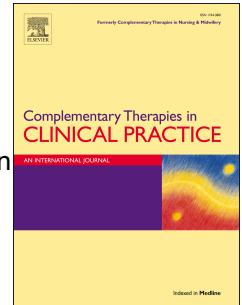


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Brian Nyatanga, Deborah Cook, Ann Goddard



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Complementary Therapies and Patient Well-being in Palliative Care

A prospective research study to investigate the impact of complementary therapies on patient well-being in palliative care

Brian Nyatanga – Senior Lecturer, Academic Lead Centre for Palliative Care, University of Worcester

Deborah Cook – Senior Lecturer, University of Worcester

Ann Goddard – Complementary Therapy Co-ordinator, Primrose Hospice

Correspondence: b.nyatanga@worc.ac.uk Tel +44(0)1905 855381

Centre for Palliative Care, Allied Health and Social Sciences, University of Worcester, Henwick Grove, Worcester, WR2 6AJ

Author Contribution:

Brian Nyatanga: conception of idea and design of study, interviewed all participants, analysed interviews, prepared 1st draft and final paper for intellectual content

Deborah Cook: acquisition and review of existing literature, editing of drafts of the paper and approving final version

Ann Goddard: coordinated participants on site and provided access, acquisition of complementary specific literature, proof reading of drafts and approving final version.

ABSTRACT

Complementary therapies are being used more in the UK over the last two decades and yet very little evidence of their benefit is available. The aim of this study was to investigate, through face to face interviews with patients, using a phenomenological approach the perceived benefits of the different therapies in terms of their overall patient well-being. Eight patients; mean age 52.87years, range 40-64years presenting in the palliative care phase for life limiting conditions comprising one male and seven females agreed to participate in the study between March and September 2015. All eight participants reported perceived benefited from the therapies and that their identified concerns had been ameliorated. Participants reported feeling relaxed, calmer and being able to carry on with their daily lives and refocussing on themselves and what is important in life. Complementary therapies played a positive role, and therefore, an acceptable model of supporting palliative care patients.

Key words: *complementary therapy,, patient well-being,, palliative care,, end-of-life care, concerns*

Introduction

Complementary therapies (CTs) despite lacking a well researched scientific background are being used increasingly by the general population and health care professionals. Many patients may seek CTs because of their increased interest in their personal well-being (Thompson 2005) and the low technology of the treatments, which encourages a more 'self-care' model of health. Using statistics from 2001, Thomas & Coleman (2004) found that 10% of the general UK population had used a CT in the previous year. However using more recent data (Hunt et al 2010; Posadzki et al 2013) show there was a 44% and 51% respective prevalence of life time use of complementary therapy among the UK population. The same authors analysed in the same study the prevalence over 12 months (one year) and reported 26.3% and 41.1% respective use of CTs among the same UK population.

Despite this evidence, it is not clear what the uptake between 2013 and now is, although it may be safe to predict higher figures using CTs. However, figures from Thompson (2005) are specific that access to CTs within the NHS is increasing; with 43% of Primary Care Trusts and 50% of GPs having access to CT services. With the recent changes in the structure and funding of the NHS this may have changed, but with the emphasis on maintaining well-being and health promotion (DOH 2012), CTs may be utilised more often. Well-being has become very important in the NHS recently especially in mental health (NICE 2016), demonstrating a growth area for which CTs can be helpful. Even with some areas having access, CTs are often on a self-referral basis with a financial cost for the patient, which may mean that service

provision is not equitable to all (Thomas & Coleman 2004). Within the palliative care setting CTs are commonly now utilised (Macmillan 2011), for example, in most hospices (36%), hospitals (31%) and up to 20% based in voluntary sector. However, there does not seem to be robust qualitative evidence to show the impact of these therapies on patient well-being. Bouverie (2016) stated that Macmillan Cancer Support, a large UK based charity, have suggested the need for more high quality research on CTs; *"We know that the scientific evidence base is growing for the use of some therapies in cancer care. However, we would like to see more high-quality research into complementary therapies in order to support patients, health professionals and commissioners to make informed decisions on the application of these therapies."* (1st April 2016).

Literature Review

According to Posadzki et al (2013) using a systematic literature review of 89 studies of over 97 000 participants, the most commonly available CTs are touch therapies: aromatherapy, massage, reflexology in over 90% of services; mind-body therapies; relaxation and visualisation in 80% of services; healing and energy work Reiki, spiritual healing and therapeutic touch in 45% of services, creating a wide spread of a variety of CTs.

