

Research Report

**A space of caring: NSW nurses’  
experiences of Palliative Care Volunteers  
in inpatient settings**

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## Background

This research project was developed by Palliative Care NSW to better understand the experiences of nurses<sup>1</sup> who have been involved with palliative care volunteers in inpatient settings in NSW. Palliative Care NSW through the Volunteer Support Services Programme has an interest in better understanding the relationships within which palliative care volunteers work.

About half of all the 153,000 or so deaths each year in Australia occur in hospitals<sup>2</sup>, and of these some 20,000 occur under specialist palliative care services<sup>3</sup>. Of all specialist palliative care services, delivery by inpatient care represents 73% of all services<sup>3</sup>. Typically, nurses comprise about 58% of the health workforce and about 53% of all nurses work in hospitals<sup>4</sup>. The majority of palliative care volunteers are also found in inpatient settings with about 820 palliative care volunteers attached to 19 wards, units and hospices across NSW in 2014<sup>5</sup>. Consequently, nurses are the group most likely to have contact with palliative care volunteers in inpatient palliative care settings.

Palliative care volunteers in inpatient settings typically supplement the emotional support offered by nursing staff and others (including social work, pastoral care) to patients and family<sup>6</sup>. Volunteer-based emotional support is typically offered in the context of activities like talking with patients and family, accompanying patients, offering light touch hand massage, assisting at meal times, reading to and writing for patients<sup>5,7</sup>. A study in the US indicated that a rating of 'excellent' from hospice users when asked about their care correlated to a higher number of volunteer hours within the hospice service<sup>9</sup>.

Nurses are typically the go-to person for palliative care volunteers in inpatient settings, with a nurse often acting directly or tacitly in a supervisory role to volunteers. This implies closely aligned understandings of care between the groups, but this is not necessarily the case. In particular, the research indicates that carers and families perceive the volunteer's approach to care as being uniquely different from the medical approaches favoured by clinicians, specifically that volunteers are more likely to value wisdom (generalizable knowledge) over strictly clinical knowledge<sup>8,9</sup>.

The 'differentness' of volunteers is also revealed in comments from families and carers which reveal a perception of volunteers as 'surrogate family members' offering 'friendship-style' care<sup>7,10</sup>. These different perspectives on care have been found to result in tension between palliative care volunteers and clinicians<sup>9,7</sup> and have been reported as contributing to a sense by volunteers that they are too contained or 'policed' by clinicians, consequently leading to feelings of role-related stress<sup>6</sup> and of being undervalued in the clinical setting<sup>9,7</sup>. We are interested in knowing in what way, if any, these perceptions are reflected in comments from nurses in NSW and the ways in which volunteers are beneficial or not to patient care.

Specifically, this research project is intended to help us understand the points of tension and celebration for nurses in their work with volunteers and how these might be addressed in order for us to better develop palliative care volunteering in NSW.

## Method

During March-April 2017 Palliative Care NSW surveyed nurses<sup>1</sup> working in adult palliative care inpatient settings. Services were selected on the basis that they had designated inpatient palliative care 'beds' and/or were routinely supported by palliative care volunteers. The survey was not targeted at nurses in paediatric settings, or in aged care settings.

An online survey was developed with 6 questions consisting of both structured and semi-structured formats. Structured questions included closed-ended questions with Likert scales as well as multiple choice options. An unstructured question allowed for additional comments by respondents. A pilot of this survey was validated by two external participants who were experienced in adult palliative care service delivery as nurses, and their comments were incorporated into the final survey design.

Contact with nurses was made through managers of relevant palliative care volunteer services in NSW. An email was sent individually to each volunteer manager who was asked to forward the survey details and web-link to their nurses and request their involvement. Reminders were sent after 2 weeks and in total, the survey was open for 4 weeks.

