

Research Report

Paediatric palliative care:

A survey of a hospice volunteer service

Megan Burke, Policy Officer, Palliative Care NSW
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Background

This paper resulted from collaboration between the children's respite and hospice service Bear Cottage in Manly NSW, and Palliative Care NSW. Bear Cottage is highly regarded for its specialised care with children. Palliative Care NSW through its members has an interest in promoting high quality palliative care across the health sector and NSW community.

This research project was developed by Palliative Care NSW to provide insights into the characteristics and features of volunteers at Bear Cottage. It is hoped that these insights will yield guidance on how volunteers in similar settings can be better engaged in end-of-life care for young people with life-limiting illnesses.

According to the World Health Organisation "palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family"(WHO, 2016). Whilst this definition closely reflects the principles for adult palliative care, the unique needs of dying children can be quite different, due not only to the trajectory of their conditions but also the nature of the family context within which care is provided.

In paediatric palliative care the patient is not the main decision maker, particularly if they are very young. However this can change throughout a child's illness as they become older and more capable of making decisions, as well as developing a sense of what is important to them as an individual. The extended trajectory of some life-limiting illnesses in children may mean that they receive palliative care for many years, making their experience quite unique from a typical adult experience that might be only a few days or weeks in some cases.

Reducing social isolation and providing companionship are some of the primary goals of the palliative approach. Existing research identifies the unique needs of adolescent and young adult palliative

patients, and suggests that their psychosocial needs can best be met with (Rosenberg & Wolfe, 2013):

- A tailored approach to patient's level of independence and maturity
- By facilitating social support, peer relationships, and interactions
- Minimising isolation with physical or web-based "space"
- Providing age-appropriate, multidisciplinary supportive care

Paediatric palliative care is often referred to as an 'emerging subspecialty' (Liben, Papadatou & Wolfe, 2008) of palliative care, with most existing research having focused either on the development or evaluation of home palliative care programmes for children (Dangel, Fowler-Kerry, Karwacki & Bereda, 2000), the children's hospice movement (Scott & Burgin, 2004) or has addressed more conceptually the challenges and needs of paediatric palliative care (Williams-Reade, Lamson, Knight, White, Ballard & Desai, 2015; Liben et al, 2008).

If we are to apply the above WHO definition to young and adolescent patients this may involve playing video games, socialising with their peer group or general conversation about popular culture. While all volunteers play a significant role in supporting these patients, there is a specific niche that could be very effectively filled by increasing the number of young volunteers, particularly males.

Very little research appears to have been conducted on the roles or experiences of volunteers in paediatric palliative care, even though they are acknowledged as a crucial and significant part of a child's 'hospice family' (Scott & Howlett, 2009).

This notion of a 'hospice family' is one that is particularly relevant to Bear Cottage, a facility that is renowned for the home-like environment it provides for patients and their families, and as a service that could not operate without a team of volunteers.

As the only children's hospice in New South Wales, and one of only three children's hospices in the country, Bear Cottage plays a crucial role in the provision of palliative care to children and their families from all over Australia. The facility was established entirely through community support, at a cost of \$10 million, and welcomed their first families in May 2001. Bear Cottage enjoys a strong relationship with the local community and are well supported by a large network of volunteers. Maintaining this support is obviously beneficial to the work of Bear Cottage.

So measuring the characteristics and experiences of the Bear Cottage volunteers is a useful means of establishing a benchmark for volunteers within a successful children's hospice, as a basis for reviewing and improving strategies to support and utilise volunteers. But it is also a window into the heart and motivations of volunteers for the children, siblings and families of Bear Cottage, a window that offers unique insights into the way in which Bear Cottage and palliative care is embraced by the community.

It is hoped that the findings of this research would not only be applicable to Bear Cottage, but could effectively be applied to community visiting schemes that support young people with life-limiting illnesses and their families in the home, as well as the hospital or inpatient setting.

Method

In early 2016 Palliative Care NSW collaborated with Bear Cottage to develop an online survey that would provide insight into the volunteer experience.

Once the survey design had been agreed upon, invitations explaining the project that included the survey link were emailed to volunteers via the volunteer coordinator at Bear Cottage. Participation in the research was voluntary and anonymity was guaranteed by de-identification at the collection phase.