The National Cancer Review (2011) indicated that CTs should be used in palliative care, but there was a need for more robust research. Traditionally the use of CTs has been challenged by the medical profession because of this lack of scientific evidence (Hunt et al 2010; Posadzki et al 2013); however perhaps the view is becoming more open as patients report the benefits of CTs, and also patients will have more choice

in their personal health care budgets (Wilkinson 2012). Outcome measures in this arena are difficult to evaluate, as the holistic approach indicates that several forms of therapy and interventions are utilised to create effective timely care, so the tools used have to reflect this complexity (Thompson et al. 2008, Paterson et al. 2007).

Literature suggests that there is a wide range of available CTs, but all aim to develop a balance in the whole person, increasing physical, psychological and spiritual wellbeing (Zappa & Cassileth 2003, Ernst et al 2003, Tavares 2003; Posadzki et al 2013). This holistic approach strongly correlates to the palliative care ethos, according to the 'Improving Supportive and Palliative Care for Adults with Cancer' (NICE 2004), Care of dying adults in the last days of life guideline (NICE 2015). The recently published draft (Supportive and palliative care: Service delivery (NICE 2016) recognise the need to offer extra care and support to patients with life limiting conditions.

The fact that more and more people are using CTs and the continued existence of places like the Mulberry Centre in Twickenham, The Haven and Primrose Hospice in Worcestershire, The Creative Living Centre in Manchester and many others across the UK which offer CTs, is testimony of their value to patients affected with life limiting illness. These are subjective experiences which need to be captured into qualitative evidence.

There are calls for CTs to be used with conventional treatments to alleviate symptoms (Molassiotis et al 2005; Posadzki 2013), increasing the psychological and emotional wellbeing of the patient. NICE (2004) also indicated that CTs should be evaluated and research completed to determine the effect and value of CTs in this

setting. This view was first highlighted by Tavares in her 'Guidelines for Complementary Therapies in supportive and palliative care' (2003). In their deliberations, The House of Lords (2000) also noted that there was a lack of scientifically controlled evidence and therefore it was difficult to support CTs. In addition, research in this area can be limited due to lack of funding (Cant 2012, Tavares 2003), ethical approval difficulties (Ernst et al 2003, Tavares 2003), small or limited samples (Thompson et al 2008, Cant 2012) high attrition rates (Tavares 2003) and many therapists lack research experience (Tavares 2003). However, to expect scientifically controlled evidence from this patient group receiving CTs is to ignore the lived experiences patients go through which are subjective and often result in multiple realities, which can not be accurately captured scientifically. The experiences of human beings are best captured through qualitative approaches and we need a strong evidence base for CTs, which is rigorous and transferable.

The guidelines produced by the Prince of Wales team, reviewed the limited current body of evidence relating to nine common therapies: acupuncture, aromatherapy, homeopathy, hypnosis and hypnotherapy, massage, reflexology, reiki, spiritual healing and therapeutic touch. These therapies were considered in relation to cancer, Motor Neurone Disease (MND), Multiple sclerosis (MS) and Parkinson's disease (PD). Since the report in 2003, there are now a greater number of life limiting diseases that are treated in palliative settings; such as Chronic obstructive pulmonary disease (COPD), renal disease, heart failure and dementia, just to name a few. Therefore new evidence across these diseases is needed and necessary.

To conclude, despite this wide use of different therapies, there is no real qualitative evidence charting how patients evaluate them. These therapies make a subjective difference to each patient, therefore it is important to capture the individual narratives and assess the impact on quality of life and feelings of well-being. It is not clear whether patients go for therapy with a desired or intended therapeutic outcome or whether they just want something different from conventional treatment. Therefore, the aim of this study was to explore the patients' experiences of receiving complementary therapy during their palliative care phase.

The purpose of the study was to:

- Understand the nature of concerns experienced by patients with life limiting conditions as they manage their quality of life.
- Gain a detailed understanding of how these patients value complementary therapies and their perceived benefit on the way they feel about themselves (well-being) at this stage of their life.
- Understand the impact complementary therapies made on the key concerns reported by patients on their MYCaW form
- Ascertain therapies which are perceived as most beneficial by patients experiencing complementary therapy treatment.
- Provide an opportunity for patients receiving complementary therapies to reflect on the service and identify areas for improvement

Study Methodology

In order to understand the different lived experiences of the patients who received complementary therapy, interpretive phenomenology (IP) based in the Heideggerian

philosophy was employed, with a view to delving deeper into patients narratives of the experiences. IP allowed researchers to probe all participants through semi-structured interviews to understand their understanding and meaning of experiencing complementary therapies. IP offers an important dimension, unlike descriptive phenomenology, which allows the researchers to interpret patients' narratives whilst using the researchers own frames of reference (Parahoo 2014). In other words, as researchers we use our self-knowledge of complementary therapy, the literature around it and other relevant sources to reflect on the interview data and in order to interpret what patients are telling us (van Manen 1990). IP derives its strength from its philosophical dimension that provides clear direction and principles necessary for conducting such research. The use of phenomenology naturally utilises relatively small sample sizes, therefore there was no intention to generalise the findings from this study. However, it is critical to emphasise that the findings are likely to resonate or extemporize with others who receive complementary therapies. Denscombe (2017) is clear the strength of this methodology is that it allows for competing versions or alternatives realities of what complementary therapy is for patients receiving it to be highlighted. The point to emerge is that there may not be one correct or right approach, but that experiences may differ on cultural and social grounds and therefore different theories on the same experience may in fact be valid. Therefore, results from this study will be reported from varying perspectives and realities of the world view of experiencing complementary therapies.

