Palliative Care NEW SOUTH WALES | Palliative Care Volunteering

Research Report

Palliative Care Volunteering in Residential Aged Care Facilities in NSW: A sample study in Western Sydney LHD

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Background

This research project was developed by *Palliative Care NSW* with the intention of shedding light on the participation of volunteers in residential aged care facilities (RACFs) in NSW, particularly their involvement in the palliative care of residents. *Palliative Care NSW* through their membership has an interest in promoting high quality palliative care across the health sector and NSW community. This research will hopefully provide guidance on how volunteers can be better engaged in end-of-life care for older Australians.

According to the Australian Institute of Health and Welfare over the last 20 years the proportion of people dying who are aged care residents has increased (AIHW, 2014). With current research suggesting that there will be more than twice as many people aged over 80 years old in 2050 than there are now (Colombo, Llena-Nozal, Mercier & Tjadens, 2015) this number will continue to rise.

This trend is confirmed by projections for the catchment for this study, Western Sydney Local Health District (WSLHD) which currently (2015) has a population of 926,911 people of which 25,154 people are over the age of 80 years. This is expected to rise to 1,139,689 people by 2025 of which 39,507 people will be over the age of 80 years (Centre for Epidemiology and Evidence, 2015). This represents an expected increase of some 14,353 people over the age of 80 years within 10 years.

As the population ages and people continue to live longer with more high-care needs then the provision of high quality palliative care in RACFs will become an ever more important issue. The Productivity Commission report *Caring for older Australians* stated that palliative care is 'core business' for any aged care system (2011).

The recent AIHW report *Use of Aged Care Services before Death* (2015) analysed 116,481 deaths of people over 65 in 2010–11 and showed that about 50% of older Australians died in hospital probably while accessing specialist palliative care. Whilst it is unclear just how many of these were RACF clients we know from the report that about 45% of all people over 65 accessed residential aged care immediately before their death. Proportioned for NSW, the potential impact on the state-funded palliative care system from these RACF residents will be some 15,724 additional people.

Volunteers represent an important adjunct to specialist palliative care services in many parts of NSW, with some 1,242 palliative care volunteers active in 38 services across the state in 2014 (Hansen & Huntir, 2014). Volunteers typically function as supernumeraries, improving the experience of people in palliative care by variously offering companionship, psychosocial support and practical assistance.

In RACFs the contribution of volunteers now and into the future could be crucial in alleviating pressures from RACF staff challenged with meeting the complex care needs of this diverse group of people. *The Guidelines for a Palliative Approach in Residential Aged Care* (2006) acknowledge the importance of the 'integration of trained volunteers into multidisciplinary teams [that] can enhance the provision of a palliative approach to residents' (NPCP, 2006).

We acknowledge the different meanings of the terms 'palliative care' and 'palliative approach' which suggest different acuity and specialisation. It was not within the scope of this research to critique these meanings, and instead the term 'palliative care' is used to capture the breadth of meanings.

Specifically then this research project seeks to understand how palliative care can be adopted or enhanced in RACFs by effectively incorporating volunteers into the aged care team.

Method

Throughout September 2015 *Palliative Care NSW* interviewed staff working in residential aged care facilities (RACFs) within the Western Sydney Local Health District (WSLHD) to gain an insight into how different services utilise volunteers, and explore attitudes towards volunteer involvement in palliation.

This was a sample study of RACFs in the WSLHD area (n=12) and not all RACFs were surveyed, with participants being invited at random. Invitations were emailed to facility managers and volunteer coordinators across the WSLHD and follow-up phone calls were made to arrange interview appointments with those interested in taking part. Participation in the research was voluntary.

The interview consisted of 16 semi-structured questions for services that had volunteers working directly with residents, with open ended responses encouraged to clarify attitudes and preferences throughout the interview. For respondents representing a service that did not utilise volunteers, 2 open ended questions were asked to explore their attitude towards volunteering, and whether their service could benefit from a volunteer program.

