



Palliative Care
NEW SOUTH WALES



Palliative Care
Volunteering

Research Report

Where-to with our volunteers?

Results of a survey of Palliative Care

Service Development Officers in NSW

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Background

This report considers the role of and support for palliative care volunteers as expressed through comments by palliative care Service Development Officers. The project was developed as part of the *Volunteer Support Services Program* at Palliative Care NSW to better understand the way in which volunteers are located in the delivery of palliative care services by Local Health Districts in NSW.

The contribution of volunteers to community engagement and improved outcomes for health services and the community is recognised in the NSW Health Policy Directive '*A Framework for Engaging, Supporting and Managing Volunteers*'¹. The success and longevity of a volunteer service is predicated by the support shown from the health service management team² and therefore the views of management representatives are likely to be insightful of the recognition of volunteers by the Local Health District management team.

Across NSW are 15 Local Health Districts and several Statewide Networks that organise health services for their catchment populations. As of 2016 each Local Health District has some involvement of palliative care volunteers in their delivery of palliative care services. In addition the Sydney Children's Hospital, a Statewide Network, has members with palliative care volunteers supporting children and families.

Under the 2010 *Palliative Care Development Planning Framework* state government funding was allocated to each Local Health Network (now Local Health District) to recruit a Palliative Care Service Development Officer to manage

and coordinate the development of Local Health Network Palliative Care Service Plans³. Given the overviewing nature of their role the Service Development Officer is uniquely positioned to understand the needs of the catchment and the features of the palliative care service response, and for this reason the Service Development Officer was identified as the liaison person for this survey of palliative care volunteers.

The majority of palliative care volunteers in NSW are supported directly by hospitals and community health centres (70%) with the remainder being supported by smaller community organisations. In this way palliative care volunteers, volunteer coordination and referral processes are present within each Local Health District and would likely be known to the Service Development Officer.

As part of this study a review was undertaken of the published information from each Local Health District about palliative care volunteers, including the service delivery plans published by each Local Health District (such as Clinical Services Plans, Health Services Plans, Palliative Care Service Plans or Community Health Plans) and online information about volunteers. The way in which volunteers are acknowledged in these publications further enriched the findings of this report.

In this report the term 'volunteer' should be taken to refer to 'palliative care volunteer', and the term 'volunteer manager' is used to collectively represent the various titles that are applied to the role with immediate oversight for volunteer management (such as Volunteer Manager, Coordinator of Volunteers, Volunteer Leader or Supports Coordinator).

Method

In May and June 2016 the Volunteer Support Services Program initiated consultation with Service Development Officers (SDOs) in 15 Local Health Districts and 1 Statewide Network (n=16) in NSW to explore how volunteer services fit into clinical services plans/models of care and their respective visions for the future of palliative care volunteering.

The aim of the consultation was to provide SDOs the opportunity to describe their respective volunteer services from a strategic perspective and to capture their comments on challenges and visions.

SDOs or their equivalents in Local Health Districts were interviewed by telephone by a Project Officer. All services were represented, in most cases (n=14) by the SDO themselves although in 2 cases the SDO referred our enquiries to the volunteer manager or relevant senior nurse.

The consultation took the form of semi-structured interviews, guided by questions relating to the management and governance of the volunteer service, challenges and plans for the future. Responses have been de-identified and grouped thematically to provide insights into the views reflected by SDOs as management representatives.

The interviews also yielded rich comments from the SDOs about how they envisioned volunteering in the future, and these points have been distilled and captured in the closing section of this report.

Findings

Overwhelmingly the respondents provided positive endorsements for the role of volunteers within their palliative care service. This is indicated by comments from interviewees (which are shown in the report as indented quotes) as follows:

"In-home support is a unique service, integral to palliative care and to ensure quality of life."

"Volunteers are complementary to the palliative care inpatient service."

"Volunteers are a pivotal part of our service, couldn't do without them."

"(The volunteer) service works really well... (and)...is highly regarded."

"Volunteers are highly regarded. The focus is always on staff plus volunteers. There is Executive commitment."

"Volunteer role is under appreciated. The same model has worked well for 20 years."

"(The volunteer service is a) unique service, a very efficient service, integral to palliative cares and ... ensures quality of life."

"Volunteers work very well; it would be hard to manage without them."

While these comments are positive and encouraging, to some extent the purpose of this report was to look behind these generic expressions of support to contemplate the structural and dynamic characteristics that reflect on volunteer involvement.