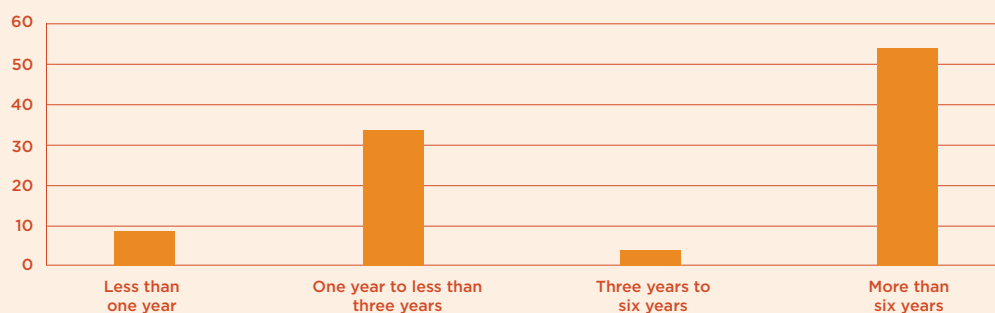
In completing the survey the nurses were required to self-identify as having worked with volunteers who provide direct patient support on an adult palliative care hospice, ward or unit. Respondents were not required to identify themselves or their service within the survey questions and were informed that their responses would be de-identified and aggregated for publication. An opportunity was available for respondents to add their email address if they chose to be sent the final report, alternatively, they can access the report via the publically accessible website for the Volunteer Support Services Programme. A total of 36 respondents completed the survey.

# Findings

## Who and where

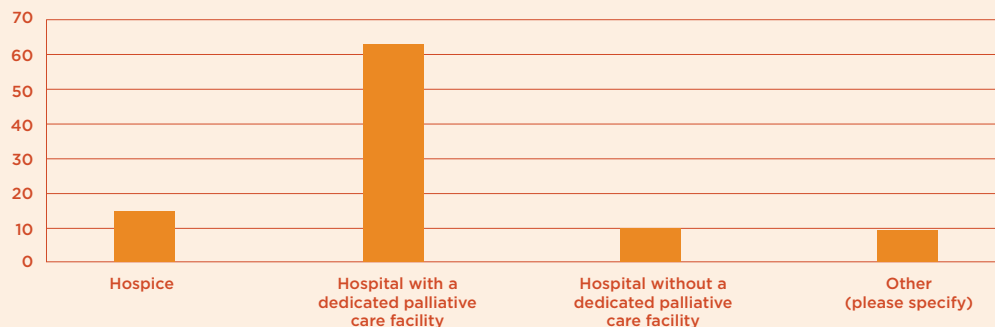
Nurses' make up around 58% of the health care profession<sup>11</sup> and when compared with other clinical staff, nurses spend more time and work more closely with patients<sup>10</sup>. In the survey, the majority of respondents best described their role as Registered Nurses (53%). Other roles for respondents included Clinical Nurse (19%), Endorsed Enrolled Nurse (8%) and Assistant in Nursing (3%). In terms of length of service, the majority of respondents indicated that they had been working with palliative care volunteers for more than 6 years (53%).

**Table 1 : How long have you been working with a service that has palliative care volunteers?**



Across NSW a variety of palliative care service arrangements exist, depending on the clinical service design adopted within each of the 15 Local Health Districts. For inpatient care, the models include community support with or without identified inpatient 'beds'. Some hospitals may offer specialist inpatient care, while others offer generalist palliative care with input from specialist medical and/or nursing staff. Of the nurse respondents to the survey, some 64% indicated that they worked in a hospital with a dedicated palliative care facility, while 14% worked in a hospice and 11% in a hospital without a dedicated palliative care inpatient facility.

**Table 2: Which best describes the inpatient setting where you are currently employed?**



**In relation to your experience with volunteers...**

Respondents were asked to rate themselves according to a series of prompts relating to their experiences with volunteers. The ratings by the proportion of respondents are shown in the table below. The prompt which attracted the most Strongly Agree responses (50% of all respondents) is ‘Volunteers are contributing to better Palliative Care Outcomes’. When the scores for Strongly Agree and Agree are added together for this prompt the total represents an agreement by 89% of all respondents.

*“We have had a very strong palliative care (volunteer) program for 20+ years”.*

.....

Other prompts that scored a high level of agreement (Strongly Agree + Agree) include ‘Volunteers display empathy and emotional awareness’ (89%), ‘Volunteers develop meaningful relationships with patients’ (86%) and ‘I understand the role of a volunteer in Palliative Care’ (83%). These are further explained in the table below.

