

Investigating the provision of complementary therapies by palliative care volunteer services

**Title: Perspectives on the value of complementary therapies within palliative care volunteering.**

**Introduction**

In recent years, there has been a growing body of research in the use of complementary therapies (CTs) amongst various palliative care volunteer services throughout NSW. The National Center for Complementary and Integrative Health defines CTs 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” (NCCIH, 2017). Various studies on patients with life-threatening illnesses have demonstrated that CTs have a wide range of benefits in areas of social, psychological, physical, and spiritual well-being (Demmer, 2004). In most cases, CTs are provided in combination with conventional medicines to further enhance the clients overall happiness and comfort (Horowitz, 2009).

The use of CTs has been challenged by traditional mainstream medicine for quite some time due to the lack of available evidence surrounding its impact and effectiveness. Although this notion has become less prominent as research has continued to arise highlighting both the positive short and long-term impact CTs have on patient outcomes. The idea that CTs 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 CTs.

Palliative care volunteer services who provide CTs often deliver specific modalities to cater for individual client needs. These are types of CTs that can range from reflexology to Reiki, and specialise in different areas of the clients social, physical, psychological or spiritual environment. They all aim to increase positivity within the client while reducing feelings associated with stress, anxiety, and physical pain (Horowitz, 2009). Previous research has highlighted that even as little as one CT session with a patient can lower blood pressure, heart rate, and anxiety scores post therapy (Wilkinson, Aldridge, Salmon & Wilson, 1999).

Palliative care patients have also reported that CTs 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 individuality (Demmer & Sauer, 2002). So not only do CTs promote health treatments to a variety of people suffering from a variety of ailments, they also directly impact one’s perception of their health in significantly positive ways. The value CTs provide on both physiological and psychological levels is another indicator of the importance in continually evaluating these programmes.

It is important to note that ethical issues do exist when conducting research with patients. One example is obtaining informed consent and assuming that it remains valid even when a patient’s health starts to deteriorate (Lawton, 2001). To circumvent such problem, this research instead focuses on the managers of palliative care volunteer services. This will allow for insights to be drawn that will generate improvements in how managers and volunteers conduct these types of therapies. In essence, benefiting both the service and the patient.

This research has been developed to understand the wide range of CTs being offered, how well received they are, and the associated challenges and benefits of managing and delivering these therapies to clients. The primary aim of this research is to inform and enhance volunteer service delivery across NSW and to improve outcomes for individuals receiving palliative care, as well as their families and carers.

### **Method**

The research instrument developed was an online survey consisting of 18 questions. Multiple choice questions, Likert scales, as well as open questions that required a short answer response were used. The questions followed a logical sequence starting with the type of CT being offered, total number of hours and volunteers associated with that CT, required training or qualifications, successfulness, plans to expand, and finally benefits and challenges specific to the management of these CTs. Participants were also given the opportunity to comment on questions to add their own additional thoughts and opinions.

Emails were sent out highlighting the given research to 53 managers of palliative care volunteer services throughout NSW. Of those, 19 replied stating that they offer CTs as part of their service and would be interested in participating in the study. Completion of the survey was on a voluntary basis and all responses were de-identified to ensure anonymity.

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. 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, there was a total of 10 respondents equalling to a 52% completion rate. Participants were also given the opportunity to be notified once the final report has been published via email.

### **Findings**

#### *Service Delivery*

Considering the vast variety of CTs that are available, there are a certain few that tend to be more popular amongst volunteer services. Within the sample, there was a total of 16 different CTs practiced, all of which had been in operation for differing periods of time. As seen in Figure 1, the most common modalities used were that of hand massage with a total of 90% of respondents using this therapy as part of their service, followed by 60% highlighting foot massage as a key modality. Art therapy, music therapy, pet therapy, hairdressing, and manicure were represented in 30% of the responses. This was followed by body massage, reflexology, and aromatherapy found in 20% of the services surveyed. The least popular

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modalities were that of Reiki, yoga, play, and acupuncture being in only 10% of the sampled responses.