Governance and reporting arrangements

The study found that volunteer programs across NSW vary widely in terms of how they are governed and managed, in the rationale of their role, and in terms of the various functions that they perform.

One of the variations noted in governance arrangements was the inclusion of the volunteer manager in the governance process (case conferences, LHD meetings, memorial events and on site committees meetings). Some respondents indicated a high level of involvement and some indicated little involvement in these processes. To some extent this is influenced by the working hours of the volunteer manager. Our study of palliative care volunteer services in 2014⁴ indicated that the average time commitment to the volunteer manager role was 0.71 full time equivalence across all services in NSW, with only 8 of the 38 services having a full time volunteer manager (and of these 3 volunteer managers were performing a full time role in a voluntary capacity).

Other factors reported by SDOs as affecting the inclusion of the volunteer service in governance processes included the location of the service (for example community or inpatient) as well as geographical and logistical complexities of involving the volunteer manager in decisions about client referrals..

Reporting structures for volunteer manager positions also vary across the state. Respondents indicated that some volunteer managers report directly to the SDO, some to the clinical Nurse Consultant, some to the Nurse Unit Manager or Nurse Manager.

"(The volunteer manager has) close contact with the SDO and consults often."

"I think she meets with the Nurse Manager but I'm not sure."

"We have a business meeting monthly with a standard agenda and minutes."

Some respondents noted isolated incidents of tension between nursing staff and volunteers, as has been reported in other studies of volunteering⁵. These SDOs suggested that conflict likely arose from a perceived lack of clarity in roles and priorities for volunteers, particularly those in community settings where volunteers tend to perform more autonomous roles.

According to respondents it is not unusual that the funding pool for nursing services is shared by volunteer management, and it is possible that this negatively impacts on nursing ratios and consequently also impacts on the nursing/volunteer relationship.

A small number of respondents indicated that volunteer managers provide regular written reports or routinely collect quantitative data (number of visits, activities, education sessions and recruitment and retention figures). In some services qualitative data is obtained, for example, a volunteer satisfaction survey. In any case it seems that, with a few exceptions, there is limited analysis of data amongst services.

"Data is collected but it doesn't go anywhere."

Some respondents indicated that the volunteer service is clearly included in the quality accreditation activities of the palliative care service, but in other cases there is uncertainty about the inclusion of the volunteer program. Although some services have a schedule for review of the volunteer program they appear to be in the minority and this appears not to be an accepted or standard process.

Volunteer engagement and management

Respondents indicated that the role of volunteer manager was critical to the success of the program. In the absence of a person in the role, or in the absence of funding for the role, respondents characterised the volunteer service as 'struggling' and 'probably won't survive', or as being inherently 'limited' and taxing on the resources of the nursing staff.

"Without a Volunteer Coordinator the service has been struggling along."

"Volunteer programs are currently not working without a coordinator and probably won't survive."

"Without a Volunteer Coordinator the scope is limited."

"In the absence of a coordinator the burden is on nursing to recruit, train and support."

"In (the senior nurses role) there is not much time to support volunteers especially palliative care inpatient volunteers."

Without a volunteer manager the respondents noted that leadership of the volunteer program defaulted to a senior nurse (Nurse Unit Manager of the Clinical Nurse Consultant). The larger the volunteer cohort the less sustainable this arrangement, particularly when the vacancy becomes protracted. Two respondents reported extended periods without a volunteer manager, one of which was vacant for about 12 months, and consequently significant time and effort will now be required to re-establish these services.

Even where funding existed for a volunteer manager role, some respondents acknowledged that the demands on the position outweighed the resources that could be afforded. This resulted in undue pressure on the volunteer manager.

“Executive thinks it’s a good idea but it isn’t a priority for resourcing.”

“The risk (posed by the volunteer manager workload) isn’t sustainable as it is...needs more help.”

“The (volunteer manager) is in a hard place.”

Even where funding existed for a volunteer manager role and was adequate for the requirements of the service, some respondents acknowledged that the skills and ability of the volunteer manager was crucial to making the service work.

“The coordinator needs to be the right one, have the right mix of skills.”

“Volunteers flounder without leadership, a higgledy-piggledy service, not really happening.”

All respondents said that they would like to see an increased commitment to staffing and other resources to provide a service that meets growing needs and to adequately support volunteers.

The respondents collectively indicated a number of other concerns which warrant further studies. These include a concern that only a limited number of volunteer managers have Key Performance Indicators, that in general there is no budget for volunteers except for the volunteer manager position, and that it is not unusual for the incumbent volunteer manager to be expected to perform other roles (running the carer’s program, managing other volunteer groups like psychiatry and rehabilitation inpatient, or fundraising) even though they may only hold a part time position.

