Research Report

Faded away: The life and death of a district volunteer initiative in the bush and lessons for the future of palliative care volunteering

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Palliative Care NEW SOUTH WALES | Palliative Care Volunteering

> *So…(without support the volunteer effort)…slowly just faded away, and I was really sad about it, so many great people, so willing, and yet it was just allowed to fade away.*
>
> (Volunteer)

Background

The history of palliative care is illuminated by stories of effort and achievement. Often volunteer services are breathed into life with much enthusiasm. The service then grows slowly but surely as support for the work of the volunteers gathers momentum. Stories such as these speak about the willingness of practitioners and members of the community to support their people at end of life, and are testimony to the energy and hard work of the local practitioners, community spirit and the happy coincidence of opportunity.

But not always. Sometimes the story is an initial flourish followed by a slow fade. Such is the nature of this story.

This report looks into the history and the experience of a palliative care service in regional NSW to establish a volunteer initiative across multiple sites. The program was supported for a time but then slowly declined, much to the disappointment of many. In addition to acknowledging the commitment demonstrated by the individuals involved, the report is interested in how a similar disinvestment can be avoided in the future. Ultimately the aim is to use their experience to identify what features would constitute a sustainable palliative care volunteer program in a similar regional area. During March 2016 the author travelled and met with the participants in this study, taking notes and visiting sites of relevance. Two of the original volunteers were included in the study. Participants requested anonymity. These observations and notes[1] form the basis of this report.

The study

In 1995 a regional specialist palliative care service saw a need to provide volunteer support to people who were identified as palliative but living outside the regional centre and in many cases were socially isolated due to their illness. There was already a palliative care nursing outreach service developed to support the primary health care providers with pain and symptom management and support the physical needs of patients. It was decided to address this need by developing palliative care volunteering teams within their region. These volunteers would be trained by the specialist palliative care service using the recruitment and education program they already had in place.

In each location this required the involvement of the local community health team. In most places the only locally based health professional were the community nurse, GP and part time allied health staff (if available). Support of the community nurses was essential to ensure support and local coordination for the volunteers, and for ensuring that patients receiving palliative care were offered the volunteer service. In short, for ensuring that volunteers were regarded and included as part of the team.

In some communities it was the community nurse who identified the need and approached the specialist palliative care service about incorporating volunteer support. These nurses had insight and commitment to their community needs. But staff move on or retire.

In reflecting on their experiences the agreement with managers was obtained, the process was implemented but as with many things in health changes in management and nursing staff occurred and this commitment fell away over time. The palliative care team acknowledged the necessity of being thorough in maintaining the managerial commitment through discussions about the valuable role a volunteer can play in supporting the local community. The community nurse was also required to understand the value of the volunteers within the team and how they can assist with caring for patients.

The implementation wasn't straight forward. It was critical to win the confidence of nursing staff, and have the volunteers regarded as part of the team, but often communication was through the managers rather than directly to the nurses and allied health staff. Volunteers were not included in discussions with clinical staff. One of the practitioners noted:

> *"What didn't happen was adequate preparation at the sites with the managers and the nurses. The only volunteers that most staff had worked with were the flower ladies, and so because they, the staff, weren't aware of the volunteer training program they didn't have any faith in the volunteers or in the role they did. In one case the volunteers were banned from talking about patients even in support meetings with clinical staff...really it was a huge public relations disaster because those volunteers were the public face of our palliative care service and they go back out and talk about what is being done to them."*

One of the volunteers, who trained in a later training group, the 3rd in this town, expressed concern at the lack of understanding of the unique role that the volunteers provide, and her interaction with the local community team:

> *"You are dealing with people who are at a really vulnerable time in their lives...the families we were helping had to trust that we could be trusted that we weren't just a bunch of rosy glowers...the community nurses didn't realise the importance (of the volunteer service), they would see us around, they would say hello, they knew us well, but they just didn't have the time. One of them said to me one day "you know, we do the work that you do" but they didn't."*

