



Palliative Care
NEW SOUTH WALES



Palliative Care
Volunteering

Research Report

Investigating the provision of complementary therapies by palliative care volunteer services

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Introduction

In recent years, there has been a growing body of research in the use of complementary therapies amongst various palliative care volunteer services throughout NSW.

In Australia a commonly accepted industry definition of complementary therapies appears to be lacking, with most emphasis being placed on 'complementary medicines'¹. In the USA the National Centre for Complementary and Integrative Health defines complementary therapies as a "group of diverse medical and health care systems, practices, and products that are not presently considered to be a part of conventional medicine"².

Various studies on patients with life-threatening illnesses have demonstrated that complementary therapies have a wide range of benefits in areas of social, psychological, physical, and spiritual well-being³. In most cases, complementary therapies are provided in combination with conventional medicines to further enhance the client's overall happiness and comfort⁴.

The use of complementary therapies has historically been challenged by mainstream medicine for some time, alleging the lack of evidence surrounding its impact and effectiveness. Over time this debate has become less prominent as research increasingly highlights both the positive short- and long-term impact of complementary therapies on patient outcomes⁵. The idea that complementary therapies are becoming more popular and volunteer services are utilising them more frequently opens up an avenue of research into how we can better manage and deliver complementary therapies.

Previous research has identified that palliative care volunteer services provide complementary therapies⁶. The modalities have as a general aim the desire to impact positively on the client's social, physical, psychological or spiritual environment, to increase positivity within the client while reducing feelings associated with stress, anxiety, and physical pain⁴. Previous research has highlighted that even as little as one complementary therapy session with a patient can lower blood pressure, heart rate, and anxiety scores post therapy⁷.

Palliative care patients have also reported that complementary therapies have improved their quality of life by allowing them to develop adaptive coping strategies, giving them a greater sense of control, and bringing forward aspects of their individuality⁸.

The Volunteer Support Services Programme has an interest in understanding and improving the capacity of palliative care volunteer services in NSW to better support individuals receiving palliative care, as well as their families and carers. So the aim of this research is to understand the types of, and rationale for the, complementary therapies being offered and the associated challenges and benefits of managing and delivering these therapies to clients within programs that involve volunteers.

In performing this research we acknowledge that NSW Health, through their website, offers this caution to consumers of complementary (and alternative) therapies⁹:

The term “complementary and alternative therapies” refers to a diverse group of practices and products not considered part of evidence-based, conventional medicine... Complementary and alternative therapies may not provide you with any benefit, and may actually cause harm. For example, some complementary therapies may have important unwanted effects (side effects), or may interact with conventional and prescribed medicines or with each other. If you are considering using complementary or alternative therapies, it is important that you discuss this with your doctor to minimise the risk of harm.

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In performing this research we are also aware that amongst some commentators the term ‘complementary therapies’ is identified as a role performed by qualified practitioners whereas the term ‘complementary approaches’ is more appropriate to practices for which unqualified or volunteer practitioners engage. This report does not seek to define the term complementary therapies or to contest the ideas around complementary approaches, but rather it seeks to report on what services claim complementary therapies to be.

Method

An online survey was developed consisting of 18 questions including multiple choice questions, Likert scales and open questions that required short answer responses. The questions followed a logical sequence starting with the type of complementary therapy being offered, total number of hours and volunteers associated with that complementary therapy, required training or qualifications, successfulness, plans to expand, and finally benefits and challenges specific to the management of these complementary therapies. Participants were also given the opportunity to comment on questions to add their own additional thoughts and opinions.

In early 2018 emails were sent to managers of 41 palliative care volunteer services throughout NSW, of which 19 respondents (46%) indicated that they offered complementary therapies as part

of their service and would be interested in participating in the study. The self-selected 19 participants were then contacted a second time via email inviting them to complete the online survey as well as outlining both the opening and closing dates. The survey link was also included and participants were given a total of two weeks to respond. Completion of the survey was on a voluntary basis and all responses were de-identified to ensure anonymity.

