <sup>99</sup> suggest, further research is required to explore the reasons why patients and families accept or decline the services of a volunteer. Such knowledge can then help to determine where the focus of attention to address intermittent need and perceived underutilisation lies – if it is lack of knowledge of the services, then energies could focus on better promotion, and the volunteers themselves may have an increased role to play in its promotion in rural communities, given the urban location of the volunteer coordinator. Resources directed at multiskilling and/or extending the skills <sup>31 49 50</sup> of rural in-home support volunteers to address intermittent need based on lack of critical mass, may still fail to resolve the issue if there is a reluctance of people in rural communities to accept volunteer in-home support based on other concerns that might need attention, such as privacy and precedence of family support. When considering the introduction of rural volunteer in-home support, and when reviewing progress, rural communities in partnership with the urban-based volunteer services, may need to explore how intermittent need and its possible causes may impact on the delivery of the service, and adapt services accordingly.

## Fragmented nature of rural health system

This study suggests that there are challenges for urban-based volunteer in-home support services and rural volunteers to establish and maintain credible working relationships with local service providers and the rural community associated with the fragmented, under-resourced nature of aspects of the rural health system. In the rural health environment where there is the dominance of a medical model of care <sup>121</sup>, opportunities for urban-based volunteer coordinators to build trusting relationships through important mechanisms such as interdisciplinary and intersectoral collaboration <sup>122</sup> appear to be fewer than in the urban centres where the volunteer coordinators are based. In addition, there are the challenges associated with a work environment where role ambiguity and blurring are salient factors in both volunteer domains, but particularly in the field of hospice palliative care <sup>35</sup> <sup>123</sup>. The findings indicate that the rural volunteers may be disadvantaged through the lack of a local coordinating presence to forge strong links with local service providers and the community, fostering understanding and appreciation of the positive contribution of volunteers.

Creating a strong sense of place for volunteers within highly structured, hierarchical health services can be challenging according to Merrell <sup>124</sup>, and this study suggests even more so in the fragmented, under-resourced rural health environment. Merrell <sup>124</sup> contends that managing ambiguity between paid and volunteer workers is a prominent feature when dealing with the complexities of roles and boundaries. The ambiguous nature of volunteers is often described as a peculiar position of being "somewhere inbetween" <sup>53 p 14</sup>, having some qualities of the 'professional' as a benefit of training, yet neither being a professional nor merely lay carer, friend or neighbour <sup>35 53</sup>. These findings were repeated in this study, where sentiments expressed by some volunteers included: "we're considered that person in-between", and from another "it gets blurry I guess". At times the ambiguity led to a feeling of territorial overlap "then I suppose we're encroaching on the Home Care girls". The hierarchical notions of professionalism with the superiority of expertise over other qualifications and practical

experiences as described by Vangelista <sup>16</sup>, contributed to a volunteer in this study experiencing a feeling of being undervalued:

...but not everybody's equal...they (Service Providers) were very dismissive of volunteers...because we're not trained professionals...what would we know.

Merrell <sup>124 p 100</sup> argues that relationships between paid and volunteer workers can be enhanced if organisations "make explicit their motives and purpose of involving volunteers in service provision". Similarly, a volunteer coordinator in this study proposed the same undertaking by the volunteer services:

I think each (Volunteer) program has to...somehow show that it's needed and worthy of being there.

This study suggests that for urban-based volunteer in-home support services, doing so in the resource poor rural environment can be challenging. Simply adhering to calls in the literature for clearly delineated roles between health professionals, paid workers and volunteers as a means of maintaining boundaries <sup>16</sup> may be of limited value unless the roles, policies and practices devised within an urban context take into consideration the impact of their implementation according to the exigencies of the rural context <sup>86</sup>. Opportunities for interprofesional and volunteer dialogue or team work to build relationships and understanding of what the volunteer in-home support role might encompass are manifestly less available in the rural health setting, beset with fractional, non-overlapping positions, staff turn-over and gaps in service. In addition to this, the intermittent nature of the demand for the volunteer services may be a contributory militating factor, limiting the occasions for increasing capacities to understand, which may best be "learned locally by doing" <sup>81</sup> p <sup>310</sup>, with reference to Lavergne and Saxby <sup>2001</sup>.

