

Research Report

People I have known: The experiences of rural and regional community visiting palliative care volunteers in NSW

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Background

This research project was developed by Palliative Care NSW to better understand the experiences of palliative care volunteers in NSW who are involved in visiting adult patients and families in the community, typically at home in regional and rural areas of NSW¹. Palliative Care NSW through the Volunteer Support Services Programme has an interest in better understanding the challenges and contexts within which palliative care volunteers work in an effort to champion and develop palliative care volunteering across the state.

In 2014 there were about 612 community visiting volunteers across the state, with about 422 (69%) supporting adults in rural and regional NSW². There was a nearly even distribution of these volunteers across not for profit (8 services, 196 volunteers) and Local Health Districts (8 services, 226 volunteers). However, when compared with all palliative care volunteers in NSW the proportion of community visiting volunteers in not for profit services (55%) is higher than the statewide average of the same group as a proportion of all volunteers of 30%. This largely results from the observation that not for profit services are over-represented in rural and regional areas and that not for profit services also tend to have a lower commitment to hours of employment for the volunteer manager and a higher likelihood that the volunteer manager is performing in an unpaid role².

Community visiting volunteers are actively involved with providing emotional and practical support to adults and families at home through companionship and respite. Depending on the nature and policies of the service they may be involved in practical support, assistance with transport and delivering or collecting equipment². These roles tend to be more diverse and autonomous than those of palliative care volunteers in inpatient settings.

Role diversity and autonomy is observed amongst community visiting volunteers attached to hospices in Britain who take part in the lives of patients by assisting them to appointments, identifying and forming supportive social networks, providing information and even organising and coordinating care. The place of palliative care (hospice) community volunteers in Britain is coincident with narratives of community development and compassionate communities^{3,4,5}. An observation by the authors that volunteering in Britain appeared to be shaped by 'privilege, opportunity, compassion, community and conviction'⁶ as well as our interest in autonomy among volunteers led us to explore educational profiles of community visiting volunteers as part of this report.

Palliative care volunteering in rural and regional areas includes volunteers helping their own community in times of need. These needs may extend beyond palliative care alone to also helping with activities of daily living like shopping, travel to appointments, respite care and social visits⁷. They can often concentrate on the quality of life aspects of care and encompass a holistic viewpoint.

The experience of living in smaller rural communities carries additional implications for the way in which volunteers are supported. There is greater potential for relational impact upon the death of one person if they are part of a community where 'everyone knows everyone'⁸. There is also a greater potential for relational impact resulting from the consequences of ethical dilemmas regarding to privacy and confidentiality for volunteers^{7,8}.

The experience of community visiting volunteering in regional and rural areas is embedded in the experience of life in rural and regional areas where inpatient services are fewer and geographical isolation from specialist support may be greater. In this way, the role of community visiting volunteers in rural and regional areas may well be to actively connect the patient and family back to their community⁹ rather than just into palliative care. Encouraging volunteers to fill these more generalist roles would also be beneficial for community aged care services providing palliative care in rural areas where cost-effectiveness is crucial. The justification of registered

nurses to perform tasks that relate to companionship and home care is difficult to rationalise economically¹⁰.

There is also a concern that the ageing of paid care workers in regional and rural areas will be problematic for future provision of high-quality care, as those approaching retirement age are less inclined to take on additional study or role responsibilities¹⁰. Encouraging people to volunteer and take on general companionship and home care roles could alleviate the potential for shortages in the future.

Method

Palliative Care NSW surveyed palliative care volunteers attached to known palliative care volunteer services in rural and regional NSW in April-May 2017. Services (n=10) were selected on the basis that they were within a Regional and Rural Local Health District in NSW, that their main focus was supporting adults, and that some or all of their volunteers performed visiting roles into the community for patients and families in palliative care.

An online survey was developed consisting of 21 questions in total. Quantitative data was obtained through closed-ended questions utilising Likert scales and multiple choice. Some open-ended questions were utilised to obtain thick data for thematic analysis.

Contact with volunteers was made by through their volunteer manager. An email was sent individually to each volunteer manager who was asked to forward the survey details and web-link to their volunteers and request their involvement.

A reminder was sent to volunteer managers 10 days after the initial request, and a follow-up phone call was also made. In total, the survey was open for 5 weeks.

Purposive sampling was used for this survey, focusing on rural and regional volunteers that worked directly with palliative care patients and their families within a community setting. A total of 28 respondents completed the survey, representing 6.7% of all potential respondents. The response rate across all questions was 100%.