According to the practitioners, achieving equal status for the volunteers within the team, or at least an acceptable status sufficient for support and referrals to be made was also a challenge, when there were staff changes and the role of the community nurses was also changing. Although managers had committed to supporting the palliative care program, when people left or had a change in role the new person in the role often was not told it was part of their role even though there had been attempts to write it into the position description. Community nurses do not necessarily have the skills, knowledge or want to manage volunteer teams:

> *"Because the community nurses did not always have a lot of respect for role of the volunteers, they didn't see them as professional, it's like 'oh they're hopeless, you put them out there and (anything could happen)...I just don't trust them'. At some sites the volunteers weren't seen as part of the team."*

The representation of volunteers as 'hopeless' amid the comments observed by the practitioners stands in stark contrast to the reflections of another volunteer trained under this initiative who recalled the group were 'women of great quality' and included some registered nurses.

Breaking down barriers between paid staff and volunteers was crucial. Training was used as a vehicle for not only educating the volunteers, but for negotiating shared understanding with staff:

> *"In the early days we realised there were some barriers when the volunteers were introduced, so we invited the staff into their training program and they did it together...I wouldn't say it worked 100% but it did break down barriers...and a lot of the staff said that they learned heaps."*

As the staff reflected on their motivation to develop volunteering they commented on the need for volunteers to be accountable for their work, the necessity of communicating this to the clinicians with which they would be working, and the importance of keeping a professional management system in place for volunteers. A clinician noted:

> *"I think that volunteers are part of the professional palliative care service and they need to be treated as professionals, so that they are handed over to (as nurses do) so that the volunteers know that they are held in high regard and they also know the team so when something happens that is outside of their role they have someone to feed that back to... all of those checks and balances broke down or were never put in place...some of the volunteers were traumatised and bitter."*

These comments further support the need for a consistent, and by inference a paid manager of volunteers role.

From a management perspective the funding to employ coordinators was only part of the formula, as the service also needed adequate coordination and management of workplace health and safety risks, and to clarify boundaries of practice for the volunteers:

> *"It's more than funding...for me it's a staged process, first you need people and systems in place to support the volunteers that is inclusive of the bigger picture, that links volunteers into the existing services and the system for referrals. If a hospital or facility says 'we don't want them' then we would be better to not do it at all."*

> *"There has to be a proper risk (occupational health and safety) assessment (for home visits). I (a team member) once went to a referral meeting in a small town and the community staff said to the volunteer group "Ok, Mr so and so lives about 8 km out of town - who wants to go"... and someone offered to go and the staff member said..."well off you go and see him, I'm not even sure that he wants a volunteer but see how you go" and I was horrified... That's the benefit of having a coordinator in the town, that if there are difficult issues with the family then there is someone who can go in with the authority to sort it out. Having a coordinator go and visit a family means that the volunteer knows what to expect. Even knowing how to respond to changing circumstances the volunteers need to know their boundaries."*

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The task of coordinating volunteers was nominated to staff in paid roles and connected to the community health service. Predominantly the role was allocated to one of the community nurses.

Each interviewee expressed support for a paid volunteer coordinator role dedicated to the management of volunteers. They related stories about how in some locations the role of volunteer coordinator was 'passed around' to one of the community nurses who was neither properly resourced nor had an understanding of the role of the palliative care volunteer. A practitioner commented:

> *"In one instance a coordinator requested training for a group of potential new volunteers but didn't see the need to be present or participate herself, she thought she knew all that was required to be known, but she didn't, and because she didn't participate she also didn't get to know or develop an initial relationship with the volunteers. A coordinator or manager needs to know their volunteers if they are going to make an appropriate placement with a patient and family.*

> *"We agreed to do the training if the health district would provide the volunteer coordinator. We managed the teams for a number of years having developed them to have a sound foundation and then recognised that we couldn't grow them further (for logistical reasons). So we spoke to the regional managers again and said 'are you willing to take this on' and let the teams now grow in the uniqueness of their own community, and they did, but...there was no funding, so it was usually again assigned to the community nurse with no extra hours, just tacked on...sometimes it worked ok if the community nurse had a passion for palliative care but it was often given to a community nurse via a job description and was not really what they were interested in or had the appropriate leadership skills for, or it was passed to (another allied health clinician) but the nurses did not always recognise those clinicians (or the volunteers) as part of team so the referrals stopped..."*