A total of 12 respondents were interviewed over the telephone. Of these 25% did not utilise volunteers in their service and 33% utilised volunteers in their service but not in palliative care. The balance of 42% had volunteers in their service and considered them to be involved in palliative care.

The respondents represented a wide range of roles, 25% of respondents were Care Managers with the rest of the sample divided quite evenly between facility managers, clinical managers, assistants to managers, Directors of Nursing, Project and Development Managers and Pastoral Care Managers.

A variety of RACFs were represented in this sample, 50% were privately operated and 50% were not for profit (NFP). 67% of the NFP services were faith based. The average number of beds in the services represented was 98 beds, with the smallest service having 52 beds and the largest having 134 beds. All RACFs had been in operation for at least 10 years, with 75% operating for more than 16 years.

Findings

Concepts of 'Palliative Care' in Residential Aged Care Facilities

This research highlighted some notable differences in how palliative care is defined within the RACFs studied, and the patterns it illuminated may have significant effects on volunteering and the provision of palliative care in RACFs more broadly.

Those respondents who utilised volunteers but not for palliative care typically described palliative care as an event which occurred within the "last couple of days of life". They talked about families becoming involved "at this point" and about palliative care being part of the role of paid staff such as the Registered Nurse. These respondents were concerned about the appropriateness of introducing a volunteer, or a "stranger" to a resident who was dying.

Contemporary notions of Palliative Care are time-generous and eschew a 'last-minute' focus on care. For these respondents it was clearly about terminal care, where the 'goals are more sharply focused on the resident's physical, emotional and spiritual comfort, and support for the family' (NPCP, 2006). In direct contrast to this, when these same respondents were asked to describe the roles their volunteers fulfilled, commonly mentioned were activities such as sitting and talking, playing music, reading poetry, having a cup of tea. While these roles could clearly be seen to alleviate social isolation and provide comfort and support to residents, these respondents did not describe them as part of palliative care.

"When I talk about palliative care I'm talking about the last couple of days of life, because, let's face it, everyone who walks through the door of a nursing home is palliative, no one is going home again."

In comparison, the group of respondents who utilised volunteers that were involved in palliative care acknowledged that the role of volunteers "just being present, just being" with a resident was part of palliative care. There was an emphasis on providing "emotional and spiritual support" and the importance of "companionship" was mentioned several times.

While the activities performed by volunteers were similar across the two groups, there appears to be an opportunity to adopt a broader understanding of palliative care across RACFs to ensure volunteers are aware that they are involved in the palliative care of residents. This could help to overcome the negative stereotypes of palliative care and promote volunteer participation and RACF training and support programs.

"A lot of volunteers are reluctant [to become involved with palliative care] – perhaps because of a lack of understanding, training and a certain amount of fear."

Volunteering and Organisational Culture of RACFs

Across the sample, attitudes to volunteering varied greatly. Anecdotal and personal experiences appeared to heavily determine an individual's perception of volunteering. However, from an organisational perspective, when asked whether volunteer participation could improve the quality of palliative care provided, there was a belief amongst services that did not utilise volunteers at all, as well as those that did not utilise them for palliative care, that their provision of palliative care was currently adequate, due largely to the level of staff expertise and current practices. Combined with a belief that "volunteers are here to help us, not the other way around" there seemed to be a general belief amongst this group that the needs of volunteers for training and support often outweighed the benefit to the organisation.

When contrasted with the views of services that utilised volunteers in palliative care, these concerns are even more pronounced and could be one of the most significant challenges to improving volunteer participation in RACFs for palliative care. It was imperative to the group not utilising volunteers in palliative care that volunteers were adequately screened and trained prior to commencing service in the RACFs.

As volunteering was not considered "core business" some respondents found it difficult to justify the time and resources that would be required to recruit, train and retain volunteers for palliative care. This reflected the concern that volunteers often required a significant amount of management and support that these services were unable to justify.

"We don't have the time to do education, and to provide the support or training needed."

When compared with services that were utilising volunteers in palliative care, and believed they contributed positively to the service, there was clearly an appreciation of the importance of "investing" in volunteers through training, feedback and inclusion in the aged care team.