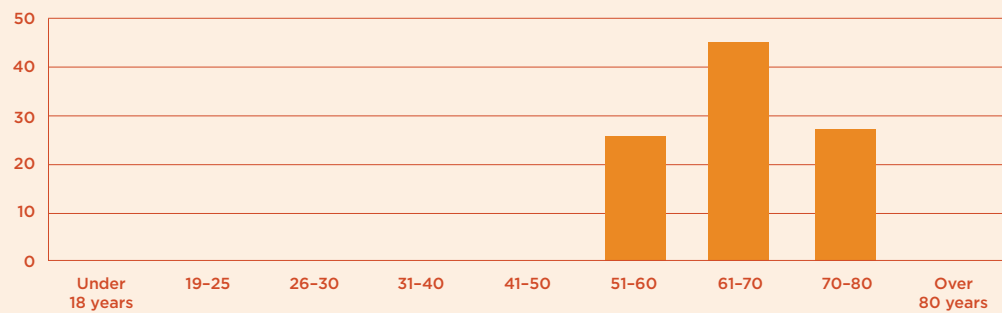
Some limitations of this research related to time-frames and the ability to cover large geographical areas across regional and rural NSW, hence an online survey was chosen as the most efficient instrument for conducting this survey. This research acknowledges that the response rate may have been negatively impacted due to limited internet access in rural areas, as well as a resistance from volunteers from older age groups to engage in online activities.

Findings

Demographics

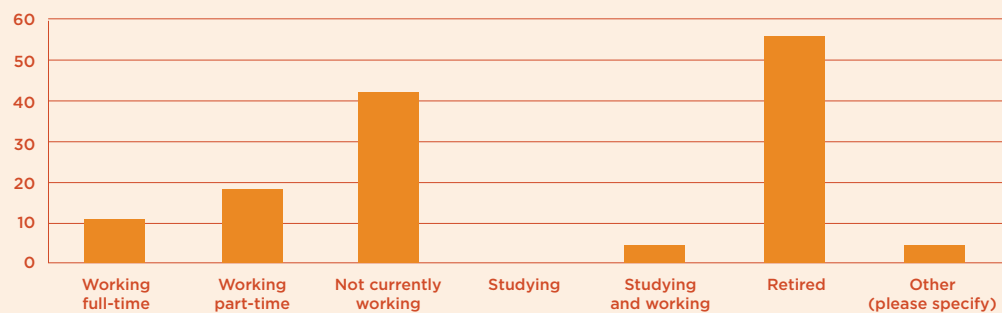
This research analysed the demographics of community visiting palliative care volunteers. The majority (71%) of respondents to the survey were female. Volunteer workforces are commonly imagined to be heavily female biased. Interestingly, the split in this study was close to 70/30 female to male. The median age for all respondents was 61-70 (46%) and other respondents were either 51-60 years (25%) or 71-80 years (29%) of age. There were no respondents outside of these age groups. These findings were consistent with a UK study identifying the 'typical' palliative care volunteer as someone likely to be female, 55 or over, retired and white¹¹.

Table 1: Please select your age group



Respondents were most likely to be retired (57%) with some indicating they work full (11%) or part (18%) time. One respondent indicated that, in addition to their volunteering role, they were sole carer for an elderly relative.

Table 2: Which of these best describes your current situation (in addition to volunteering)?



When asked about tenure some 54% of respondents indicated that they had been involved for 1-5 years, and 36% indicated involvement beyond 5 years. Only 21% had been volunteering in their role for more than ten years. This decline in tenure could possibly be due to the advancing age of the volunteers.

Some 79% of respondents reported some post-year 12 education, with about a third of these indicating post-graduate qualifications, and 50% of respondents having achieved TAFE/College qualifications. Although the educational profile of palliative care volunteers is not well documented this finding reflects anecdotal evidence that they often hold non-school qualifications. In comparison the Australian Census results indicated that some 59% of people aged 15 to 74 years had completed a non-school qualification, and that this correlated with employment related skills¹². In general we feel that this finding points favourably to the capacity of the respondents to exercise autonomy within their roles, a key part of the role of community visiting volunteers.