Follow-up emails were then sent one week prior to the closure of the survey both reminding and prompting participants to respond if they have not yet done so. Of the 19 participants targeted for the survey, 10 respondents (52%) completed the survey. Participants were also given the opportunity to be notified once the final report has been published via email.

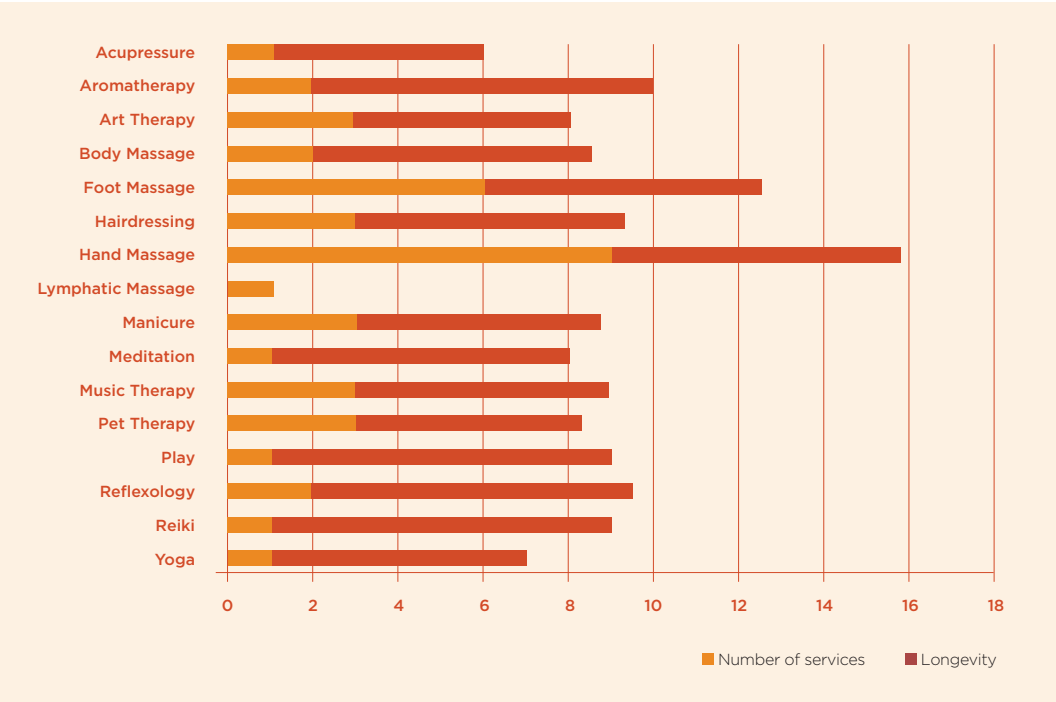
Findings and Discussion

Modalities and volunteers

The study identified 16 different complementary therapies were practiced by palliative care volunteers. The most common modalities used (see Figure 1) were hand massage with a total of 90% of respondents using this therapy as part of their service, followed by foot massage (60%). Art therapy, music therapy, pet therapy, hairdressing and manicure were identified by 30% of the respondents. These were followed by body massage, reflexology and aromatherapy identified by 20% of the respondents. The modalities of Reiki, yoga, play and acupressure were identified by 10% of the respondents.

Figure 1 also indicates the duration for which the modalities had been used with the longest running modalities being body massage, hand massage, foot massage, Reiki, pet therapy, reflexology, hairdressing, manicure, aromatherapy, and play/craft, which have all been in operation for over 10 years. These statistics are consistent with previous research suggesting that mind-body therapies that promote relaxation and comfort are more commonly used in palliative care services¹⁰.

Figure 1: Modality by number of services & years modality has been offered



Across all 16 modalities respondents indicated the involvement of a total of 342 volunteers as indicated in Figure 2. The modalities in which volunteers were most commonly involved were hand massage (n=136) followed by foot massage (n=116). Respondents indicated that volunteers practiced massage therapies 261 hours per week. Next most commonly practiced modalities were hairdressing, manicure, and aromatherapy at a total of 32 hours. Art, music, and pet therapy were practiced 20 hours per week, followed by reflexology, Reiki, yoga, and meditation with a total of 11 hours per week. Finally, volunteers also spent 11 hours per week practicing both acupressure and play.