Interestingly, these services believed they still had room for improvement. One service that utilised volunteers in palliative care stated:

"We can do much more, we just need to have a volunteer coordinator and we could have volunteers trained better, comprehensive training that would see the volunteers as a part of the team, the "real team".... We need to train, value, appreciate what they do, it's just as important as the paid work of nurses."

These distinctly opposing views on the cost-benefit of volunteers may be a telling point in why some services are more likely than others to include volunteers in their palliative care of residents. It also suggests that volunteers in palliative care may be more broadly adopted if they had external training and support services available to them.

The study also found that services without volunteers in palliative care typically averaged 10 volunteers per service contributing about 2 hours per week each. Compare those services with volunteers involved in palliative care which had on average 5 volunteers per service contributing about 12 hours per week each.

This inverse correlation may suggest that volunteers who spend more time in their RACF getting to know residents and staff can be more effectively included in the residential aged care team, and contribute to the palliative care of residents. Services that utilise larger numbers of volunteers for fewer hours may be more task focused, with less emphasis on establishing deep relationships with residents and rather in providing overall support, often in group activities, with less one-on-one time.

Volunteers in palliative care seem to be most effective when they have established relationships with staff and residents, are trained and supported and valued as part of "the team" (Claxton-Oldfield & Claxton-Oldfield, 2008; NPC, 2005). Confidence in being able to train volunteers was a significant predictor of their uptake by RACFs. For example in RACFs where volunteers were not utilised in palliative care, some respondents often questioned whether volunteers could ever be "physically and emotionally stable enough" to deal with someone dying.

Preparation, Training and Management of Volunteers in RACFs – Expectations vs Reality

Across all groups, respondents expressed concern about managing "volunteer expectations" within "the reality" of residential aged care. The research suggests that inadequate preparation for volunteers before they enter a RACF may contribute to what respondents described as problematic expectations by volunteers:

- Volunteers being unprepared for the sensory aspects of residential aged care, such as smells and sounds.
- Volunteers being unfamiliar with challenging behaviours of residents, particularly those with Dementia.
- Volunteers being uninformed about palliative care, instead associating the term "palliative care" with the belief that a resident is about to die.

Better preparing volunteers for the specific challenges of RACFs could directly improve the provision of palliative care by addressing preconceptions, stigmas and negative connotations of aged care and palliative care simultaneously. Training that specifically teaches volunteers about palliative care could be most effective if introduced prior to volunteers being confronted with the emotional and physical challenges that will inevitably arise in this setting. Comprehensive initial training also provides volunteers with broader knowledge and subsequently a greater understanding of the residential aged care setting overall (NPCP, 2005). It is possible that the expectations of volunteers actually reflect a lack of adequate preparation for the aged care setting, including the needs of challenging residents and residents whose care requires palliative care.

As previously mentioned, training and management of volunteers was described as a resource issue for RACFs. The time and management required to establish and maintain an effective volunteer program was often given as a reason for not extending the inclusion of volunteers into the area of palliative care. However, for the services that did utilise volunteers in palliative care, there were several distinct characteristics in the way they managed volunteers. These services spoke of:

- Informal and formal feedback to volunteers
- Recognition of volunteers within the service – Morning teas, Christmas parties etc.
- Inclusion in discussions about the care of residents as well as keeping volunteers up to date about changes in a resident's condition
- A higher degree of autonomy for the volunteer to determine how they will interact with residents
- Encouraging the establishment of professional but meaningful relationships between volunteers and residents

> *"The other day I asked a volunteer how she felt with regard to a couple of residents when they were ill, she really wanted to be with these residents, and be involved in their palliative care as she was very close to them."*

This research suggests that the services making best use of their volunteers are actively including them in workplace communication and interaction, and affording them autonomy and flexibility to assist in the provision of quality palliative care.

While no services mentioned specific training in palliative care for their volunteers (even those utilising volunteers in palliative care did not provide specific training in this area) it was the management and support of volunteers that differed most dramatically. There was a willingness to invest in the volunteers, to provide what was essentially "on-the-job-training" if the volunteers were interested in helping with the palliative care of residents. In comparison, services not utilising volunteers in this way, were not as open to this investment in volunteers.