The lowest confidence expressed by respondents was shown for the prompts ‘Management responds to feedback about volunteers’ and ‘Volunteers are well supervised and supported’ and ‘Volunteers communicate well with clinical staff’. Respondents were most likely to respond ‘I don’t know’ to these prompts: ‘Management responds to feedback about volunteers’ and ‘Volunteers receive sufficient training for their role’.

Several of these prompts relate to tasks of volunteer management. It is clear from the pre-existing literature that the key to successful implementation of volunteers within a palliative care inpatient setting is an active volunteer supervisor who provides a framework under which the volunteers operate<sup>12</sup>. The responses of low confidence or lack of clarity may reflect a lack of trust in volunteer management or simply a lack of knowledge about the processes behind volunteer management. Part of the role of the volunteer manager is to raise awareness of the role of the volunteer in order to clarify misconceptions of volunteers that could be interfering with their utilisation<sup>13</sup>.

**Table 1: In relation to your experience with volunteers, to what extent do you agree or disagree with the following statements?**

	<b>Strongly Agree + Agree</b>	<b>Neither or Disagree</b>	<b>Disagree + Strongly Disagree</b>	<b>I Don't Know</b>
Volunteers are contributing to better palliative care.	89%	11%	0	0
Volunteers display empathy and emotional awareness.	89%	8%	0	3%
Volunteers develop meaningful relationships with patients.	86%	11%	3%	0
I understand the role of a volunteer within palliative care.	83%	14%	3%	0
Volunteers respect patients and carers wishes.	82%	11%	3%	6%
Volunteers understand the scope of their role.	78%	11%	11%	0
Volunteers receive sufficient training for their role.	66%	14%	8%	11%
Volunteers communicate well with clinical staff.	64%	19%	11%	3%
Volunteers are well supervised and supported.	64%	19%	8%	8%
Management responds to feedback about volunteers.	53%	19%	8%	19%

In further analysis of the data, the survey responses indicated that those nurses who had been working with volunteers for more than six years were more likely to have more positive thoughts towards volunteers and appear confident in understanding the scope of a volunteer and the training required of them. Nurses' who either worked in facilities that didn't fully utilise volunteers or simply had not been working with palliative care volunteers for as long were more likely to answer 'I don't know' to statements regarding volunteer roles and training.

The nurses who expressed more confidence in the volunteer's abilities shared more positive feedback regarding their involvement in the workplace. For example, one participant noted

*"Before having volunteers a lot of my time was spent trying to provide comfort and support over and above what I already do. It is a relief to know if a patient has no family (for example), a volunteer will sit with them!"*

Nurses who worked within a hospital that did not contain a dedicated palliative care facility were more likely to answer 'I don't know' than other inpatient settings which were more palliative care focused. This could be due to the lack of dedicated palliative care volunteers within these non-specialised palliative care facilities. There are many misconceptions regarding volunteers within healthcare and, as such, if clinical staff and patients are unfamiliar with their presence they are more likely to be anxious or concerned with the volunteer's presence<sup>14</sup>.

For example, a respondent who had been working with palliative care volunteers for less than a year stated:

*"Some patients become frustrated... (it would be good) if there was a way to feed that back so they don't keep getting visited".*

This comment suggests the need for more active management and better communication between volunteers and the rest of the palliative care team. Likewise, this comment from a respondent indicates the need for volunteers to be empowered to speak to alternate staff about their concerns:

*"The ward staff can be very busy the volunteers are trusted within their role and need to know to speak with the manager when they have concerns if staff too busy".*

The nurses who had the most respect and positive interactions with the volunteers were Clinical Nurses. A Clinical Nurse is a Registered Nurse who has undertaken additional training within a specialty area such as palliative care. As specialists in the field, they offer a valuable perspective<sup>15</sup>.

Conversely, respondents who were unsure of the volunteer's role or who reported negative interactions were more likely to be community-based nurses or enrolled nurses. These roles offer less interaction with volunteers than, for example, a registered nurse. Similarly the statement, 'I'm worried volunteers will replace paid workers' was shared by nurses whose roles or work facility greatly limited their involvement with volunteers.

In relation to volunteer skills and experience, and how that affects their interaction with patients, one respondent offered this suggestion:

*"I feel the life experience of the volunteer can have both a negative and or positive impact on what they do at times. I feel this needs to be explored further with a professional (i.e. clinical psychologist)."*

**In your personal experience as a Nurse...**

Respondents were asked to rate themselves according to a series of prompts relating to their opinions and preferences with volunteers. These ratings by proportion of respondents are shown in the table below. In general, the responses to the prompts in this set of questions were spread more across the scale.