Figure 2 also shows where particular complementary therapies are being practiced across four different settings:

Inpatient care, outpatient care, residential aged care facility and client's home. The most commonly used setting for all modalities was inpatient care with 15 modalities (about 94% of all modalities) practiced, and the only site at which art therapy, music therapy, pet therapy and yoga were practiced. That these modalities are only practiced in inpatient settings suggests that they may be more commonly practiced as group events.

The second most popular setting was the client's home, the location for 9 out of 16 (about 56%) modalities. Moreover, only 4 therapies were practiced in aged care facilities followed by an additional 3 at outpatient clinics. This demonstrates again that Complementary therapies are most commonly administered in settings that are easy for the client to access.

Figure 2: Modality by volunteer involvement, location and number of services

Modality	Number of volunteers	Hours spent practicing per week	Location and number of services			
			Inpatient care	Outpatient clinic	Residential aged care facility	At client home
Acupressure	5	5	1			
Aromatherapy	11	11	1			1
Art Therapy	6	6	2	1		1
Body Massage	9	28	1			
Foot Massage	116	70	3			
Hairdressing	11	10	3			
Hand Massage	136	139	1			1
Lymphatic Massage	1	1	2		1	1
Manicure	14	11		1		
Meditation	1	1	8		2	6
Music Therapy	9	6	3			1
Pet Therapy	8	8	5		1	3
Play	6	6	2	1		1
Reflexology	3	8	3			
Reiki	3	1	2		1	2
Yoga	3	1	1			

Formally recognised qualifications are required to deliver certain modalities. Of the 16 therapies listed, 12 modalities (75%) required professional qualifications. These therapies included hand, foot, and body massage, art, music, and pet therapy, hairdressing, manicure, yoga and

aromatherapy as indicated in Figure 3. For those modalities that required professional qualifications some 70% of respondents stated that specific training was provided by the volunteer service, while 47% stated that the volunteer had already been previously trained in a specific modality before joining their service.

Figure 3 – Modalities by nature of training for volunteer role

Modality	Professionally qualified	Not prof qualified but specific training provided	Volunteers were previously trained before coming to my service	No qualification or training required
Acupressure	1	1		
Aromatherapy	1	1	1	
Art Therapy	1	2		1
Body Massage	2		1	
Foot Massage	1	6		
Hairdressing	2	1	1	
Hand Massage	1	7		2
Lymphatic Massage	1		1	
Manicure	1	2		1
Meditation		1		
Music Therapy	1	2	1	1
Pet Therapy	1	1	2	
Play				1
Reflexology	2	1	1	
Reiki		1		
Yoga	1			

The role of training can be broken further down into two sections; assisted practice, and qualified practice. To illustrate, some respondents stated that volunteers are not necessarily qualified in massage therapy but rather they act as assistants for trained professionals. One respondent stated *“a qualified massage therapist gives demonstrations and supervises our volunteers doing massage”*. On the other hand, another respondent stated that their *“volunteer was a registered nurse with further certificate training in remedial massage”*.

This inconsistent approach to training across volunteer services may mean that the same therapies are being practiced differently. This finding suggests that the client's general well-being and happiness may take precedence, or at least be of higher priority, than how a particular modality is administered. Alternatively the variation in approaches to training might suggest that some services are insufficiently preparing their practitioners. Perhaps a more standardised training regime would be more beneficial in ensuring volunteers are adequately prepared for their roles.

The findings in Figure 3 also indicate that there are some modalities for which one service may require professional qualifications that are not required by other services. This is the case for art therapy and music therapy as well as hand massage. On the other hand, there is an overlap with additional services not requiring any professional qualification for these therapies. What this finding suggests is that whether or not a volunteer needs to be trained or have qualifications to practice a particular therapy appears to be influenced by what the service deems adequate and acceptable.