Sampling

A total of ten patients in their palliative care phase who met the inclusion criteria agreed to participate but eight were interviewed individually between May and August 2015. The other two patients fell ill on the day on the interviews and therefore were excluded. Patients were identified by the complementary therapies co-ordinator at the hospice and asked to participate when they were half way through their therapies; i.e. had received three out of six sessions. Prior to the interview all participants were given an information sheet and a covering letter in advance. Those who agreed to take part were asked to complete a consent form on the day of the interview but before conducting the interview. This process allowed for any extra questions to be clarified and further explanation to be given about the study.

Ethical consideration

This study obtained ethics approval from the university of Worcester, which is also the institution where all but one of the researchers worked and were based.

In addition, Ethical clearance was also obtained from the Hospice, where the study was conducted, and where patients received their complementary therapies. Participants' identities were protected by a system of coding (p1-p8) which only identified transcripts and therefore assured their anonymity.

Data Collection

Semi-structured interviews were preferred to discuss the entire experience which included before, during and after the complementary therapies. Data was also collected using the MYCaW forms which captured patients' needs or concerns prior to receiving complementary therapies. In brief, the MYCaW (Measure Yourself

Concerns and Wellbeing) is a questionnaire designed for individuals receiving support for cancer (Paterson et al. 2007; Jolliffe et al 2015). The questionnaire is designed to measure patients' perceived severity of individual concerns and also levels of wellbeing at the beginning and end of a course of complementary therapy treatments. This questionnaire was adapted from an already validated questionnaire called the MYMOP (Measure Yourself Medical Outcome Profile) (Paterson, 1996). The validity of the MYCaW has been tested through numerous piloting across cancer care centres, NHS hospital Trusts providing cancer care and home care settings where complementary therapy took place (Patterson et al. 2007) and recently Jolliffe et al (2014) tested it for validity and responsiveness over time (n=82) and reported that it allowed for personalised patient outcomes to be quantified.

Before their first treatment, all patients were asked to specify up to two main concerns that are affecting them at that moment. Concerns and wellbeing are then rated on a Likert-scale. Concerns can be rated from zero to six, zero being "Not bothering me at all" and 6 being "bothers me greatly" (Paterson et al., 2007). Wellbeing is also rated from zero ("*As good as it could be*") to six ("*As bad as it could be*") (Paterson et al. 2007). At the end of the course of complementary therapy sessions, patients are then asked again to rate these concerns and their level of wellbeing; this can be done independently or with assistance in completion. Free-text space is also provided on the follow-up questionnaire to record any other factors (apart from complementary therapy) that may be affecting their concerns ("*Other things affecting your health*") or any other important changes they wish to report (Paterson et al. 2007). Patients are also asked to report, in the free-text space,

on what has been most important to them during the course of therapy (*“What has been most important for you?”*) (Paterson et al. 2007).

For purposes of this study, only the key concerns were elicited and because interviews took place after the third therapy session, the rest of the information that could have been elicited from the questionnaire was gathered during the interviews.

Data analysis from the interviews

All the eight interviews were transcribed by an independent professional transcriber who had a contract with the University of Worcester, and was bound by the Data Protection Act (1998) to have a duty of confidentiality. The analysis was undertaken manually to promote visibility of all possible themes and the coding allocated to each of the themes. The understanding of a theme adheres closely to Braun and Clarke’s (2008) assertion that a theme captures important information in relation to the research question. Here any theme elicited is deemed to represent some level of patterned response or meaning within the interview data (Braun and Clarke 2008). Because of these two fundamental principles, a theoretical thematic data analysis was preferred for this study. The analysis had three phases conducted in order to arrive at the main themes:

Reading each transcript; Reading again and highlight all relevant data and third, allocation of codes, themes and sub-themes.

No new themes were generated after the sixth participant. Data from all participants were compared and contrasted in an effort to identify common as well as unique experiences.

Findings

The findings are presented under three main categories showing a number themes from each one (see table 1):

1. Pre-complementary therapy - capturing patient experiences before starting their therapy
2. During therapy - eliciting patient experiences of the treatment and other aspects happening during the therapy period
3. Reflection on therapy - patients making observation and comment about the service, processes, duration of treatment and many more. This reflective element gives patients a platform to suggest ways of improving complementary therapies.