The survey consisted of 19 questions including a 3 part open-ended question which was optional for the respondent to complete. Rating and Likert Scale questions were used to gauge attitudinal differences and opinions relating to motivations for volunteering and to identify what volunteers considered important in their volunteer experience.

The initial email was sent to 110 volunteers all of whom had been active within the house in the previous 3 months. A total of 59 respondents completed the online survey. Volunteers who only performed duties related to dog walking and events were excluded from participating. Reminder emails were sent weekly to improve completion rates. Although a 54% completion rate was considered successful for the purposes of this research it is important to note that the percentages in this report are based on the sample group and not on the total volunteer population.

The thematic analysis of this data is valuable for illustrating ideas and identifying trends within the sample group, but does not claim to represent views of people who did not participate in the survey.

Findings

What motivates Paediatric Palliative Care Volunteers and how can we keep them engaged?

Understanding the reasons why people volunteer is important when developing volunteering programs, establishing feedback protocols within those programs and generally supporting volunteers particularly within a field such as paediatric palliative care. For example when the respondents were asked to identify all the tasks their roles entailed, a diverse range of roles were identified with over 70% of respondents working directly with patients and their siblings as well as performing housekeeping duties. These figures clearly reflect the emphasis on maintaining a 'home-like' environment within Bear Cottage.

By better understanding what attracts people to volunteer initially, recruiting appropriate people can be made easier by targeting certain groups within the community where there may be a deficit. As Claxton-Oldfield, Tomes, Brennan, Fawcett & Claxton-Oldfield (2005) discovered in research that looked at palliative care volunteerism among college students in Canada "it is possible that more people might get involved in palliative care volunteer programs if they knew more about the philosophy and goals of palliative care".

Male and Female Volunteers – How do they differ?

For male respondents the most common reason for initially volunteering at Bear Cottage was "to support a family in need" (88%). Interestingly however, 50% of the male respondents also reported that they chose to volunteer because "it sounded challenging and rewarding". This in itself as a reason is not surprising, as there are obvious challenges to working with sick and dying children, however, when compared to how many women mentioned this factor as a motivation, there appeared to be quite significant gender-based differences in motivations.

Female respondents made up 83% of the sample, but only 26% of these women considered the challenges and rewards as a contributing factor in their decision to volunteer at Bear Cottage. The most common reason for volunteering being a belief that they "had the relevant skills to contribute meaningfully" (67%). While this research project did not have the scope to investigate this further, this finding could perhaps be viewed as representative of female respondents who had retired from professions that provided them with a strong sense of identity and social connectedness. This hypothesis is supported by existing research that identifies these women as tending to be more prolific in their post-retirement activities that would almost certainly include volunteering.

Borrero & Kruger (2015) identified in their study of retired professional women that “common identity characteristics included the importance of social connectedness, interest in continued learning, continual involvement in aspects of one’s former work role, and a strong interest in helping others”. While this research did not investigate the previous work experience of volunteers, the fact that 44% of all volunteers were not working or retired could be explained in part by this social trend, but could also represent the stay-at-home-mothers who choose to volunteer. It should also be noted here, that the percentage of volunteers studying and/or working is higher than the retired cohort which suggests that there is a common misconception that people who work and study are less likely to volunteer their time.

If it is a goal of paediatric palliative care to increase participation rates of men in a volunteering capacity, perhaps this could be a consideration in recruitment strategies. While it is not within the scope of this paper to critique the gendered discourses of caring, the value of diversifying the volunteer base to include more males could have profoundly beneficial impacts on male paediatric patients and male family members.

Bear Cottage acknowledges the importance of increasing the participation of men in volunteering roles, particularly throughout the working week when their availability is more likely to be limited due to work commitments. By targeting their recruitment towards shift workers and medical students they are endeavoring to overcome this challenge through ongoing assessment of their needs as a service, and by creatively utilising the personnel resources within their community.

This research did not have the scope to explore this topic specifically. Further research into the needs of adolescent patients could identify ways that male volunteers, particularly from a younger age group could make a meaningful contribution within the field of paediatric palliative care.

Age and life experience – Is it a motivating factor for volunteering?