Unlike in the urban setting where the hospice palliative care volunteer coordinator participates in formal interprofessional palliative care meetings and is located in close proximity to the specialist palliative care service, allowing for the development of informal networks, such opportunities do not currently exist in the rural settings that were the subject of this study. As in McKee, Kelley and Guirguis-Younger's study <sup>86</sup>, there was no evidence in this study of formal interprofessional rural palliative care teams, let alone one inclusive of volunteers, to build an awareness and understanding among local service providers of the possibilities for the hospice palliative care volunteer role. The lack of relationship with rural volunteers was evident in this local service provider's statement:

I can't actually remember talking to them (Volunteers) directly...if I have seen them it would be perhaps...having a quiet chat if you run into them...I can't actually recall that as much of a relationship.

The focus in this study of the hospice volunteer coordinator's attention to promoting the service with the urban-based specialist palliative care service as the main referral source of rural clients may be contributing to a sense of lack of exposure to the volunteer

service at the local community level. The urban-based volunteer coordinators in both domains of this study nominated their inability to regularly visit the numerous rural communities as a major hindrance to providing a service. Primarily, lack of sustained, continuous funding for a local coordinating presence was raised as a major obstacle, with the services being reliant on competing for short-term project-related funds to extend their services to rural areas. The findings of this study support those of Merrell <sup>124 p 100</sup> who argues that:

Appointing an individual, usually a volunteer coordinator, who links the bureaucracy of the NHS [or Department of Health and Human Services in this instance] with the associational world of the volunteer can play a key role in managing ambiguity and enabling volunteer and paid workers to work together effectively.

Initiatives such as developing new volunteer roles, for example Assessors and Peer Support are effective to some degree at strengthening the rural service delivery. There may be a place for a more active service promotion role for rural volunteers. However, the findings indicate that there is a need for the authority associated with the appointment of a locally based rural volunteer coordinator position, which can enhance interaction with the formal rural health system.

## Rural volunteers' strong sense of connection to their local community and volunteer organisation

The findings indicate a strong sense of loyalty, dedication and commitment by the rural volunteers to their local community and to the volunteer service, which at times may lead them to extend themselves (or a desire to) beyond the official guidelines prescribed within the urban context. The findings suggest that this may be due in part to the volunteers responding to the needs of the local community dictated by conditions associated with rurality, which may differ from those in urban settings. The urban-based volunteer in-home support services in this study could be viewed as 'specialists' collaborating with rural service providers and communities seeking to establish rural volunteer in-home support. As such, there is the potential that as less rural-focused organisations, they may risk failing to some degree to understand the local context of the specific rural communities they engage with <sup>68</sup>. It has been argued that volunteering and community development are inextricably linked <sup>50</sup>. The findings from this study suggest that ensuring elements of a community capacity development approach may aid in facilitating the development of rural volunteer in-home support services that are tailored to specific rural communities' needs. Significantly, the findings of this study further suggest that urban-based management of rural in-home support volunteers appears to be inhibitive, without some manner of locally based leadership and management, which are universal domains of community development and empowerment <sup>125</sup>.

The findings suggest a sense of distinctiveness in operating volunteer in-home support in a rural context which may be associated with aspects of rurality. An urban-based

volunteer coordinator commented on an impression of difference and the challenge of applying guidelines derived in the urban setting:

...the (rural) volunteers operated a little differently to the volunteers based in the city. I couldn't impose the sort of guidelines that people in the city – you train them and explain all the guidelines and work through it with them and everyone's ok with that. But it seems to me that "oh you've got to be joking, you don't expect me to say or do that for goodness sakes, people in the country don't operate like that".

There were calls from various participants throughout the study for changes to suit the rural conditions – "I guess that the organisation has to refocus...and acknowledge that they may have to change to accommodate" (Volunteer). A preparedness of the urban-based volunteer in-home support services to work with community-centred approaches emerged as a crucial factor in this study for the success of rural volunteer in-home support. This is consistent with the findings of McKee, Kelley and Guirguis-Younger high in their study of hospice volunteering with rural seniors, which could also apply to rural volunteers supporting families with children:

Policies and programs...should be community driven and adapted to the unique needs of each community, in order to preserve the natural caring networks which have always been the foundation of healthy communities.