We use direct quotes from patients to convey their messages as purely as they expressed them.

Table 1: Categories and Themes for the interview data

Categories	Source	Themes	Source
Pre-complementary therapy	5.1	Main concerns identified on MYCaW	5.1.1
		Previous experience of CT	5.1.2
During complementary therapy period	5.2	Types of CTs	5.2.1
		Perceived benefits	5.2.2
		Other interventions	5.2.3
		Unexpected gains	5.2.4
Reflections	5.3	The whole experience	5.3.1
		Feedback for service improvement	5.3.2

Pre-Complementary Therapy

Main concerns identified on the MYCaW form were also instrumental to the therapist co-ordinator's decision on which type of therapy to offer the patient. The concerns were mainly associated with emotional states with a few physical complaints. All but one patient (p6.17) registered two main concerns, and one patient (p6.17) registered only one. The concerns were double checked with the ones listed on the patient's MYCaW form for accuracy. These concerns are now given below in table 2;

Table 2: Main concerns by participants

CONCERNS	PARTICIPANT P=
Numbness of feet	1.10
Anxiety	1.11
Unable to relax	2.4; 3.8
Unable to be keep a positive outlook in life	2.5; 3.8
Hot flushes	4.5.3; 6.17
Poor sleep pattern	4.9
Feeling tense and fire fighting	4.5.1
Emotional fall out (feeling tense)	5.5
Back pain	5.8
Tension and feeling twitch about life	7.21
Poor body image	7.21.1
Low mood (depression)	8.15
Acid reflux	8.16
Swollen ankles	8.17

Previous experience of complementary therapy

All but two participants (p3 & p6) had experienced a form of CT before they came to the hospice, and also before they were diagnosed with a life limiting condition. Two participants (p5 & p7) had experienced more than one type of complementary therapy before coming to the hospice. The rest of the participants had only experienced one type of complementary therapy before coming to the hospice. The two participants who had not experienced CTs in the past were aware of CTs and explained that they came to the Hospice with an open mind, willing to try whatever therapy was recommended to them. The remaining six had felt some benefit from previous therapies, so they were hoping and expecting to derive benefit from therapy this time around.

During Complementary therapy treatment period

All participants had received three therapy treatments out of the prescribed six prior to taking part in the interview. The therapies offered here were Reflexology, Massage, Acupuncture, Indian Head Massage and Reiki. One patient (p8) received two therapies, Reiki and acupuncture alternately as this combination was deemed suitable for the expressed concerns. One patient's mother also received three sessions of therapy at the same period and reported that it was very helpful (p1.16)

Relationship with therapist

Some patients felt close to their therapist and believed they had formed a positive relationship with their therapist (p2, p4, p5, p8). This relationship formation was made possible by the continuity of having the same therapist each time they came

for the treatment (p2; p4; p5.14, p7). P1 felt comfortable and safe enough to divulge sensitive issues to the therapists that they would otherwise not disclose to their parents. P1 explained *“there are things that I said that I wouldn’t speak to my parents about or my partner because it’s all too sensitive, you know, too emotional I suppose”* (p1.14).

Whereas p7, found the therapy that good she wanted to have the therapist to herself: *“It was great. I asked her to marry me but she wouldn’t”* (P7.6). It is difficult to try and make sense of this quote, but given what normally happens emotionally when you want to marry someone, it can be argued that the patient was displaying a similar affect of wishing to be close albeit metaphorically. The suggestion for the therapist to marry her might be conveying a deep sense of how she appreciated the positive impact of the treatment and not at an emotional level. A few more participants felt a connection with their therapist and felt safe: *“I felt accepted, I feel that I am in a safe place, and I’m accepted for the fact that I’m me and I have got a brain tumour and I’ve only got half a head of hair”* p2.7. This participant was also complimentary to the idea of being treated by the same therapist:

“She is the same therapist, the continuity and the trust is there, which is nice. I like the fact that I speak with XXX and then we’re building up a relationship as well, that I can trust her and she can chat to me, so it’s nice” p2.8

Perceived benefits of therapy

Since all the therapies received were evaluated by all the eight participants as beneficial we have extracted some quotes from each therapy that was used to show

the degree of benefit for each participant. The dedicated time and space to talk to the therapist was perceived as beneficial by P1, who explained: *"I don't necessarily talk about my illness particularly, or my anxiety to my friends. I will but the majority of the time it is about trying to forget what is going on. Whereas with the therapist obviously it was to offload and I could say things to her that I wouldn't possibly say to family or friends"* (p1.14)