The age and gender breakdown for volunteers who participated in this survey is most effectively shown in Table 1.

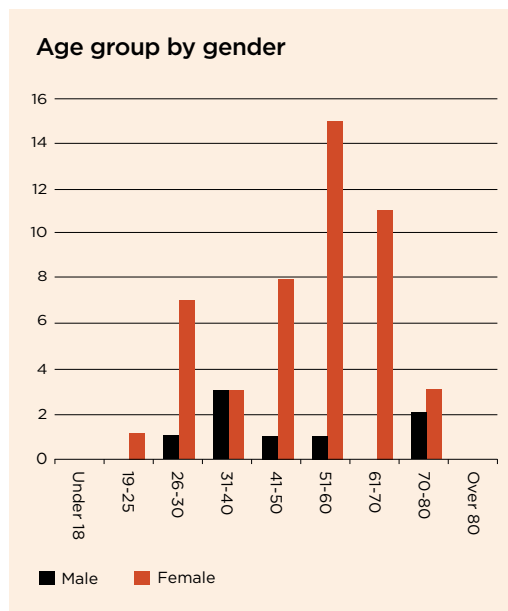


Table 1. (N=2 refused to answer Q15: Gender) (N=1 refused to answer Q16: Age Group)

Differences in the participation levels of male and female volunteers can be seen in this chart with only 14% of respondents being male. This chart also identifies 51-60 year old females as the most highly represented age group, constituting nearly 30% of the overall respondents, although data obtained from Bear Cottage indicate that the number of actual volunteers in this group is closer to 20%, still making it the most highly represented volunteer group.

It should be noted that one of the limitations of this research is that participation was voluntary and therefore the actual volunteer breakdown can only be viewed as a representation of this service and should not be interpreted as actual volunteer numbers. The actual gender breakdown from data provided by Bear Cottage indicates that the male to female participation rates are 32% and 68% respectively, with even more men volunteering on the weekends.

However, the thematic conclusions drawn from this research are evident in existing literature that has also identified this trend, with a UK study identifying the 'typical' palliative care volunteer as someone likely to be female, 55 or over, retired and white (Morris, Wilmot, Hill, Ockenden & Payne, 2012) this is perhaps indicative that there exists some scope to more extensively encourage recruitment of men as well as volunteers from other age groups to complement the existing volunteer base.

Life experience – Is it a motivating factor for volunteering?

When motivations for volunteering in paediatric palliative care were analysed according to age, some patterns emerged across this sample, and while not unexpected, these patterns demonstrate changing motivations throughout the life course of people who choose to volunteer. This data illustrates how a volunteer's main motivations may be influenced by their own life stages suggesting a correlation between volunteer age-related experience and expressed motivation to volunteer.

<30 years: I love helping and caring for children wherever help is needed (80%)

The focus while on "helping" in general, focused on the statement that was specifically about children's needs.

31-40 years: To help young people – both patients and siblings (83%)

Much like the even younger age group, these respondents have focused primarily on the needs of the children, both as patients and siblings.

41-60 years: To support a family in need (69%)

These volunteers were more likely to have families of their own, with 64% of this group also having children or grandchildren under the age of 18 years, suggesting this is where their main empathy lies.

61-80 years: I think I have the relevant skills that enable me to contribute meaningfully (75%)

Whether this is recognition and gratitude of a life spent learning, or an obligation to give back to the community, this age group predominantly felt that this was their main motivation for volunteering in paediatric palliative care.

"It is nice to give something back after working with, and receiving great pleasure from children for the last 39 years"

Comment from respondent (aged 61-80 years)

To better understand what volunteers found fulfilling and what was important to them, the study also asked respondents to rate the importance of several statements. Between the ages of 18 years – 60 years the majority of respondents identified – giving back to the community as important or extremely important to them personally. In the age group 61-80 years and over there was only a very slight variance from this trend, with the majority identifying the statement – *feeling helpful is important to me* as important or extremely important to them personally.

These results suggest that personal fulfilment for these volunteers was not attained through personal growth, or educational opportunities, but primarily through involvement in their community, and the feeling that even though many in the older age group were retired or not working, that they still had a contribution to make to their community.