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A volunteer who managed the volunteers in an unpaid role while a community nurse was being recruited, believed that the paid coordinator's role is pivotal to the successful management of the volunteer service:

> *"The coordinator's role needs to be a funded role; it gives you that step removed from the volunteers, so that when a volunteer is going beyond the boundaries, it gives you more authority to address it. If you are a volunteer making a judgement on another volunteer (your lack of credibility) can cause a bit of dissention in the group, whereas a paid role is one step removed..."*
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> *"There truly needs to be a connection between the referring body and the volunteers otherwise the referrals stop...it's a pivotal role... keeping the service professional, maintaining support to the volunteers, keeping everyone within the boundaries it's essential."*

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The practitioners also noted the importance of the volunteer coordinator being savvy to local tensions, parochialism and family histories, making sure that the volunteer was well received by the family, and that the person was linked into a service that was well regarded by them. The dispersed population in regional centres creates challenges for service management:

> *"If you had a volunteer coordinator with clearly defined geographical area then I think it would work...the coordinators could be bought together, for meetings or training, so that they meet as a group...they would link in and report to the health district at management level so that any issues could be addressed quickly. They could have access to shared training resources and staff, and they could periodically be included in meetings with the palliative care team. This would ensure standardised procedures for the volunteers across the health district... We would probably need about 1 FTE (full-time equivalent) coordinator in each location bearing in mind that they not only have the volunteers to manage but they would also need time to liaise within the facilities...it's no good giving the (coordinator's) job to one of the palliative care nurses, it's a different role, it is a separate discipline."*

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One volunteer remembers the disappointment of the cessation of the service and the sense of futility:

> *"So (without support it) slowly just faded away, and I was really sad about it, so many great people, so willing, and yet it was just allowed to fade away.*

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Another volunteer adds her own footnote on the effect felt within her local community following the demise of the volunteer service:

> *"I've been hearing lately of families who have gone to hell and back on their own (without support), and it makes it hard after death and funeral and things... afterwards they can get very bitter and grief takes on a different hue and it doesn't need to be. When everybody goes back to their everyday lives these people are left on their own with no-one to follow up on them and ... these people have done it tough unnecessarily (because the volunteer service wasn't available to them)..."*

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So are palliative care volunteers in the community a thing of the past? Has the demand for community support changed since the time when this volunteer initiative was started? The practitioners noted:

> *"I think the need is greater now than before, so many people with end stage chronic illness. (For example) I have a patient now...who needs support as she dies and with the fact that she is dying. Now if they had a volunteer, the volunteer could go in there and spend time with them...(volunteering is) just such an important part of the whole process.*
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> *"Volunteers are skilled by life and training and importantly have the gift of time that not all persons working in health have these days...you can very easily and quickly medicalise death, but having the volunteers there sort of takes away from some of that."*

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Discussion

A number of themes are evident in the comments of the participants in this study.

Volunteers as 'others'

The strongest theme is the commentary on the way in which the volunteers were accepted within the community teams in the local centres. When describing non-supportive environments for volunteers, participants used words and phrases that suggested a 'disconnect', regretting that the community team 'didn't really understand' volunteers or that they didn't understand the way in which the volunteers were prepared for their involvement in the team. When describing supportive environments, participants idealised a volunteer manager as able to 'connect' volunteers into the team.

Participants suggested that the degree to which volunteers were perceived as 'part of the team' was predictive of the way in which the volunteer service was included in or marginalised by the community team. These beliefs, based on the observations of the participants and comments made to them, suggest that the community teams were often uneasy about the presence of volunteers, their motivations and even of the motivation behind commencing the volunteer service. When establishing new volunteer services these tensions must be considered and articulated with the community team so that the motivation behind the service can be properly understood.