In commenting on paediatric volunteer programs the SDOs noted challenges unique to their service context, including limited volunteer outreach in regional and rural areas, matching families with volunteers and legal limitations preventing volunteers to be alone with children which prevents the service from offering respite to families through volunteering.

Respondents also commented on the recruitment of volunteers. A majority of services commented that they would like to recruit younger volunteers as the average age is 65 years plus suggesting the need for a succession plan. A few respondents noted that nursing staff had expressed a reluctance to refer to volunteers in cases where the volunteers are perceived as ‘aging and disinterested’.

There were no clear themes to emerge from the respondents about their volunteer performance or recruitment, although one respondent noted a concern with inpatient volunteers and another indicated that they were able to rely on enquiries with actively recruiting in the community.

"Inpatient units rely very heavily on volunteers but they are older and on other committees so the commitment (from volunteers) isn't there."

"We get word of mouth-get enquiries all the time; we don't need to actively recruit."

One or two services encourage applications from health science students, for example, medicine nursing or physiotherapy, whilst other services are very reluctant to consider this cohort given that their participation was more likely to be time-limited.

Inclusion of volunteers in service plans and publications

Inclusion of volunteer programs in clinical service plans occurs but this is not consistent across the state. Of the 16 respondents more than half reported that their volunteer program is included in the clinical service plan (or equivalent), 3 reported non-inclusion, 2 indicated that their service was currently working on a plan.

The remaining 2 respondents indicated that the NSW Plan⁶ and the Agency for Clinical Innovation's (ACI) Blueprint⁷ effectively represented their current plan/s. It is worth noting that the NSW Plan (2012-2016) is soon due to lapse and the ACI model addresses clinical service delivery issues to the exclusion of non-clinicians like volunteers.

It appeared to be the exception that volunteers are consulted prior to the development of a clinical services plan even if the volunteer program is included in the plan. However 1 LHD had conducted volunteer

focus groups as part of the standard planning process. In another the volunteers had been consulted for the first time in the development of a new model of care.

Published information was studied in the hope of gaining insights into the way that services envision the contribution of volunteers. The content of all LHD websites was reviewed. The listing of volunteer services on LHD websites across NSW varies from one with a separate volunteer tab, to a simple mention under the palliative care services tab, to no mention at all. Significantly, one volunteer service has its own discrete website, managed by the volunteer manager.

Some websites and material emphasised the personal qualities and community mindedness of volunteers:

"A Palliative Care Volunteer is a very special person who has chosen to give their time to assist patient and their cares..."

"(Volunteers are) excellent listeners, warm, empathetic and compassionate, with a strong commitment to facilitating a patient's needs and wishes."

Other material emphasises the volunteer as a workforce element in the provision of care. In some LHD websites references to the volunteer program are included under the heading of 'Employment'.

"Volunteering: Make a Real Difference! Our hospitals and health centres, our staff, our patients and their families rely on volunteers who help out in countless ways - from reading..."

"As a volunteer, you will be an integral part of our future and the future well-being of our patients..."

And a third theme to emerge was the emphasis on support for a volunteer program as evidence of organisational commitment to community partnerships in service delivery:

“(We are) committed to involving consumers and the community in a number of ways. Examples include community representation on hospital boards, supporting hospital auxiliaries, providing volunteer programs...”

“(One of our goals is to) enhance internal and external partnerships in caring for the dying patient including volunteers, community based services...”

Within LHD publications volunteers are generally acknowledged in words and photographs in media releases/awards, the Cancer Services Newsletter and Report, the Annual General Meeting and Report, Intranet Bulletin Board, Facebook and Twitter. In some LHDs volunteers are regularly given public recognition and appreciation, for example through Volunteer Appreciation Day or Volunteer Awards. These initiatives are consistent with the recommendations in the Framework for Engaging, Supporting and Managing Volunteers⁸.

Volunteer services are publicised variously in brochures. For example, there are facility brochures with one paragraph devoted to volunteers or volunteer specific brochures for prospective clients as well as for volunteers.

Service development and aspirational thinking

Through their comments the SDOs collectively outlined what they saw as essential and highly desirable features of a volunteer service. Leading the list were two key points: demonstrated commitment to the volunteer program from the Executive; and strong leadership from the volunteer manager.