Understanding volunteer satisfaction through the support they get from staff

It was also important to Bear Cottage to understand the extent to which volunteers felt supported, by both the volunteer coordinator and the staff overall. This survey asked volunteers to assess the level of support they received at Bear Cottage, with overwhelming satisfaction.

Over 96% of volunteers felt *extremely well supported* from the volunteer coordinator, with slightly lower overall levels of satisfaction when asked about support from staff, with 78% feeling *extremely well supported* and 16% *feeling somewhat supported*. These results suggest that overall volunteers felt they were adequately supported, and when analysed in conjunction with the question about how likely they would be to recommend Bear Cottage as a place to volunteer, 97% of respondents said they would be *likely* or *extremely likely* to recommend it.

Overall, volunteers were positive about their experience and intended to continue volunteering at Bear Cottage. 42% estimated they would continue volunteering for between 1-5 years and 45% anticipated they would continue for 5+ years (12% were unsure).

Understanding the challenges and rewards within the volunteer experience

Paediatric palliative care is a field of care that carries with it certain connotations of sadness, and unsurprisingly this research confirmed that coping with the death of a child was one of the most challenging aspects of volunteering at Bear Cottage. When given the opportunity to answer an (optional) open ended question – What is the most difficult part of volunteering in paediatric palliative care? (Q12) – 28% of respondents explicitly mentioned difficulty in coping with the “death of a child”.

“When a child you’ve known and helped care for passes away.”

Comment from respondent in response to Q12: What is the most difficult part of volunteering in paediatric palliative care?

Despite the sadness and difficulty volunteers expressed about this aspect of their work, when asked to select words to describe their overall experience, the most frequently selected words were overwhelmingly positive. Respondents were able to select five words from this list to describe their experience (total >100% because multiple answers were allowed). From these responses it is clear that volunteers at Bear Cottage derive meaning, fulfilment and inspiration from their experiences well beyond that which can be explained by satisfaction from the performance of roles or duties alone. This is a positive reflection on both the organisational culture of Bear Cottage as well as the way volunteers are engaged and supported, and shows how the two are inextricably linked.

Answers	Response Percent
Meaningful	87.7%
Rewarding	82.5%
Fulfilling	68.4%
Inspiring	66.7%
Grounding	57.9%
Challenging	36.8%
Uplifting	33.3%
Sad	21.1%
Educational	15.8%
Essential	10.5%
Spiritual	7.0%
Depressing	3.5%

Is volunteering its own reward?

Interestingly, when asked to self-assess the impact respondents believed their volunteering made, the responses were quite judicious, with 40% of respondents believing they only made a moderate impact, 24% believe they made a little, and 27% believed they had a lot of impact with only 8% believing their contribution made a great deal of impact (1% couldn't answer).

"It's only a small amount of time out of my week but it feels good to be able to make a small tiny difference"

Comment from respondent

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Interestingly these findings align with previous survey results (conducted by Bear Cottage). Although the service acknowledges volunteer contributions as invaluable and believes that each volunteer makes a significant impact, they also believe that the overwhelming generosity and the humble nature of their volunteers explains their reluctance to self-assess their own importance as high.

While volunteers overwhelmingly believe the impact they have is minimal on the lives of the patients, their families and Bear Cottage itself, they are more willing to express their desire to give back to their community and be helpful in some way, identifying it as one of the most important aspects of their volunteering. Some 88% of respondents selected the statement *feeling helpful is important to me* as quite important or extremely important to them, with 92% of respondents acknowledging that *giving back to my community is important to me* as either quite important or extremely important to them.

This suggests that services are most effectively supported by volunteers when they are a valued part of the community, the benefits to the volunteers are that they feel engaged with the needs of their community and enjoy being a valued member of that community. As mentioned earlier this is particularly important when considering the number of volunteers that are retired or not currently working (44%) and may have previously derived a great deal of personal value and satisfaction from their paid work, but who wish to continue participating and contributing as a volunteer within their community.

The benefits to volunteers who can remain active and in touch with their community through volunteering have been highlighted in previous research (Borrero & Kruger, 2015) and cannot be underestimated. However it also suggests that the reciprocal relationship between the community and the volunteer is one that benefits both parties equally and Bear Cottage is an example of a service that supports, and in turn is supported by the community and engages volunteers extremely effectively.