The longest running modalities are 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 services (Nyatanga, Cook & Goddard, 2018).

*Figure 1.*

<i>Modality</i>	<i>Frequency</i>	<i>Average time spent in practice across all services (in years)</i>
Hand Massage	9	6.78
Foot Massage	6	6.5
Body Massage	2	6.5
Lymphatic Massage	1	<i>Not given</i>
Art Therapy	3	5
Music Therapy	3	6
Pet Therapy	3	5.3
Reflexology	2	7.5
Reiki	1	8
Yoga	1	6
Meditation	1	7
Hairdressing	3	6.33
Manicure	3	5.67
Aromatherapy	2	8
Acupuncture	1	5
Play	1	8

Volunteers who are willing to devote their time are an essential component of the palliative care experience. Across all 16 modalities offered by the various services studied, there was a total of 334 volunteers. The highest proportion of volunteers are practicing hand massage ( $n=136$ ) and foot massage ( $n=116$ ). The overall breakup can be seen in Figure 2.

*Figure 2.*

<i>Modality</i>	<i>Number of volunteers</i>	<i>Hours spent practicing per week</i>
Hand massage	136	139
Foot massage	116	70
Body Massage	9	28
Lymphatic Massage	1	1
Art Therapy	6	6
Music Therapy	9	6

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Pet Therapy	8	8
Reflexology	3	8
Reiki	3	1
Yoga	3	1
Meditation	1	1
Hairdressing	11	10
Manicure	14	11
Aromatherapy	11	11
Acupressure	5	5
Play	6	6

Volunteers are practicing massage therapies 261 hours per week. This is followed by hairdressing, manicure, and aromatherapy as the second highest at a total of 32 hours. Art, music, and pet therapy are practiced 20 hours per week, followed by reflexology, Reiki, yoga, and meditation with a total of 11. Finally, volunteers also spend 11 hours per week in total practicing both acupressure and play.

Figure 3 highlights participant responses on where particular CTs are being practiced across four settings. The most common setting used to practice CTs is in inpatient care. Respondents stated that 15 out of the 16 therapies listed in the survey are practiced inside of this setting. Art, music, pet therapy and yoga are the four therapies only practiced in inpatient care. The reasoning behind this may be because they can be administered in groups rather than individually, and hence inpatient care would be the most suitable setting to do so. Following this, the clients home is the second most popular setting with 9 out of 16 CTs being practiced here. Moreover, only 4 therapies were practiced in aged care facilities followed by an additional 3 at outpatient clinics. This demonstrates again that CTs are most commonly administered in settings that are easy for the client to access.

*Figure 3.*

<i>Modality</i>	<i>Inpatient care</i>	<i>Outpatient clinic</i>	<i>Aged care facility</i>	<i>At client home</i>
Hand Massage	8		2	6
Foot Massage	5		1	3
Body Massage	2	1		1
Lymphatic Massage		1		
Art Therapy	3			
Music Therapy	3			
Pet Therapy	3			
Reflexology	2	1		1
Reiki	1			1
Yoga	1			
Meditation	1			1
Hairdressing	3			1

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Manicure	2		1	1
Aromatherapy	2		1	2
Acupressure	1			
Play	1			

To practice certain modalities, some require formally recognised qualifications while others may only need specific training by the volunteer service. Of the 16 therapies listed, 12 required professional qualifications. These therapies included hand, foot, and body massage, art, music, and pet therapy, hairdressing, manicure, yoga and aromatherapy. As seen in figure 4, 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 4.*