Reflexology therapy was received as beneficial to the numbness of feet, which was one of the concerns identified on admission: *"Well I think the first one I put down was about the numbness in my feet, which obviously goes with the reflexology, and that helped tremendously and that has all gone now"*. P1.10

P2 received Reflexology every couple of weeks and this helped by offering time to reflect on self and life in general; allowing time to connect back with how they were really feeling: *".....reflexology gives me time to connect back with what I'm really feeling and to feel that I'm okay to have that time, and I don't have to be worrying about the pills that I'm taking or that kind of thing."* P2.6

One participant who had just had back surgery had their type of therapy changed from Massage to Reflexology and commented that *"...it was great"* p7.4. However, more importantly was the positive outcome from the reflexology: *"....I had it (reflexology) two weeks after my operation, and I walked in and when you've had the operation that I've had you have a very typical stance of being hunched over and quite protective. And I walked out feeling like a big weight had been lifted and I could walk normally and it was fantastic"* p7.5

Another participant who received Indian Head Massage summed up the experience as follows: *"The first time I experienced the Indian Head Massage, I think it's fair to say at the point because of chemotherapy I had no hair, so my scalp was completely bald, and for me the effect was incredible, absolutely incredible. I would dare to go as far as saying hypnotic"* p3.5 This participant's spouse was also offered the same Indian Head Massage and the participant decided to sit in and watch, without realising what the impact would be: *"and oddly enough, because I sat in while my spouse had the same Indian Head massage, it actually made me emotional. I don't know why, but it made me incredibly emotional. And the young lady that was actually doing the treatment said it was quite common that partners whilst watching the other one actually become emotional, and I have no idea why."* P3.6. This experience could be helping with emotional cleansing of the participant's issues surrounding illness and their relationship with significant others.

P4, felt much calmer after therapy, and therefore helped with dealing with life issues in general. *"The first time I came for Reiki, I went back to work, and I was so calm. The difference was just amazing. And that calmness has carried on"* p4.5

P5 received Acupuncture and found it to be relaxing as well as being therapeutic: *"It was relaxing, very calming, lovely ... and I actually went away feeling very healthy and light and raring to go"* p5.5. *"Until like, you know, it is a release. You know, its like crying is a release"* p5.7

Acupuncture was also offered and received by the husband of p5, which perhaps justifies the need for such therapy to partners: *"I mean he feels everything that I feel. He's going through every meeting, every doctor, everything we see he is having the*

same response that I'm having although it's not happening to him. You know, it's almost worse for him because he's on the outside and can't do anything so it's, you know, the stress is there. He obviously supports me and I try and support him but it's hard when you're both feeling the same and it's the heightened emotion of it all is difficult" p5.11.1

Reiki proved to be beneficial and relaxing: *"...when I had the second therapy I was much more relaxed than the first time, so that's fine, you know"* p6.5. *"...just receiving the Reiki treatment, it was very relaxing and the music they play, put on is very relaxing"* p6.6

P8 received two complementary therapies Acupuncture and Reiki alternating each week: *"...when I am actually having the Reiki I find it so relaxing, and it stays with me I would say for the rest of the day. But I was a bit concerned that other day when they practitioner informed me that other people say it lasts for a week"* p8.5. However, this participant was also quick to explain why the relaxation only lasted for a day: *"I thought well I'm a very highly strung person so I find it difficult to relax anyway, so for me lasting the rest of the day is really good"* p8.5.1. Although Acupuncture was also beneficial, this participant preferred Reiki for relaxation: *"I thought the Acupuncture would be the thing that I found the most useful being so sceptical about the Reiki, but actually I find them both beneficial. But I find I get more relaxation through Reiki than I do through the Acupuncture"* p8.3.1. It is possible that the therapies work on different parts of the body and treat different problems/concerns. The participant had the benefit of experiencing two therapies, therefore affording her a choice.

Below, Table 3 offers a summary of all the benefits at a glance:

Table 3: Summary of perceived benefits

Perceived benefits	Source
Time and space to offload	P1, 7.11
Time to reflect	P2.4, 6.5,
Time to connect with own feelings	p2.5,
Being allowed to be kind to yourself	p2.6
Feeling relaxed	p3.7, 5.5,
Feeling deeply relaxed	6.4, 6.5,
Being in the zone /moment	7.12,
Feeling calmer than before therapy	8.5, p3.11
Partners receiving therapy too	P4.5
A release of emotions	P5.11,
De-stressing	P5.7
Relieved the tension	P5.8
	P7.10

Other interventions during Complementary Therapy period

It was important to ascertain whether patients receiving complementary therapy were simultaneously engaged in other therapeutic intervention elsewhere. This was important to understand so that judgements could be made on whether such extra activity might have contributed to the reported outcomes by patients in this study. All but one participant (p3) had another intervention while receiving complementary

therapy which they found helped with the overall feeling of well-being. The other interventions ranged from chemotherapy treatment (p1.22), dog walking (p2.10; 5.9), exercise to keep fit (p4.12), daily walks lasting 20 minutes (p6.9) and Acupuncture from another service (p7.16) and p8.8 started listening to soft music after sampling it while receiving complementary therapy with the therapist: *"I have started listening to music and just try to relax, you know, like mood music and things to sort of take myself into a different place when I get overstressed"* p8.8. This could be a way of empowering self-management to improve mental well-being.