Creyton <sup>50 p 2</sup> in promoting a capacity approach to working with volunteers, links working with volunteers and community development. He contends that:

A capacity approach to volunteer programs considers how to enhance the capacities of the volunteer and of the organisation (and by result of the broader community)...Traditionally there has been an artificial distinction between working with volunteers and community development...In capacity programs there is recognition that working with volunteers is in part about building community.

In building community, it would appear essential for urban-based volunteer in-home support services to develop an awareness of the specific rural context they are engaging with, as needs may vary from one rural community to another. Central to this understanding may be the interface of rural volunteer in-home support with what Beard et al. <sup>9 p 6</sup> describe as "some rural socioeconomic and cultural factors influencing health". Many of the factors proposed by Beard et al. <sup>9 p 6</sup> were evident in this study, such as stoic behaviours, isolation, population ageing, access to health services, movement to cities of young families, close-knit communities with high collective efficacy, and socioeconomic disadvantage. Experiences described in this study where rural volunteers have felt they have "broken rules" (Volunteer) to assist families in an effort to respond to the often harsh rural realities associated with the above noted factors, suggest a need for urban-based volunteer in-home support services to adapt their services according to the rural imperatives of the communities they seek to support.

The findings suggest that for the urban-based volunteer in-home support services, the ability to gain a rich understanding of the local rural context is hampered, to a significant degree, by the lack of some manner of a local volunteer coordinating presence. This presented as a substantial concern shared by many participants of the study, across the two volunteer service domains. The key factor of some form of local ownership was identified as a resounding feature which might assist with the infusion of local relevance and applicability, and the forging of strong connections with local service providers and the community. It is in keeping with community development and empowerment principles <sup>125</sup> and may aid in what MacLean and Kelley <sup>69 p 66</sup> describe as "maintaining the integrity of the rural community" and McKee, Kelley and Guirguis-Younger <sup>86 p 169</sup> refer to as "valuing local autonomy".

For urban-based volunteer in-home support services seeking to establish services in rural communities, community-centred approaches may entail a preparedness to "be willing to give up control. Commit to do things differently" <sup>125 p 30</sup>. In response to a perception of "*gate-keeping*" (Volunteer Coordinator) by rural staff, and a sense of conflicting loyalties for rural volunteers centring on the issue of a lack of a local coordinating presence, a volunteer coordinator envisioned a locally centralised volunteer service. A vision of a more integrated and comprehensive rural volunteer healthcare service, with a locally based, centralised, fully funded volunteer coordinator position with strong links to 'specialist' volunteer services in the city, potentially offers a model for rural volunteer in-home support which could overcome the fragmentation of services characteristic of the general health system, and provide services tailored to the specific communities' needs. It is a vision supported in the volunteering literature in studies such as those conducted by Esmond <sup>49</sup>, Flick, Bittman and Doyle <sup>44</sup> and Hollin <sup>71</sup>.

The findings suggest that the commitment, enthusiasm and loyalty of the rural volunteers may be harnessed through a community capacity development approach. It provides a means of engaging with the rural community and bringing them on board through non-threatening community education and group focus initiatives. Some manner of local coordination can play a critical role of infusing local relevance and solid connection with local service providers and the community, with the viability of rural volunteer in-home support depending on the sustained dedication of all concerned.

#### **CHAPTER SIX**

#### CONCLUSION

The aim of this study was to explore the experience of rural volunteer in-home support through urban-based management of rural-based volunteers, in order to further the understanding of the nature of this form of intervention strategy in rural communities. It therefore focused on endeavouring to respond to the specific research question: What are the factors that facilitate and/or hinder rural volunteer in-home support through urban-based management of rural volunteers? The study sought to realise this aim through undertaking a qualitative research study design with the use of semi-structured, in-depth individual interviews and a focus group, and thematic analysis. These methods were used to explore the experience of hospice palliative care and supporting families with children rural volunteer in-home support through the representation of three perspectives: Volunteer Coordinators, Service Providers and Volunteers.