<i>Modality</i>	<i>Professional qualification needed</i>	<i>Specific training provided</i>	<i>Volunteers were previously trained before coming to my service</i>	<i>No qualification or training required</i>
Hand Massage	<b>1</b>	7		<b>2</b>
Foot Massage	1	6		
Body Massage	2		1	
Lymphatic Massage	1		1	
Art Therapy	<b>1</b>	2		<b>1</b>
Music Therapy	<b>1</b>	2	1	<b>1</b>
Pet Therapy	1	1	2	
Reflexology	2	1	1	
Reiki		1		
Yoga	1			
Meditation		1		
Hairdressing	2	1	1	
Manicure	1	2		1
Aromatherapy	1	1	1	
Acupressure	1	1		
Play				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 therapists 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

inconsistency in training across volunteer services may mean that the same therapies are being practiced differently. Even when differences in delivery may be apparent, this finding demonstrates that as long as the clients general well-being and happiness is improving, how a particular therapy is administered does not matter. On the contrary, this high variability may mean some services are practicing CTs ineffectively, and perhaps a more standardised training regime would be more beneficial in ensuring volunteers are equipped with the right information.

Similarly, as seen in Figure 4, some services require professional qualifications for art 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. Again, this finding demonstrates that whether a volunteer needs to be trained or have qualifications to practice a particular therapy is influenced by what the service deems adequate and acceptable.

Various palliative care volunteer services may include particular modalities based on their programmes outcomes, or client's needs. Results indicate that 52% had included a type of CT as part of their service due to volunteers already being previously trained within that modality. Followed by 42% of respondents stating that the specific modality was already in place at their volunteer service before they became a manager. A further 31% stated that they implemented a specific or multiple modalities because they thought it would be beneficial to their clientele. Considering the primary motivating factor for implementing CTs is based on whether volunteers are trained in that area, this could potentially mean that more uncommon therapies are overlooked. This not only limits variety in terms of having multiple CTs available, but it can also prevent managers from providing a therapy that may be more useful for client needs in favour of a modality that their volunteers have been already trained in.

In terms of service delivery, two main categories emerged highlighting how managers and volunteers actively promote the various CTs provided by their service. Firstly, therapies are promoted individually, and secondly, through program rosters. A total of six out of the eight participants who responded to this question use individual methods, while two utilise program rosters. Respondents stated that “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 (Pesut, Hooper, Lehbauer & Dalhuisen, 2014). 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 patients room”.

### *Challenges*

When managing palliative care volunteer services managers face a variety of challenges. The most significant barrier faced is the lack of volunteer availability. As noted earlier, volunteers are an integral part of the palliative care experience. Without them, volunteer services would

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find it difficult to maintain and practice CTs. To demonstrate, respondents stated 37% of the time that ‘trained volunteers are not available at the times client request’, with a further 3 out of 8 claiming that ‘they do not have enough trained volunteers’. This highlights that a key area of concern managers are facing is being able to match client availability with volunteer availability. Furthering this point, services not having a large number of volunteers trained may result in unnecessary conflicts when trying to manage what volunteers are doing and who they are seeing.

These points can be demonstrated by one manager stating that “I find it difficult to match volunteer availability with demand”. Another interesting point found is that the relationship between availability can shift on to the client. This means that a volunteer may be available on certain days however the client at those selected times has other commitments. This is illustrated in a comment from a respondent who stated 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”. This finding is consistent with a further 37% of respondents claiming that timing is a major issue in being able to organise and schedule appointments between volunteers and clients.

This leads on to the next barrier faced by managers and that is client uptake. A total of 25% of respondents stated that when offering CTs 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 therapy. One respondent stated that “volunteers will not provide the service due to cultural and religious backgrounds”. This suggests that certain clients may be unable to participate in certain therapies that may be beneficial for their symptoms due to religious affiliation. A way of mitigating this could be 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. Similarly, clients themselves can be unwilling to engage in therapies due to their deficits in social and physical abilities. One respondent stated that they have had “inpatients refuse to engage with Art Therapy”. This can mean that volunteers are reluctant to put their skills into practice and may need to change their approach or use a less socially engaging therapy like massage.

In addition, 25% of respondents stated that they do not have access to specific equipment or required materials 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 overall. It may be beneficial for managers to focus their efforts on tackling problems like time management and volunteer availability together.