Unexpected gain - Inclusion of partners

Two participants had their partner or relative receive complementary therapy as well. This was not planned in advance and therefore it is being treated here as unexpected gain as the partners found the therapy also beneficial: *"My mum took the opportunity and came, and I think she had three sessions of therapy when I was first diagnosed, and she found it really helpful"* p1.16.

Another participant's p3.6 experience of his wife receiving Indian Head Massage has already been captured above under 'perceived benefits of therapy'.

The husband of p5 was offered Acupuncture (p5.10) and after that he was looking into paying for it himself outside of the hospice. This suggests that it was also beneficial to the partner. There was another added benefit which p5 articulated well: *"I think absolutely it should be offered to the close family. Obviously funding is the problem now isn't it. But I mean I look at it that he's going through the same as I'm going through. He's feeling and going through exactly the same emotions that*

I'm going through, although it's not happening to him. It's still the same to him. It's still as massive and everything for him so absolutely perfect to have that support because it would help me obviously to know that he's being supported" p5.11

Reflections on complementary therapy service

Reflections were captured to understand participants' evaluation of the whole experience of receiving complementary therapies, while providing constructive feedback to the service providers about how the service could be further improved in future provision.

The whole experience

All participants reported a very positive experience with different therapies offered to them and therapists who treated them. Many commented on the benefits of continuity of being treated by the same therapist which meant they could easily form working relationships and felt more relaxed to divulge their inner concerns. They also felt they did not have to keep repeating their 'story' each time they came for therapy, but instead they were able to build on to the story: *"I'm accepted here and they're very welcoming. And the lady that does the reflexology, she's the same lady, the continuity and the trust is there, which is nice. So it's not as if I'm having lots of different people doing the treatment. I like the fact that I speak to xxx(name removed) and then we're building up a relationship as well, that I can trust her and she can chat to me, so it's nice" p2.8.*

Another participant captured an interesting and yet fundamental adage about the popularity of complementary therapies at the hospice: *"You know, I understand it's*

complementary, I understand they do their best, and they are incredibly busy which in my opinion, humble opinion, to be that busy means it must be working. It must be doing something, people are finding it useful. So, you know, it's the old adage isn't it? If you go to the chip shop and there's a queue, and the chip shop next door there's no queue, you stand in the queue" p3.15.

"I think the service has been brilliant. I was referred and seen very quickly. I was assessed by xxx(name removed) who was lovely. Very open and warm and made me feel that, you know, I could say what I wanted to say and clearly understood what I was saying which is important because you don't have to keep repeating yourself or, you know, explaining how you feel, especially when you're obviously emotional. So as far as I can say that no, the service has been very, very good here" p5.13. The same participant felt overwhelmed with emotions while reflecting on the service received and broke down in tears just briefly: *"You know, they do incredible work here. I've got nothing but total admiration for what goes on here. I couldn't have got through what I did without them, and that includes everybody, absolutely everybody. And the therapists were just absolutely – well....."* p3.19 and then at this point, the participant become emotional (tearful) and could not complete the sentence.

One participant felt their partner would have benefited from receiving complementary therapy too: *"But there are times when I think to be the husband of somebody that's going through this it would have been quite nice for him to have had somebody just to talk to or something actually. I mean he's been with me through all my appointments and everything, and so he's heard everything first hand and he's been able to ask questions or if he's felt what they've said might upset me in*

some way he's been very supportive. But I think it might have been nice for the husband or the wife or whatever to have, and I'm sure they do that if there's a need but I suppose it's priorities" p4.11.

P6 was also complimentary in the overall evaluation of the therapy received: *"...she's been very good, very pleasant. Puts on lovely music, does the treatment. When she's finished she touches you slightly and she'll say just stay there and come up when you feel ready. So I couldn't suggest anything really, because it's, she's been very good"* p6.14.