The prompts which attracted the highest level of agreement (when adding scores for Strongly Agree + Agree) included 'I would like to see more volunteers in my service' (70%), 'I find the more volunteers on the ward, the better the patient outcomes' (58%) and 'I think we might lose volunteers if we don't better support them' (58%).

The respondents seemed to be ambivalent about several of the prompts. These included 'I don't know whether our

volunteers are doing as well as volunteers in other palliative care services', which suggests that more awareness raising or comparative information about other services might add confidence to nurse involvement. Other responses without a clear bias for-or-against included 'I want volunteers to have a broader role' and 'I think volunteers should be designated to specific patients' and the nature of these responses tends to suggest that status-quo is preferred.

The prompts which attracted the highest level of disagreement (Strongly Disagree + Disagree) included 'I'm worried volunteers will replace paid workers' (89%) and 'I spend too much time dealing with volunteers' (89%). The disagreement was also significant in these prompts: 'I want to be more involved in the recruitment and training of volunteers' (44%) and 'I think volunteers should be designated to specific patients' (39%).

**Table 2: Reflecting on your own personal experiences as a nurse, to what extent do you agree or disagree with the following statements?**

	<b>Strongly Agree + Agree</b>	<b>Neither Agree or Disagree.</b>	<b>Disagree + Strongly Disagree</b>	<b>I Don't Know.</b>
I would like to see more volunteers in my service.	70%	22%	8%	0
I find the more volunteers on the ward, the better the patient outcomes.	58%	31%	6%	6%
I think we might lose volunteers if we don't better support them.	58%	31%	8%	3%
I don't know whether our volunteers are doing as well as volunteers in other palliative care services.	42%	31%	20%	8%
I want volunteers to have a broader role.	36%	36%	25%	3%
I think volunteers should be designated to specific patients.	28%	28%	39%	6%
I want to be more involved in the recruitment and training of volunteers.	14%	39%	44%	3%
I'm worried volunteers will replace paid workers.	0	11%	89%	0
I spend too much time dealing with volunteers.	0	11%	86%	3%

In further analysis of the data the survey responses indicated that those nurses working in a hospice or hospital with a dedicated palliative care unit were more likely to answer positively to statements such as 'I would like to see more volunteers in my service' and 'I find the more volunteers on the ward, the better the patient outcomes'. The anxiety about volunteers displacing paid workers apparent in other countries<sup>16</sup> was not evident in this study amongst nurses.

## Concluding comments

The results of this survey demonstrate a significant level of support for volunteers across the group of nurse respondents. The responses generally indicate appreciation for the work of the volunteers with patients and family as well as a desire for more volunteers (within the capacity of the location).

With this study, we have sought to make some observations about the role performed by volunteers through the eyes of the professional group that is most likely to be familiar with them – nurses. We accept that this is not a definitive measurement of whether or not volunteers are improving the patient experience.

Some other limitations of the study must be acknowledged. Firstly, due to the controls to ensure the privacy of participants we have no way of gauging how well spread the 36 respondents were across the available inpatient palliative care services. Secondly, the limited time afforded participants (4 weeks) may have played a part in limiting opportunities to respond where email contact was not made in sufficient time. Thirdly, the prompts were short and may have benefited from more explanatory material to ensure that the intent of the sentence was better clarified.

Nevertheless, the survey confirms that there is a clear correlation between facilities that specialise in palliative care and the positive impact volunteers have on patients and the rest of the palliative care team. These facilities often feature an active and well-resourced volunteer manager who provides guidance and acts as a negotiator between volunteers and nurses, facilitating the formation of mutually respectful working relationships.

Volunteer Managers, Nurse Unit Managers, Clinical Nurses and Service Development Officers are amongst those who will benefit from better understanding the interaction between nurses and volunteers outlined in this report.



## 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](http://www.volunteerhub.com.au)).

### Suggested citation:

Marsden J, Bowman K, Burke M & Huntir A (2017) *A space of caring: NSW nurses' experiences of Palliative Care Volunteers in inpatient settings*, Palliative Care NSW, Surry Hills.

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