### *Benefits*

There are a variety of different benefits when volunteer services provide CTs. These benefits can include the relief of pain, aiding in relaxation, and enhancement of the clients psychological, physical and social well-being. Below in figure 5 highlights the top three benefits for 15 out of the 17 CTs listed in the study.

Figure 5.

	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
Hand Massage		✓	✓	✓					
Foot Massage			✓	✓	✓				
Body Massage			✓	✓	✓				
Lymphatic Massage				✓					✓
Art Therapy		✓					✓		✓
Music Therapy	✓	✓					✓		
Pet Therapy	✓						✓		✓
Reflexology		✓		✓			✓		
Reiki		✓							✓
Yoga		✓				✓			✓
Meditation		✓					✓		✓
Hairdressing				✓			✓		✓
Manicure		✓	✓						✓
Aromatherapy		✓	✓	✓					
Acupressure		✓		✓		✓			
Play	✓		✓				✓		

The highest rated benefits when administering CTs are 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, clients have expressed that the “care shown to them is a gift and it feels good”. This high sense of comradery formed between client and volunteer enriches their lives and strengthens their spiritual and emotional well-being. 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 contribute to promoting feelings of worth, compassion, and comfort. This finding is consistent with 9 out of 10 respondents stating that they rate the overall benefits of hand, foot, and body massage as either successful or highly successful.

Being a good distraction can sometimes be all a client needs to boost their psychological well-being. Therapies like play, hairdressing, pet, art, and music therapy all aim to do so. Even when these therapies may not directly provide the client with physical pain relief, each

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contribute in expanding the client's social environment. Volunteers simply engaging in conversation with clients can have significant effects on them feeling acknowledged and trusted.

As mentioned above, the volunteers themselves benefit greatly from providing CTs. One respondent stated that "staff also feel a sense of well-being when they see the positive impact therapies have on their patients". Volunteers are rewarded through acting in sincere and empathetic ways as they learn to value and appreciate life and the dying process (Huntir, 2015). Not only does this benefit the client's well-being knowing they have a trusted and earnest volunteer by their side, but it also has an effect on the families happiness.

### *Service Improvement*

Within the study, there were five key main areas that managers thought could improve their service. The first was volunteer availability. Up to 88% of respondents stated that the best option to improve their service would be by having more volunteer available. This finding is consistent with participants mentioning that volunteer availability was the highest associated barrier when delivering their service.

Secondly, 4 out of 9 respondents stated that they would like to introduce new types of modalities as part of their service. Again, not having enough trained volunteers and timing constraints are challenges that prevent managers from implementing such therapies. This again highlights that the barriers mentioned earlier have a direct impact on how CTs 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.

In addition, a further 44% stated that recruiting qualified practitioners would be beneficial for their service. This could allow for services to free up more additional time and have more available appointments for clients if needed. A further 3 out of 8 stated that they would like to increase the amount of hours spent on existing CTs. Finally, 22% stated that it would be beneficial for their service to offer CTs more frequently.

## **Discussion**

As seen, palliative care volunteer services across NSW provide a wide range of CTs. What differs though is how these therapies are delivered. This can be due to either the clients direct needs or how the service chooses to practice that specific modality. What this means, however, is that even though services may practice the same therapies their overall individual expression may not be the same. Due to this flexibility it is important to have evidence-based approaches to better enhance the efficacy and service delivery of CTs.

A major theme present in the data was the relative popularity of massage therapies. Previous research has highlighted that massage therapies are amongst the most common CTs to practice due to their relative ease on both the client and volunteers part. As seen above, the volunteer services in this study have factored this into their service delivery as massage therapies have the highest amount of hours spent on them with the most amount of volunteers

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practicing them. The underlying factor present here is that therapies that are easy to practice are easy to run. So, the question arises as to what is the best and most practical way to incorporate different therapies in volunteer services.

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 CTs cater to different areas of the clients psychological, spiritual, social, and physical environment, adding new types may help balance this holistic approach to care. So, in the services who provide massage for relief of pain and relaxation, they may also want to introduce 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. It can also provide the service with the opportunity for more volunteers to join and hence increase overall availability.

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