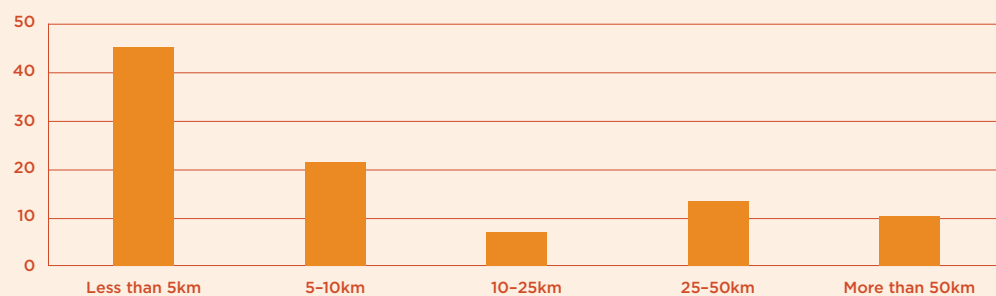
Volunteer Commitment

The majority of respondents (61%) indicated a contribution of between 2-5 hours per week in their volunteering role, with 29% indicating less than 2 hours per week. This is consistent with a commonly accepted weekly contribution by volunteers in palliative care of up to 4 hours².

Understanding why people volunteer in palliative care is crucial for improving recruitment and retention of volunteers. This research found that the main reasons people chose to volunteer in this role were because they had experienced palliative care as a friend or family member of someone who was dying (32%) or that they felt they had the relevant skills to contribute meaningfully to the role (29%). Many (18%) said they loved helping and caring for people wherever help is needed but some (14%) volunteered specifically to support a family or carer in need.

Respondents typically travelled less than 5 km to visit their last client (46%) but surprisingly some 11% had travelled more than 50km in their last visit to a client. Some 29% had travelled more than 50km at some time in their volunteering experience. In a Metropolitan context, 50km roughly correlates to the distance across the Sydney Metropolitan area from Hornsby in the north to Cronulla in the south.

Table 3: When thinking about your last client visit, approximately how far from your home did you travel?



Some 89% of respondents indicated that they normally used their own vehicles to travel to their client with 7% of respondents indicating that they used their organisation’s vehicles.

For 64% of respondents, the cost of travel was met by themselves without the possibility of reimbursement from the organisation. For those attached to organisations willing to meet their travel costs, some 18% of respondents indicated that the cost was reimbursed after they had incurred it, 7% indicated that they were paid in advance for their anticipated costs, and another 7% indicated that they declined reimbursement as they considered the absorption of travel costs to be part of their voluntary contribution.

Client contact

In the last 12 months, half of the volunteers surveyed had been involved with 1 or 2 clients, with 18% having been involved with 3 clients. Some 11% of respondents indicated that they had been involved with more than 10 clients over the past 12 months, while 7% of respondents indicated no client involvement at all in the same period.

When asked ‘What roles do you normally perform with or for your client/s?’ a significant majority of respondents indicated ‘social support and companionship’ (86%) as the most likely descriptor of their role. The following table shows all responses (total exceeds 100% as multiple responses were allowed). *Note that no respondents indicated that they assisted with domestic tasks.*

Role	% respondents
Social support and companionship	86
Carer respite	43
Visits into the community	39
Assistance with family/children	11
Assistance with equipment	11
Assistance with mobility	7
Biography	7
Other - Assistance with meal preparation	7
Assistance with domestic tasks	0

When discussing the contribution of their volunteering to patients and families, the majority of respondents felt they had made a lot of impact (43%), a great deal of impact (32%) or a moderate impact (21%). No respondents that their contribution had made little or no impact on patients and their families.

In addition to the quantitative part of the survey, we included open-ended questions such as; ‘In your experience, what is the most difficult part of volunteering in palliative care?’. Each respondent offered one comment and in each case, it related to their empathy for and relationship with the patient and family in the context of the impending death of the patient. 46% of respondents indicated losing a relationship through death was the most difficult part of their role. Additionally, 25% of respondents replied they felt that the palliative care team was not responding adequately to the patient’s needs.

“Seeing the sadness and loss the carer’s experience”.

“Waiting for the inevitable. My client is in remission, but that won’t last forever”.

“Seeing people I have known for many years...”

Respondents commenting on the most difficult part of their volunteering.

When asked ‘In your experience what is the most rewarding part of volunteering in palliative care?’ each comment related to the respondent’s sense of being valued and beneficial. Some 75% of respondents indicated that the sense of ‘being there’, helping, supporting or making a difference rated highly in their experience of volunteering. Others (21%) expressed similar but slightly more extrinsic sentiments about seeing bonds strengthened, feeling appreciated or valued and contributing to a better society.

“Knowing that I have made a difference in the lives of the client and their family by just simply being there for them”.

“Making a difference in somebody’s life, being able to provide company and interact with them when they are visually house bound”.

“Being a helpful member of society”.

Respondents commenting on the most rewarding part of their volunteering.