The most salient findings of this study indicate that a community development approach which inherently considers the local rural context and some form of a locally based coordinating presence, are the key factors which may facilitate the development of rural volunteer in-home support services appropriate to the specific rural settings. The findings confirm the imperative of local knowledge and understanding of the rural context. The valuing of the "expertise" <sup>20 p 25</sup> of rural volunteers as members of the community, reflective of the diversity of the rural communities in which they live, is essential. The contribution of their knowledge and experience to the development and promotion of rural volunteer in-home support services through authentic whole-ofcommunity partnerships in rural communities is vital for addressing the rural social realities of parenting or living with an eventually fatal condition. The number of home visits alone cannot solely measure the success of one-to-one rural volunteer in-home support, especially when education and health promotion are offered at a whole-ofcommunity level, and informal networks of support are strengthened. A locally based coordinating presence is crucial for ensuring a strong voice and place for rural volunteer in-home support services within the rural health system, enhancing collaborative partnerships between and amongst volunteer and other service providers and the rural communities they engage with.

The findings strongly suggest that there are particularities associated with the experience of volunteer in-home support in the rural context. This implies the need for the urban-based volunteer services – which, not unlike other urban-based specialist services, are likely to present in rural settings already prepared with existing policies, procedures and guidelines – to be receptive to implementing adaptive changes according to the requirements of the specific rural community. The findings suggest that attention to rural socioeconomic and cultural factors, such as those proposed in Table 5.1 generated by this study, may be a crucial matter for urban-based volunteer in-home support services to consider in adapting their urban-centric services according to the rural imperatives of the communities they engage with.

This study has identified factors which may facilitate and/or hinder rural volunteer inhome support through urban-based management of rural volunteers and integrates them into the Table 5.1 'Flags of the experience of rural volunteer in-home support health care' (adapted Dorgan et al. <sup>89</sup>). The 'flags' equate to reference points against which urban-based in-home support volunteer services may gainfully consider the local rural relevance and applicability of their service, while the examples summarise some of the potential effects of the 'flags' and possible adaptive responses explored in the study. The 'flags' or reference points are: precedence of family support; self-reliance; multiple overlapping relationships; intermittent need; fragmented and under-resourced nature of the rural health system; rural volunteers' strong sense of connection to their local community and volunteer organisation.

The promotion of the services at the community level and the offering of the services at the individual level within a strengths perspective framework as part of a whole-of-community response tailored to the specific community, presents as a principal facilitator of rural volunteer in-home support. The findings suggest that opportunities for continuous dialogue between all parties, including the rural communities, to focus not only on the establishment but the ongoing development of locally adapted, community specific services could facilitate rural volunteer in-home support. The potential for the success of options proposed by participants in this study to help sustain rural volunteer in-home support, such as:

- refresher courses;
- multiskilling or extending volunteer roles;
- collaborative volunteer ventures centralised and coordinated in the local rural communities;

could be judiciously considered in the light of such dialogue and the improved communication and transparency it could produce.

The hindrances to rural volunteer in-home support can be potent. The application of community development approaches, with which the urban-based grassroots volunteer services are traditionally well aligned, may be significantly hindered in the rural context. Dominant amongst these hindrances are the reliance on short-term, often administratively burdensome project funded initiatives for the extension of services to rural communities, and the pressures on under-resourced rural services. An associated notable constraint includes the curtailing of community development processes under the pressure of 'project timelines', compromising the original grassroots philosophy of the smaller organisations and their ability to focus on the time consuming but necessary undertaking of developing trust with the rural communities. Pressures on rural services, combined with the dominance of the medical model of health care, and ambivalence and ambiguity about the place and role of rural volunteer in-home support, can hinder collaborative and partnership efforts and the forging of strong bilateral links between the 'specialist' volunteer services based in the city, the rural service providers and the broader rural community. Lack of a local rural-based coordinating presence for the volunteers exacerbates the situation.

Sensitivity to heightened ethical issues in the rural context may also be impeded, such as:

- awareness and understanding of the negative and positive influences of the precedence of family support where available;
- the elevated need for privacy of the home, closely linked with fears related to
  perceived stigmatisation associated with the acceptance of support as a sign of
  weakness and intensified by the increased visibility of rural clients in small
  communities;
- the potentially complex nature of multiple, overlapping relationships.

Innovative strategies to connect with communities and encourage whole-of-community engagement, such as the World Café style conversational process (see <a href="https://www.theworldcafe.com">www.theworldcafe.com</a> accessed 19.1.10), and the establishment of cross-agency health promotion resource teams which were successfully employed in a rural project seeking to implement a health promoting palliative care approach 126, can be effective means of urban-based volunteer in-home support services engaging with rural communities and raising their awareness of rural realities impacting on their health domain of interest.