With 46% of volunteers indicating their intention to continue volunteering at Bear Cottage for at least the next 5 years, and 42% for at least 1-5 years (12% were unsure) this is an example of a service that is very effectively engaging, managing and valuing volunteers while establishing itself as an invaluable part of the community in which it operates.

Discussion

Bear Cottage is a unique establishment in NSW for its role as a stand-alone children's hospice and respite service. The facility is well respected within the NSW community and often has a waiting list of willing potential volunteers.

The very uniqueness of Bear Cottage also means that comparisons with or across other adult or children's services in NSW would likely be too abstract to be meaningful. Therefore the findings of this study are better read as a summary, than a critique, of a paediatric hospice and respite service. For this reason too they effectively form a benchmark for illuminating the character and characteristics of a well-respected paediatric service.

With this in mind the report offers a number of thematic observations.

This research identified differences in the motivations for volunteering between men and women; with women believing they possessed the relevant skills to contribute meaningfully to paediatric palliative care, while men were motivated by a belief that it would be challenging and rewarding volunteer work. While these differences can in part be explained by broader social and gender based trends, the differences noted could be helpful in adapting recruitment strategies to more effectively target men for volunteering opportunities in the future. This would be particularly beneficial if attempting to attract volunteers that can most effectively support adolescent patients in palliative care, this field could warrant further attention to better understand how the needs of both patients and volunteers could be met.

Age and life experience were also areas of interest in this study that illuminated how volunteers inherently empathise more strongly with patients and families that perhaps most closely resemble their own situation. Younger volunteers relating to statements about supporting patients and their siblings, while the older cohort tended to want to give back to their community using the skills they had gained over a lifetime of learning.

Understanding these different motivations is again a useful point to consider when developing targeted recruitment strategies to increase the engagement of younger volunteers wherever needed.

In summarising what matters to volunteers it is important to consider motivations and reasons for paediatric palliative care volunteering in the first place, as these initial goals and expectations will influence their satisfaction further down the track. While most of the respondents wanted to support a family in need and give back to their community, these are intangible things that it is difficult to assess for effectiveness, therefore it is crucial that volunteers felt inherently, that their work was 'meaningful' and 'rewarding'. While there is no way to measure these aspects of volunteering, Bear Cottage seems to effectively provide feedback to volunteers that values their intangible contributions through supportive staff and an effective volunteer program overall.

Understandably, coping with the death of a child was identified as one of the most challenging aspects of paediatric palliative care volunteering. Interestingly however, it did not correlate with incidences of attrition or shortened tenure, but seemed to be more of an accepted part of the role. If the very nature of a role is to support dying children and their families then the importance of supportive and effective volunteer coordinators and staff cannot be understated in ensuring volunteers are able to cope with these challenges, and appreciate the overall experience as 'meaningful' and 'rewarding' rather than overwhelmingly 'depressing' or 'sad'.

One of the most surprising findings of this study was the lack of impact volunteers felt they made in their roles. While the scope of this research didn't investigate this in great depth, it provides an interesting insight into why people volunteer. The fact that most volunteers felt they made little impact did not detract from the meaning and fulfilment they derived from the experience. This

is perhaps a trait that is unique to the palliative care setting, where volunteering is not about changing the world, rather about the small but significant acts of kindness that can help make it better for someone else.

"Feeling like you made a small difference in helping these children"

Comment from respondent

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This research reflects positively on the engagement of volunteers at Bear Cottage and the model of support offered to volunteers. The observations may well form the basis for a longitudinal study of volunteers involved with Bear Cottage. They are also a valuable resource in developing a model of statewide support for palliative care volunteering in NSW.

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:

Burke M (2016) *Paediatric Palliative Care: A survey of a hospice volunteer service*, Palliative Care NSW, Surry Hills.

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Contact Palliative Care NSW

Phone 02 9206 2094 **Email** info@palliativecarensw.org.au

Mail PO Box 487, Strawberry Hills NSW 2012 **Office** 414 Elizabeth Street Surry Hills NSW 2010

www.palliativecarensw.org.au | www.volunteerhub.com.au



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