Some 52% of respondents indicated that they had included a particular modality as volunteers had already been trained within that modality and 31% stated that they implemented a specific or multiple modalities because they thought it would be beneficial to their clientele. Many respondents (42%, typically volunteer managers) indicated that they had inherited a specific modality that was already in place at their volunteer service before they became a manager. Considering that the primary motivating factor for implementing a modality was volunteer-readiness this response suggests that the more common therapies are more overlooked than the data suggests as managers will tend to favour modalities for which volunteers are already trained.

In terms of service delivery, two main categories emerged highlighting how managers and volunteers actively promote the various complementary therapies provided by their service: either by individual promotion (75% of respondents) or through program rosters (25% of respondents). Respondents who indicated ‘individual promotion’ typically regarded patients on a case-by-case basis such as: “when talking to patients, carers, and families, the volunteer will offer services to them if it is appropriate”; and “only offered verbally when doing client home visits or to inpatients”.

These results are consistent with findings from previous research demonstrating that face to face promotion is essential for developing trusted relationships with clients and families, and promoting active communication [11]. On the other hand, program rosters have individual activities listed on them that cater for more inpatient and aged care facility settings. One respondent stated that there is a “dedicated program in each patient's room”.

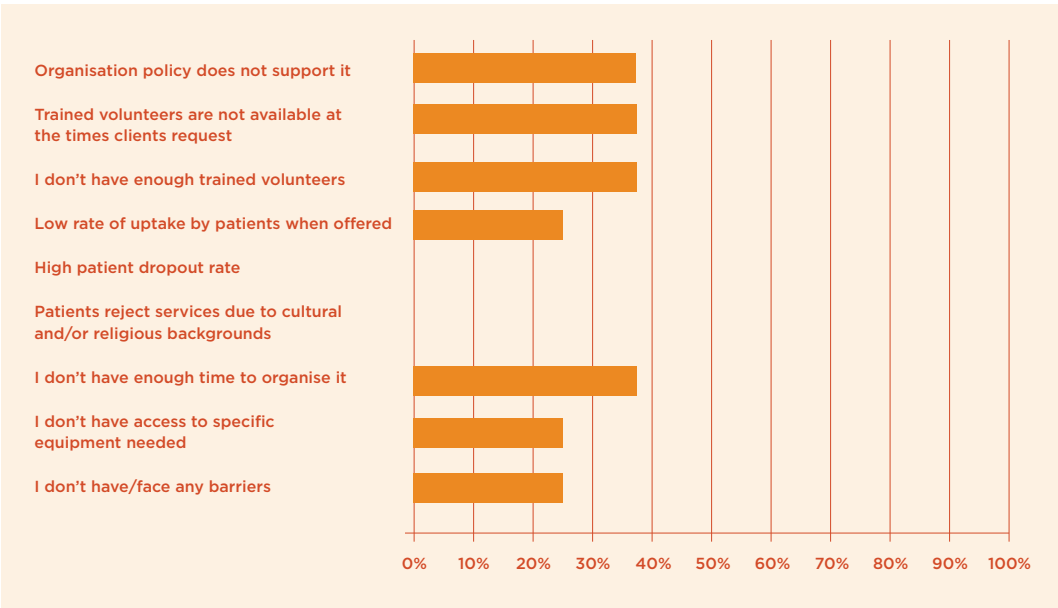
Challenges for volunteer managers

Respondents were asked “What barriers have you encountered when managing complementary therapies?” The results are tabulated in Figure 4.

The challenges faced by volunteer managers who have oversight of palliative care volunteers has been well documented in NSW^{12,13} with one of the barriers being the lack of availability of suitable volunteers. This same finding has been reflected in this study with 37% of respondents indicating that ‘trained volunteers are not available at the times clients request’ and a similar number indicating that ‘they do not have enough trained volunteers’ with one respondent indicating that “I find it difficult to match volunteer availability with demand”. Another respondent indicated that “my yoga practitioner is only available on Friday which is a busy turn-over day, therefore there is not a great uptake from clients and families”.