Other elements perceived as highly desirable were: clear boundaries for volunteers; cultural respect by and to all; inclusion in service planning; increased inclusion of volunteer by the palliative care team; support for volunteers including resources for supervision; compassion and pride in the service they perform; open communication channels inclusive of volunteers; having both community and inpatient volunteers; encouraging and engaging new and younger volunteers; and promotion and acknowledgement of the value and contribution of volunteers.

The SDOs also collectively reflected on opportunities and initiatives to develop volunteer services in the future. The following list is insightful of their collective aspirations for volunteering, although it is not suggested that all SDOs endorse all suggestions. For simplicity these ideas have been arranged into 2 groups namely Service Design and Management.

Under the heading of Service Design their ideas included: a proposal for state-wide coordination of volunteering; that volunteering services in larger LHDs be intentionally designed around a network (hub-and-spoke) model; that in areas where services have declined or need to be established then the employment of a project manager to scope the needs

and do the ground work is required; that volunteering should consider partnering with other volunteer-involving support organisations such as Universities, the Cancer Council and/or Neighbourhood Centres to maximise opportunities and avoid duplication; that confidence in volunteering would benefit from adherence to agreed standards for volunteer training and management skills; and the introduction of standardised accountability and reporting at a senior level.

Under the heading of Management their ideas included: invigorating the concept of volunteering to improve attraction and retention of new and in particular younger volunteers and volunteers from

more diverse cultural backgrounds; recruit increased resources to expand volunteer support into new areas including Motor Neurone Disease and multicultural groups; a proposal that an assistant to the volunteer manager might be a cost effective solution to capitalising on the specialist skills and abilities of the manager; a proposal that volunteers are included in monthly education schedules as part of the palliative care team; that the possibility of using volunteers in community advocacy for example in advance care planning should be explored; and proposals that the expanded use of technology be considered for networking and managing volunteers.

Discussion

The study found that there was considerable support for the concept of palliative care volunteers from the group of SDOs surveyed. Not surprisingly SDOs verbally located volunteers within their service delivery model, whether or not this had been formalised in a clinical services plan or similar. They inherently and expressly endorsed volunteer contribution within the larger effort of the palliative care team, and their collective reflections on palliative care volunteering positively endorsed a vision of invigorated and sustainable volunteer support for people at end of life.

In fairness some respondents appeared to dis-endorse volunteers where their involvement was seen as problematic or inconsistent with the larger palliative care effort (that is, where the service was not working well). These sentiments included

the sense that having volunteers without a competent volunteer manager leads to an undesirable increase in strain on nursing staff; likewise if the volunteers are not sufficiently integrated into and 'owned' by the palliative care team then their involvement may be ineffective. Volunteers in whom clinical staff lack confidence are unlikely to be properly integrated into the work of the palliative care team.

Despite the generally expressed support by SDOs for the volunteer effort the study found that volunteering featured in only a little over half of the clinical services plans. Likewise evidence of support for volunteering on LHD websites was patchy, and sent mixed messages about the purpose of volunteer involvement. In most cases there was little or no specific reference to palliative care volunteering.

The respondents suggested that commitment from within the Executive, and a leadership and governance framework, were essential features of a system of support for a successful volunteer program.

SDOs noted that across NSW there is a variety of ways volunteer services are provided to and accessed by palliative care clients and their families. Regional and rural areas are less well-resourced to the extent that some services are diminishing, and that this reality is inconsistent with the NSW Plan and the principles of equity and access to palliative care.

There was no single model for a volunteer service recommended by SDOs and this may be reflective of local needs and resources or it could potentially be historical. The expressed value of the volunteer effort by SDOs to the delivery of palliative care services inferred a need for the volunteer service to be sustainable with appropriateness of both quantity and allocation of resources.

SDOs noted that inclusion of volunteers as members of the palliative care team, involvement in planning, recognition, ongoing support, education and human resources support is essential. To do this the respondents endorsed a need for increased support for volunteer managers, and for ensuring sufficient support in human resources and governance functions.

SDOs also endorsed a systematic approach to volunteer recruitment and retention to meet the local service needs and where possible and justified to extend the role of volunteers. There was also support to explore the potential for volunteer services working in partnership with other organisations or small groups in LHDs.

Finally the SDOs envisioned a better coordinated palliative care volunteer sector, possibly with state-wide coordination, embracing commonly agreed standards, with standardised data collection and reporting, and based on intentional service design that would increase confidence amongst clinicians for volunteer referral.

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:

Flood J & Huntir A (2016) Where-to with our volunteers? Results of a survey of Palliative Care Service Development Officers in NSW, Palliative Care NSW; Surry Hills.

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