In this study, qualities ascribed to the rural in-home support volunteers, such as enthusiasm, commitment and loyalty to their rural communities and to the volunteer organisation; and the passion of the volunteer coordinators and their ability to infuse that into the volunteers, were revealed as significant factors which facilitate rural volunteer in-home support. However, such qualities in the volunteers are at risk of being dissipated if opportunities to apply their skills are thwarted. Prudent consideration of the local rural context utilising a community development approach and some manner of local coordination may help secure a sound presence for rural volunteer in-home support that will benefit rural individuals and families in need and the whole community.

# Strengths and limitations of the study and suggestions for further research

The strengths of this qualitative research study are that it provides insights into the experience of rural volunteer in-home support and aids in fostering a richer understanding of the nature of this form of service provision through urban-based management of rural-based volunteers. The researcher's "insider status" was supportive in facilitating the receptiveness of participants to partake in genuinely frank individual interviews and focus group discussion. The development of Table 5.1 'Flags of the experience of rural volunteer in-home support health care' reflects the central contention of this study that the permeation of the local rural context and a form of local coordination are vital facilitators of this form of service provision. The 'flags' represent reference points for urban-based volunteer in-home support services to consider in coming to terms with the influence of the rural context, in conjunction with local rural and specialist urban service providers, rural volunteers and the rural communities they

seek to serve. Each 'flag' or reference point provides insights into discerning and responding to particular rural socioeconomic and cultural factors which may facilitate and/or hinder rural volunteer home visiting.

The issue of perceived underutilisation presented as a vexed concern in this study for both domains of rural volunteer in-home support, particularly so in hospice palliative care, and warrants further study. Claxton-Oldfield and Claxton-Oldfield's <sup>99</sup> paper on hospice palliative care volunteers also identified underutilisation as a concern and calls for future research in the area. As noted previously in the Methodology Chapter, the inclusion in this study of the perspective of clients who accepted or declined a volunteer would have added to a richer understanding of the experience of rural volunteer in-home support, and notably so in regard to this issue. The findings from the perspectives explored in this study support those of Barnes, MacPherson and Senior's 95 study which focused on the perspective of families with new babies offered volunteer home visiting support. As in this study, the findings raised concerns of fearing stigmatisation and pressures from existing family networks as possible barriers to acceptance of a volunteer <sup>95 p 115</sup>. An action research approach to exploring the utilisation of rural volunteer inhome support over an extended period of time (given the likelihood of intermittent need) involving volunteer service coordinators, service providers, volunteers and rural community members who accept and decline a volunteer, could provide a means of developing a deeper shared understanding of the experience of rural volunteer in-home support and further assist with the provision of rural volunteer in-home support services adapted to suit specific community needs.

As Fossey et al. <sup>91 p 730</sup> point out, qualitative research "stresses the importance of understanding findings in the particular contexts and settings of the research". The researcher has sought, therefore, to provide sufficient detailed description of all aspects of this research so that the applicability and generalisability of the findings in these contexts and settings can be reasonably determined by others to their own circumstances <sup>91 p 730</sup>. The findings from this study on the experience of rural volunteer in-home support provides insights into the factors which may facilitate or hinder such volunteering in the rural context and possible adaptive responses to them. While this study focused on the experience of rural volunteer in-home support in the domains of hospice palliative care and supporting families with children, the findings may also have relevance, when judiciously applied, to other related volunteer in-home support services seeking to expand to rural communities.

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### **APPENDIX 1**

Example of a Volunteer Information Sheet and Consent Form.

Private Bag 103 Hobart Tasmania Australia 7001 Telephone (03) 6226 7344 Email <u>rural.health@utas.edu.au</u> Web <u>www.utas.edu.au/ruralhealth</u>



UNIVERSITY DEPARTMENT OF RURAL HEALTH

#### **Consent Form**

### The Experience of Home Visiting Volunteer Health Care Through Rural Outreach

- 1. I have read and understood the "Information Sheet" for this study.
- 2. I understand joining the study involves participation in an interview or focus group for 30 to 60 minutes and that I am free to withdraw at any time or decline to discuss any individual issue.
- 3. I understand that a verbal agreement to maintain the anonymity and confidentiality of focus group members and discussions will be a condition of participation for all focus group members.
- 4. I have been advised that the confidentiality and anonymity of my data will be fully protected by the coding of my identity and the volunteer organisation; the data will be securely stored for 5 years after which it will be shredded and /or wiped.
- 5. I agree the data gathered for this study will be published and that the utmost care will be taken to protect my identity. However, I understand that there is a slight risk that I and the organisation may be potentially identifiable.