"Seriously, volunteers are here to help us, not the other way around. That's their role. If they need emotional support of course we will provide that, but ongoing training is difficult, resources are scarce."

While it appears this investment in volunteers does ultimately benefit the services utilising them and contribute to the quality of palliative care they can provide, the resource shortages faced by many services must be acknowledged as a significant barrier to the improvement of volunteer training and the expansion of volunteer roles and responsibilities.

Discussion – Opportunities for Improvement

This research suggests that there is an opportunity to improve upon the palliative care currently being provided within RACFs by increasing volunteer participation in many cases.

While there is no simple solution to facilitate this, certainly, most of the concerns respondents expressed related to the challenges of adequately training, preparing and managing volunteers for their involvement in palliative care. These concerns alone, point to the need for innovative thinking about how to incorporate well trained and managed volunteers within RACFs, and perhaps warrant the development of new and innovative volunteering programs.

Respondents often described themselves and their facilities as being time and resource poor, they considered developing a volunteer program themselves as an additional burden, and just not feasible.

Perhaps a program similar to the Community Visitor Scheme (Australian Government, 2015) but with a more deliberate palliative care focus should be considered as an option for RACFs who are interested in utilising all available resources to benefit the way their service provides palliative care.

In a similar way, Palliative Care ACT (PCACT) has an active engagement with RACFs through their volunteering program in the Canberra area. The volunteers are hosted by PCACT and are placed with each RACF under the terms of a memorandum of understanding. The primary aim of the program is to support residents with palliative care, but it also serves to increase awareness of palliative care amongst RACF staff, and assists RACFs to demonstrate compliance with the residential aged care Accreditation Standards in particular item 2.9 Palliative Care (Commonwealth of Australia, 2014).

Essentially the PCACT volunteers spend time with residents, offering support and companionship within the facility. They are thoroughly screened, trained, and managed by PCACT, alleviating the burden for the RACFs themselves. While this program is only recently out of the pilot stage the early feedback has been positive and about 19 RACFs have signed memorandum of understandings. Plans for the future include engaging with more RACFs, and looking at ways to better meet the needs of culturally specific groups in the community that are currently in need of palliative care support services.

In addition to the development of new and innovative ways to include volunteers within RACFs is the necessity to educate staff, volunteers and the community about palliative care. Differing opinions on what constitutes palliative care may be contributing to a degree of confusion as to how volunteers could potentially form a successful part of the aged care team.

Where services strictly thought of terminal care, rather than longer term palliative care they were less likely to engage volunteers in this area. While it is likely that at least some of these services did utilise volunteers to provide comfort to residents and reduce social isolation they did not believe that volunteers were adequately prepared for end of life care, and therefore did not consider them part of a palliative care response.

Ensuring there is a better understanding of palliative care may also benefit volunteers by reducing the fear around the term 'palliative' which several respondents suggested made volunteers uncomfortable as they believed it meant the resident was about to die. Through better awareness and a more inclusive organisational culture, it may be possible to develop a system that can introduce the volunteer into palliative care much earlier in a resident's journey, improving outcomes for facilities, volunteers and most importantly the residents and their families.

In summary this research suggests that there is an overwhelming willingness to include volunteers more extensively within RACFs, specifically to include them in the provision of palliative care. Including volunteers in the residential aged care teams caring for these residents could provide nursing staff with more time to address the clinical needs of residents at end of life, while still providing the psychosocial and spiritual support that is essential when delivering high quality palliative care, and therefore improving the overall standard of palliative care in RACFs.

While most services spoke highly of the way they provided palliative care currently, this research did not ask how they would cope in the future, as the pressure of an ageing population with increasingly high care needs places pressure on staff and resources in many RACFs. Without a crystal ball it is impossible to see what the future holds, but this research suggests that volunteers can be, at the very least, a part of the solution to these challenges, and at the most, an invaluable part of aged care teams providing palliative care to residents in aged care facilities.

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).

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