Locating and supporting volunteers

At a systems-level there has to be 'adequate preparation at the sites with the managers and the staff' for successful implementation. From the comments of participants there appeared to have been an impoverished commitment when it came to a systems-approach to implementation. The volunteer participants referred to wanting to be seen as more than just 'rosy glowers' and 'do-gooders' if only to engender more confidence with families and vulnerable people. They also desired credibility and 'connection' with the community team for the purpose of getting referrals, but also for a sense of 'professional' collegiality and community.

One commentator in the management group shared about being 'horrified' at observing moments of poor volunteer support and noted the need for volunteers to be 'connected' and perceived by the community team as 'professional' subject to proper preparation and management. They also described the efficacy of a volunteer manager as a function of them being 'bought together', 'linked in' to and 'included in' the local service context.

Both volunteers and managers noted that managing volunteers was problematic where there was no funding commitment to a dedicated management role, resulting in im-'proper' practice in relation to 'boundaries', and evidence of poorly managed risk. Their comments also suggested that only a paid position was likely to garner the necessary support, without which a commitment to a 'professional' volunteer workforce would be undervalued by the community team.

Volunteers as community

Another theme to emerge is the volunteer as the personification of community. Volunteers spoke of their group as being people 'of real quality' and lamented the way in which the group had been left with inconsistent support and a puzzling sense of 'disconnect' in response to their willingness to 'be there' for their people who would otherwise be doing 'it tough'.

One commentator described the volunteers as the 'public face of our palliative care service' and lamented that the volunteer service (in that area) had been a 'huge public relations disaster' for its failure to properly respect the involvement of the volunteers.

These comments suggest that there may a bigger 'disconnect', one between the health service via the community team and the community itself. In this way the failure of the health service to value the volunteer service infers a service model which constructs the community as passive recipients of care. Active involvement of volunteers is inherent in a health-activist model which shifts responsibility from the medical expert to the community, and through which the presence of volunteers can help to de-'medicalise' death.

Conclusions and recommendations

This report clearly shows the need for proper planning and engagement of community health services in the implementation of a palliative care volunteer service. Caring for people in the community resonates strongly with the dialectic of palliative care, and activism through volunteering resonates strongly with the community-spirit of regional and rural centres.

So what can we learn? Most critically the development of a district-wide palliative care volunteer program should include the following considerations:

1. Volunteers must be valued by the community team and by local health service management so that they are seen as one of the team ('us'). The participants noted that to be effective in their role volunteers must be included in briefings and debriefings, in circles of confidentiality, and in discussions about patients and carers with the community team.
2. The community team must be willing to accept that the volunteer has a complementary role, but not an identical role, to other members of the team. This concept is critical and will require management support, so that the paid staff don't feel threatened within their occupational territory. In this study the practice of inviting staff to be involved in volunteer training was a successful strategy to achieve this acceptance. Resistance or animosity must be identified while also allowing for the community team to learn for themselves the benefit of the volunteers to their work.
3. Quality is essential. The volunteers must be held accountable for their work and for the boundaries within which they perform it. Apart from consistent training strategies the participants noted that a necessary element of the system to achieve this goal is the presence of a paid coordinator in an oversight role within close proximity to their town/city.
4. For both accountability and referral reasons the volunteer service must be integrated within the larger service delivery system, using a model that appropriately resonates with that system. Volunteer management may not necessarily be located within each location, but should be accessible by each team. The systems-approach should include reporting to, and oversight by, senior palliative care management.
5. Volunteers must be seen to be both local to their community and professional in the eyes of the health service. It is also critical that service users can see that the volunteers are respected by the health service. This is essential not only in order to recruit and retain volunteers, but also to engender the trust of service users in the community. Again the presence of a paid coordinator in an oversight role within close proximity to their town/city, and the support of the community team are crucial.

Acknowledgements

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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

Huntir A, (2016) Faded away: The life and death of a district volunteer initiative in the bush and lessons for the future of palliative care volunteering, Palliative Care NSW; Surry Hills.

References

1 Huntir, A (2016) Personal communications, Palliative Care NSW

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