Name от Participant:	<del></del>
Signature:	Date:
Statement by Investigator	
I have explained this project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.	
Name of Investigator:	
Signature of Investigator: Date:	

Private Bag 103 Hobart Tasmania Australia 7001 Telephone (03) 6226 7344 Email <u>rural.health@utas.edu.au</u> Web <u>www.utas.edu.au/ruralhealth</u>



#### UNIVERSITY DEPARTMENT OF RURAL HEALTH

Date

Name Address

## The Experience of Home Visiting Volunteer Health Care Through Rural Outreach

Chief Investigator: Dr Peter Orpin, University Department of Rural Health,

**Tasmania** 

**Masters Student Investigator: Fiona Jones** 

We would like to invite your participation in the above research study being undertaken to fulfil the requirements for a Masters of Medical Science. Volunteering is an integral part of the rural health care system, however home visiting volunteering appears to be under-represented in rural communities and services experience varying success in their provision.

The aim of this research is to explore the factors which impact on this important form of volunteering in rural communities, with the purpose of generating evidence which will assist it to flourish.

As a volunteer providing a service in rural communities, we are seeking your views on this matter. If you agree to join in the study, Fiona Jones will contact you to arrange a date and time for your participation, either in an individual interview (face to face or telephone), or in a focus group. The focus group will involve a group of volunteers from your service coming together to talk about areas of interest such as organisational and management concerns; training, education and support; ethical considerations in the rural health volunteering context such as confidentiality, privacy, stigma, the many roles people may hold in the community; the impact of volunteering on relationships with clients, your family and personal life. The focus group will be held in your locality and should take 30 to 60 minutes, including the provision of a morning or afternoon tea.

Your participation in this study is entirely voluntary. If you decide to participate, you are free to withdraw at any time and to decline to discuss any issue. A

verbal agreement to maintain the anonymity and confidentiality of focus group members and discussions will be a condition of participation for all focus group members. Together with this information sheet, you will be provided with an informed consent form, the signing of which will be taken as evidence of your consent to participate (you will be given a copy of each to keep). The focus group will be recorded and transcribed and the information used toward the writing of a Masters thesis which will be held by the University of Tasmania and the study may also be the subject of an academic journal and/or conference paper. Your confidentiality will be strictly protected at all times. Data, including audio recordings, will be securely stored in locked cabinets and password protected computers within the UDRH, Hobart for a period of five years after which it will be shredded and /or wiped. During this time the data will be accessible only to those working directly on the study.

Please note that while you and your organisation will not be identified, the nature of the closely connected community that we work in means that there is a risk that your comments may be potentially identifiable. However, every effort will be made in the manner in which the study is reported to ensure, as much as possible, that you and your organisation will not be individually identified or identifiable. If you have any concerns or further questions related to the study, or if you would like to receive a summary of the thesis, please contact Dr Peter Orpin (the Chief Investigator for this study) whose details are provided below.

The study has been approved by the Human Research Ethics Committee (Tasmania) Network. If you have any concerns of an ethical nature or complaints about the manner in which the study has been conducted you may contact the Executive Officer of the above committee, Ms Marilyn Pugsley (Telephone 03 6226 7479).

If you are prepared to participate in the study, please contact your Volunteer Coordinator who, with your permission, will forward on your contact details. We sincerely thank you, in anticipation, for your assistance and co-operation with this study aiming to benefit rural communities.

Dr Peter Orpin Chief Investigator

Email: Peter.Orpin@utas.edu.au

Phone: 6226 4744 Fax: 6226 4746

Fiona Jones

Masters Student Investigator

Email: <a href="mailto:fiona.jones@dhhs.tas.gov.au">fiona.jones@dhhs.tas.gov.au</a>
Phone: 6224 2515 (Monday to Thursday)

Fax: 6224 2451