Feedback for service improvement

There were four areas that participants raised as areas that needed reviewing in order to change or improve service provision. It is important to stress that the areas highlighted here do not suggest that it happened during all the three sessions of treatment received by each participant. Not all participants highlighted these areas, but it is right to report the few comments raised here for consideration by the service providers:

Publicity of hospice complementary services

One participant's experience led her to comment that the local hospitals who could refer patients to the Hospice were not aware of the complementary services the hospice offered and therefore commented on the need for more publicity *"So I did actually go back to the doctors and explain the situation, and then obviously I came, I was directed here. And I spoke to xxx(name removed) here who was absolutely brilliant,but I don't think that it's particularly well advertised out there, and for*

somebody who needed help, I needed at that point to speak to somebody and be involved with something.” p1.19

Time gap between treatments

The length of time between therapy appointments for complementary treatments was seen as too long by a couple of participants: *“eh.....the biggest improvement I think that could be made, and again I understand how difficult it can be, especially when the therapists are all volunteers, the time that you have to wait between appointments is incredibly long, incredibly long; most of the time you are waiting six weeks between treatments, between therapies” p3.14.*

Participant 7 expressed similar views about the length of time in between therapies but was helped by attending other activities elsewhere while waiting for the next therapy appointment: *“In many ways that was better in the sense that there’s not such a big gap between appointments. Because I think that’s one of the problems here is that you have an appointment and then the next one is five or six weeks later” p7.14.*

5.3.2.1 The treatment environment

The following quote makes reference to noise while receiving treatment: “Now I understand obviously the sort of place this is and so peace and quiet isn’t always available, and unfortunately for us on the day that we received the Reiki there were some children in being looked after by one of the staff because their father was here who was incredibly ill. And obviously the children were being very well looked after

and making an awful lot of noise. So you weren't able to sort of get in the zone as it were; in fact the therapist apologised on more than one occasion" p3.13.

The following quote offers both very positive accounts of the experience and also points for reviewing the service: *"I mean xxx (therapist) is brilliant, the treatment is brilliant. We've both commented there's a meeting that goes on about three doors down from the treatment room, and it finishes at about 12 o'clock, whereas my treatment finishes at 12.15, and when they come out they're loud. And that's nothing to do with xxx(therapist) or the treatment or anything. And xxx(therapist), has said I debate whether to go and tell them, but then she doesn't want to stop mid-treatment sort of thing. And I said I'm conscious of them, but I don't feel it impinges on me. But for her benefit really the people could be a little bit more sensitive if they're having a meeting near treatment rooms. But for what she does, no, she's lovely, and the people when you come in, the people are very kind. It's a lovely place, it's got a lovely atmosphere hasn't it?" p4.10;*

Funding

One participant felt that the complementary service needed more funding in order to help more patients: *"No it's just brilliant and it should be better funded. It makes a massive difference for people, and I see that" p7.19*

The same participant was also actively doing something to help other women, and responded to the researcher's question in this way; Researcher, *"would you recommend this therapy to other patients?"*

Participant, *“Yeah, and I do. In fact, I’m writing a website for women in Worcestershire at the moment talking about women things like this, that are available for them to help them”* p7.20

The quotes show an overwhelmingly positive experience towards CTs received by these participants. The benefits from each therapy tend to last for days and in some cases weeks. The fact that these findings are recognised at the half way stage of the treatment suggests how well CTs are being delivered, received and benefiting the patients.

Discussion

The intention of this research study was to explore the patients’ experiences of receiving complementary therapy (CT) during their palliative care phase and the impact it had on their well-being. Such an exploration relies on the subjective accounts of recipients and therefore these experiences cannot be generalised to other larger groups of patients elsewhere. There were different types of complementary therapies received by the participants depending on the concerns they reported when they were first admitted to the hospice programme. Despite these difference CTs, all the eight participants reported benefits from their respective CTs.

The purpose of the research was multi-fold in its attempt to present a broad picture of complementary therapies and their role and impact on patient well-being. With any study that looks at patients’ experiences of a service, it is inevitable that issues surrounding service delivery and therefore areas for service improvement are discussed, and such information can only serve as useful for improving the service.

These were best understood by asking participants to offer a qualitative evaluation of their own experience of receiving specific type of complementary therapy.

The results from this study clearly show recognisable benefits to all eight participants. The breakdown of participants was seven female and one male, and this picture is also reported in earlier studies, Hunt et al (2010) who found that 95% of women were significantly more likely to use CTs. The benefits from this current study were mainly centred around achieving a relaxed and calmer feeling about any anxieties and ameliorating the identified concerns. Although other studies (Molassiotis et al 2005) reported that CTs increase the body's ability to fight cancer, this study did not have this remit.

However, it can be argued that CTs used in this study have the ability to induce calmness and relaxation among patients, this in turn can lead to improved physical as well as emotional well-being of patients who use CTs.