Even if volunteers were available and suitable the respondents indicated that clients might not necessarily desire the modality. A total of 25% of respondents stated that when offering complementary therapies there is a low rate of uptake from clients. A potential reason for this is that various religious and cultural beliefs may stop clients from engaging in a particular modality, with one respondent stating that “volunteers will not provide the service due to cultural and religious backgrounds”. The specific reasons for this are unclear and might relate to the perceived philosophy underpinning the modality, or the gender of or relationship with the person delivering the modality. One response might be to offer to train family members of that client in a particular therapy so they can administer it to them without any conflicting views between client and volunteer. One respondent indicated that they have had “inpatients refuse to engage with art therapy” suggesting that perhaps those inpatients wanted to engage in a less structured form of art than the therapeutic approach taken by the volunteer practitioner.

Figure 4: What barriers have you encountered when managing complementary therapies?



In addition, 25% of respondents stated that they do not have access to the specific equipment or materials required for a type of modality. This is conveyed in an answer which claimed “the course for aromatherapy was costly and the time and price involved in stocking and formulating individual blends was exhaustive”. Items that are necessary for practicing a therapy may be difficult to purchase or maintain and therefore result in the service discarding the option as a whole.

It is important to note that the barriers managers are facing seem to be interrelated. This means that focusing on them individually may not be the best way to prevent them from occurring, for

example it may be more beneficial for managers to focus their efforts on tackling problems like time management and volunteer availability together rather than as separate issues.

Perceived benefits of modalities

Respondents were asked “What do you consider to be the three most beneficial components of each type of complementary therapy/ies your service provides?”

Figure 5 indicates the top three benefits for each of the 16 complementary therapies listed in the study. These include the relief of pain, aiding in relaxation, and enhancement of the clients psychological, physical and social well-being.

Figure 5: Respondents perceived ‘top 3’ benefits of each modality

	Brings carers and clients together	Provides relaxation	Facilitates communication between client and volunteer	Relieves client discomfort	Pain relief	Improves movement	Good distraction	Enhances spiritual well-being	Enhances general happiness
Acupressure		✓		✓		✓			
Aromatherapy		✓	✓	✓					
Art Therapy		✓					✓		✓
Body Massage			✓	✓	✓				
Foot Massage			✓	✓	✓				
Hairdressing				✓			✓		✓
Hand Massage		✓	✓	✓					
Lymphatic Massage				✓		✓			✓
Manicure		✓	✓						✓
Meditation		✓					✓		✓
Music Therapy	✓	✓					✓		
Pet Therapy	✓						✓		✓
Play	✓		✓				✓		
Reflexology		✓		✓			✓		
Reiki		✓							✓
Yoga		✓				✓			✓

Although Figure 5 shows the ‘top 3’ perceived benefits each of the hand massage and foot massage modalities scored a response in all of the perceived benefits types. The most common benefits were *providing relaxation, relieving client discomfort, and facilitating communication between the client, volunteer, and family.*

Whether volunteers assist a trained therapist or conduct the therapy themselves, respondents noted that clients have said that the “care shown to them is a gift and it feels good”. One respondent said that “the inclusion of massage was very positively received as part of the service by clinicians, volunteers, and patients”. In this case, the benefits of delivering these therapies apply to all involved and contributed to promoting feelings of worth, compassion, and comfort. This finding is consistent with 9 of 10 respondents (90%) stating that they rate the overall benefits of hand, foot, and body massage as either successful or highly successful.

Paediatric volunteering typically focusses on support for parents, child and siblings to assist with carer coping, sibling support and family socialising. This respondent indicated a direct connection between the relief experienced by the child and that experienced by the parents.

“For parents who are continually looking after a child, they never get a chance to go and get a haircut or some reflexology. Their needs always come second to their child. If parents are looked after then they are better equipped to look after their child. Children receiving reflexology can sleep better and be more settled, enabling parents to get more sleep.