When asked ‘In your experience what is the most unexpected part of volunteering in palliative care?’, 53% of respondents articulated they had unexpectedly positive insights into their own and other’s strengths, compassion and courage. 21% of respondents indicated that they had been surprised by some aspects of palliative care services, for example, the lateness of referrals or the behaviour of staff. Some 11% of respondents said that the lack of community awareness about palliative care, dying and death had been unexpected.

“Experiencing the courage of others”.
“How quickly it felt like the right ‘fit’ for me”.
“The client’s misunderstanding of their true palliative situation”.

Respondents commenting on the most unexpected part of their volunteering.

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Volunteering perceptions and intentions

Several of the questions were designed to give insight into the perceptions of respondents regarding their volunteering role, and of their intentions to continue. One way to gauge how respondents experienced their role was by asking them to choose a selection up to 5 words from a list of suggestions. Their responses are shown in the table below (totals exceed 100% because multiple answers were allowed).

Answers	Response %
Meaningful	93
Rewarding	86
Fulfilling	75
Inspiring	39
Challenging	39
Grounding	32
Educational	32
Essential	32
Sad	29
Uplifting	25
Spiritual	14
Depressing	4

Overwhelmingly their responses were positive affirmations of their experience. The words most obviously connected to negative connotations like ‘Sad’ and ‘Depressing’ rated amongst the 4 lowest scored words.

Respondents were asked to respond to specific prompts about their experience as volunteers. When those responses given for strong agreement and agreement are combined these are the statements that resonated most strongly were ‘I am given adequate introduction and information about my client/s at commencement’ (86%); ‘My health services listens to my feedback and concerns’ (82%); ‘There is enough autonomy in the system for me to respond to requests by my client/s’ (82%); and ‘I feel connected to other volunteers within my service’ (79%).

In response to questions pertinent to workplace health and safety ‘At times I have felt my safety threatened’ rated the highest level of aggregated disagreement (82%) with no respondents indicating their agreement. It is wonderful to show that despite the fact volunteers are working alone and in potential isolation from their service, and in situations where they might not be sure just what to expect behind the front door this time, none have felt threatened in any way.

Also, 64% of respondents agreed or strongly agreed that ‘My health service supports my emotional needs’. Feeling supported is an important factor that contributes to volunteer retention rates.

Respondents were more likely to neither agree nor disagree with ‘I want to be more included in my health service’ (43%) and ‘I want to be more closely supported by the staff’ (39%). 40% disagreed with the statement ‘Clients ask more of me than my role permits’. These figures might be explained by the fact that due to the nature of the role, community visiting volunteers tend to be more autonomous and capable of working under less supervision.

When asked about their intentions to continue some 43% indicated a desire to continue for 1-5 years and some 27% indicating they thought they would be involved for more than 5 years. Significantly some 25% were uncertain how long they would continue. Respondents indicated they would be very likely (53%) or likely (36%) to recommend community visiting palliative care volunteering to others.

While none indicated that they would be unlikely to recommend, some 11% rated their response as unsure. Overwhelmingly, volunteers were satisfied with their roles. Their intention of ongoing tenure and likelihood to recommend palliative care volunteering demonstrates this effectively.

Discussion

This survey has revealed many aspects of adult-focused, regional and rural community visiting palliative care volunteering in NSW. As the first survey of its type, we have little comparative data, but the value of the observations is in creating a picture of demographics, experiences and intentions.

One of the challenges for an organisation in supporting community visiting volunteers is the need to be mindful of the difficulties when traveling and the coincident liabilities for health and safety on the organisation. Volunteers are subject to policy and procedures with the most immediate concerns for the roadworthiness of the vehicle and the safety of the driver therein. This survey indicates that a high proportion of respondents travel to visit their client by using their own vehicles (89%) and that the distance they travel is not insubstantial. The necessity to travel beyond 50km at some times was experienced by almost a third of respondents. Although age is not necessarily an indicator of driver competence, it should be acknowledged

that under NSW law, drivers 75 years and over are required to undertake an annual medical review to renew their licence. Considering 29% of this survey's respondents are aged between 71-80 years, this requirement should be taken into consideration by volunteer managers.

Another set of management concerns relates to the reimbursement of volunteers for the costs associated with their travel. Some volunteer services offer full or limited reimbursement to volunteers, but not all. The survey revealed that a high proportion (71%) of respondents donate not only time but money by meeting the associated costs of vehicle use personally. This is another example of the commitment that community visiting volunteers bring to their role. This might be problematic in some rural and regional communities with low socio-economic demographics, where there may be limited access to vehicles and prohibitive costs associated with travel. Improving volunteering in these communities may require more financial support from the services to their volunteers.