As the name CT suggests, most patients in this study used CTs in conjunction with other interventions, and the benefits have been clearly shown in this current study. Previous studies like Hunt et al (2010) have also confirmed that use of CTs in England is substantial among patients taking prescribed medication. The duality of interventions is significant and arguably an important reminder that health care professionals should offer patients the option of complementary therapy in conjunction with their convention/traditional Western medicine. What is even more

important is documentation of CTs used and benefits to create a data base, which could inform future research.

Another important factor to consider is whether the provision of palliative CTs should be automatically offered these to patients' close family. The benefits were clearly demonstrated in this study albeit from two partners who received the therapy. Such practice would be in line with the ethos and philosophy of palliative care where care and support is also extended to those deemed important to the patient.

Impact on complementary therapists

It is always important to consider the impact of providing CTs on the therapists themselves, as they too have to work with other people's emotional needs (Nyatanga 2013). Throughout the treatments, therapists working with patients' emotional and social needs, and like most health professionals in palliative care, they too may find the emotional labour of such work emotionally draining and physically tiring. Therapists should have open access to supervision, although uptake is historically poor, we need to understand why this is the case. Therapists should have regular (monthly) meetings/discussion platform where difficult issues can be shared while increasing mutual team member support. Where necessary, a tailored support system to support each therapist individually would enable cathartic process through debrief in order to maintain their own well-being. Nyatanga (2013) has suggested that health care professionals and in this case complementary therapists, may also

benefit from social support that helps to buffer effects of negative stress and prevent therapy-related burnout.

Methodological strength

The preference of utilising qualitative and interpretive methodology was most appropriate in that it allowed for the capture of the essences of the experience (Heidegger 1962) and narratives given by participants (Denscombe 2017; Holloway and Galvin 2017). Holding face to face individual interviews proved the most successful way of understanding patients' experiences as they were able to express freely their own sentiments about the therapies. The use of semi-structured interviews allowed flexibility in the line of inquiry, while enabling the researcher to probe further in order to arrive at more depth and meaning of the experience (Parahoo 2014).

Theoretical thematic analysis was preferred for this study as it was driven by researchers' interest in uncovering information being explored in the study aim and therefore deemed most appropriate given other methods available. For example, unlike inductive theoretical analysis which is data-driven this approach is explicitly analyst-driven in that it focussed more on the data that helps to answer the research aim (Braun and Clarke 2008). Most researchers accept that inductive thematic analysis would best fit studies adopting a grounded theory methodology. This current study utilised an interpretive phenomenological approach to capture participants' experiences of receiving complementary therapies. To adopt inductive theoretical analysis here would be to deny the researchers' theoretical commitments to the study aim. The coding of data for this study was based on the research aim

which was derived from the researcher's epistemological position. It is well documented (Braun and Clarke 2008) that theoretical thematic analysis may provide less rich description of data overall, however, it allows for more detailed analysis of the perceived benefits of complementary therapy in this study as received by patients, which is of interest to the study.

Limitations of this study.

Although the study ended up with eight out of ten participants, it may be possible that the two patients who were not able to attend due to ill-health might have offered different perceptions of their experience with CTs.

The study was centred in one Hospice in one geographical region of the West Midlands and therefore only captured experiences of these few patients in this small area.

The study remit did not elicit the experiences of the therapists who provide this service, as this would have added another dimension in our understanding of impact of CTs on patients and the therapists themselves.

Conclusion

The study found that CTs were perceived as helping the patients with their identified concerns reported on the MYCaW assessment form. All the patients interviewed in this study reported positive benefits from CTs. What was clearly evidenced from the findings was how CTs enabled patients to maintain semblance of normality while living with the stress of life limiting condition like breast cancer and brain tumour.

What needs emphasising is that different CTs can benefit varying patients' palliative care needs. The allocation of specific CT depended on impeccable assessment of the concerns of the patient and then deciding on the most beneficial therapy. The other important factor to reiterate is the continuity of the therapist each time patients came for therapy. This was seen as helping at a number of fronts including building a relationship, trusting the therapist, and not having to repeat their 'story' to a different therapist.

One of the limitations for this study was the use of one small hospice. It is therefore recommended:

- That a large multi-centre study be conducted which interview patients about their experiences of receiving various kinds of CTs for different types of concerns during their palliative care phase.

All patients have reported benefiting from CTs, and the impact of this is that a lot more patients will benefit from this service.

- It is therefore recommended that such provision is reviewed with the aim of making sure that all who need CTs have access and treatments can be offered at more frequent time periods.

The role CT therapists play is central to the benefits reported here and therefore it is important to understand their own views and experiences of providing such therapy. It is also important to elicit their support needs in order to ensure that patients enjoy the continuity with the same therapist.

- Therefore future research study should be conducted to elicit their views about how best to enhance what they already do well, while preserving their own well-being. This should be an interview-based study and large enough sample to include therapist across the UK specialising in different therapies.

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