One respondent noted that the sense of relaxation afforded to clients had a positive effect on the staff and volunteers, as noted by this respondent:

It’s all about patient well-being, and these therapist often assist in helping with spiritual and emotional distress which an impact on their sense of well-being and pain. Staff also feel a sense of well-being when they see the positive impact therapies have on their patients.

This affirms other evidence of a sense of reward experienced by volunteers pursuant to their involvement in end of life care¹⁴.

Service Improvement

Respondents were asked “How would you like to improve the complementary therapies provided by your volunteer service?”

Five opportunities were identified for improvement. The opportunity that rated most highly was improving volunteer availability, with up to 88% of respondents stating that the best option to improve their service would be by having more volunteers with the modalities offered. This finding is consistent with participants mentioning that volunteer availability was the highest associated barrier when delivering their service.

The second most highly rated opportunity for improvement was the introduction of new modalities (about 44% of respondents). A further 44% of respondents stated that recruiting qualified practitioners would be beneficial for their service, predictably allowing services to free up more additional time and have more available appointments for clients if needed.

Some 38% of respondents stated that they would like to increase the amount of hours spent on existing complementary therapies, and 22% of respondents stated that it would be beneficial for their service to offer complementary therapies more frequently.

As discussed earlier having insufficient trained volunteers and being limited in when the modalities can be offered are the most common challenges that prevent managers from implementing such therapies. This again highlights that the barriers mentioned earlier have a direct impact on how complementary therapies are delivered to clients. It also signifies the importance of addressing these issues which would allow for volunteer services to run more smoothly and efficiently.

Concluding comments

As seen, palliative care volunteer services across NSW provide a wide range of complementary therapies. What differs though is how and why these therapies are delivered. Delivery may be triggered by the clients' needs or by the preference the service has for that modality, or upon the opportunity presented by having a trained practitioner available to deliver that modality.

While this study looked at the incidence and frequency of the delivery of modalities we did not attempt to measure the standards to which modalities were delivered. That is to say that even though services practice the same modalities their individual expressions may differ between services. This suggests that where a service desires a higher uptake of a modality, or where a modality succeeds in one service and not another, there might be an opportunity for an evidence-based approach to better enhance the efficacy and service delivery of complementary therapies.

A major theme present in the data was the relative popularity of massage therapies. Massage modalities (hand, foot) have the highest amount of hours spent on them with the most amount of volunteers practicing them. Perhaps part of their success lies in the combination that the therapies are relatively easy to practice after instruction and provide the widest range of benefits of all of the modalities.

Volunteer availability was another key area that seemed to be common amongst nearly all respondents. It was both the highest rated barrier managers are facing and the highest rated improvement they would like to make to their service delivery. Matching client demand with volunteer

availability can be quite limited and difficult for services if the volunteers are simply not around. A potential way to increase availability may be to evaluate timetables and rosters. Working with volunteers and being able to spread out their practicing hours across multiple days instead of one or two days a week may increase availability and free up time for the service.

Expanding on the above points, nearly half of the respondents wanted to introduce new therapies as part of their programme. Knowing that complementary therapies cater to different areas of the clients psychological, spiritual, social, and physical environment, adding new types may help balance this holistic approach to care. Hence the services that provide massage for relief of pain and relaxation may also benefit from introducing meditation and yoga which would cater to the clients spiritual and psychological well-being. This incorporation of new therapies may allow services to train existing volunteers in new modalities and it may also provide the service with the opportunity for more volunteers to join and hence increase overall availability.

Despite the expressed cautions by health agencies about complementary therapies this research indicates an overall, and at times overwhelmingly, positive response to the 16 modalities referenced in this report. Volunteer involvement in the delivery of modalities, where appropriate, appears to be validated as a means of positively enhancing the experience of people receiving palliative care, their families and carers during their experiences at and near end of life.

End notes

The Volunteer Support Services Programme

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 Programme seeks to champion the work and interests of Palliative Care Volunteer Services and volunteers in NSW (www.volunteerhub.com.au).

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