Concerns about safety can be exacerbated by the quality of the road network and the unreliability of mobile phone coverage in regional and rural areas. This could potentially prevent a driver calling for assistance or reporting a change in planned schedule or route. Infringements on safety can also be experienced in the context of a home visit where the volunteer may be exposed to variations in the person's domestic setting (such as pets, trip and slip hazards, other visitors to the house) that the volunteer may perceive as a threat to their safety. Interestingly, when asked, none of the respondents felt that their safety had been threatened. This could be seen as a testament to the diligence of services in ensuring effective risk-assessment processes and having good safety frameworks in place for their volunteers.

Emotional safety is also part of the experience of volunteers as they accompany the patient and carer at end of life. Volunteers who fulfil their role as a community visitor are working within the very personal confines of their clients' homes. This environment fosters a particular level of intimacy that may not be established in other volunteering contexts. Given that so much of this role hinges on the emotional connection between the volunteer, the client and their carer, it is important that services provide adequate support. While it is not unexpected for palliative care volunteers to experience the death of their client, in rural and regional areas where communities are smaller, losses may have a greater relational impact. It is important that services maintain adequate access to grief and bereavement support services for their volunteers. This research revealed only 64% of respondents

felt their emotional needs were adequately supported, showing there is still room for improvement in this area. This may be more of a challenge in rural and regional areas where geographical isolation often means less counselling services are within easy reach. However, with the development of online communication technologies, there is definitely scope for services to provide online forums or support groups for volunteers to engage in, thereby improving emotional support overall.

The role of the palliative care volunteer is fraught with complicated physical and emotional challenges. Managing grief and loss for themselves as well as their clients requires a highly developed emotional intelligence, balancing compassion with the necessity to maintain emotional boundaries. Volunteers value the sense of purpose they feel by being helpful and attentive to the unique needs of their clients and their carers. The involvement of volunteers in meal preparation, community outings, assisting with mobility and equipment, and assisting with family/children are all practical tasks that ease the burden of carers and help palliative patients to remain at home. This makes the role of the community visiting volunteer a vital part of the social network needed to allow a person to die at home in regional and rural NSW.

It would be easy to assume that the role of a palliative care volunteer would be overwhelmingly sad and depressing, however, the findings of this research that show most volunteers more strongly associate words such as 'meaningful', 'rewarding' and 'fulfilling' with their role, alluding to their positive experiences. This points to high levels of intrinsic satisfaction amongst volunteers in this survey, to which the health service can respond by nurturing the emotional/spiritual needs of volunteers.

As part of an allied health team caring for palliative patients, these respondents believed they could meet the needs of their clients because they felt well-briefed and supported by their health service. From an organisational perspective, being part of a system that engages volunteers and keeps them connected is a central part of the role of a volunteer manager. These responses are perhaps a tribute to the work done with these volunteers. This is perhaps further evidenced by the respondents' keen sense of connection to other volunteers within their service.

Maintaining an adequate number of volunteers in a service may prove to be a challenge for the future. Increasing diversity amongst volunteers is crucial to the ongoing success of any volunteering service, whether it is across age groups, gender groups or ethnic backgrounds it is advantageous to ensure the sustainability of the service as well as appropriateness. Although some 75% of respondents were over 61 years of age and most expected

to continue volunteering for the next five years, beyond that there is a steep decline in the certainty of their tenure. Fortunately, the data shows that participants would almost unanimously recommend community visiting volunteering in palliative care to others. Finding ways to tap into this goodwill might prove beneficial for recruitment initiatives in the future. Personal pleas and recommendations can often go a long way toward convincing others to commit time to helping their community. Respondents acknowledged that their positive experiences of palliative care provided to family members was one of the main reasons they decided to initially volunteer. This demonstrates how the inter-connectivity and community spirit often found in smaller communities might be an advantage for regional and rural volunteering services now and into the future.

End notes

The Volunteer Support Services Program

This paper has been prepared as part of the Volunteer Support Services Program which is hosted by Palliative Care NSW and funded by NSW Health. The Volunteer Support Services Program seeks to champion the work and interests of Palliative Care Volunteer Services and volunteers in NSW (www.volunteerhub.com.au).

Suggested citation:

Bowman K, Burke M & Huntir A (2017) *People I have known: The experiences of rural and regional community visiting palliative care volunteers in NSW*, Palliative Care NSW, Surry Hills.

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