



# Patients' experiences of a mindfulness intervention for adults with advanced cancer: a qualitative analysis

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## Abstract

**Purpose** People with advanced cancer often experience significant emotional turmoil that accompanies their diagnosis and cancer-related treatments. Therefore, psychological interventions become relevant to address these impacts; however, there is a lack of research into the psychological support needs of those with advanced cancer (those not yet in palliative or end-of-life stages). In this context, we developed a mindfulness-based intervention, Coping with Cancer Mindfully (CCM), to provide psychological and emotional support to adults with advanced cancer. This article reports on qualitative interviews from a mixed method study of the CCM intervention exploring its utility and the extent it provides psychological support to this population in a pre-post-intervention design.

**Methods** Adults with advanced cancer (stage III or IV) were recruited via cancer-related services in Christchurch, New Zealand. Thematic analysis was used to analyse the semi-structured interviews.

**Results** Twenty participants were interviewed. Thematic analysis showed that at baseline, participants were experiencing distress but few had been offered psychological support; they reported feeling vulnerable and battling their cancers, and were seeking help. Post-intervention interviews reported that most participants' perspectives had shifted, from a state of vulnerability to one of self-encouragement, increased optimism, and taking new actions regarding their situations. The CCM intervention was identified as a readily available and positive tool of support.

**Conclusions** Our findings suggest that those with advanced cancer should be offered options of psychological support at any stage post-diagnosis. At such an intense period in their lives, people with advanced cancer are likely to benefit from tailored psychological interventions. The CCM intervention with its focus on acceptance, meaning in life, and mindful coping has been shown to be acceptable to participants and as a supportive tool.

**Keywords** Mindfulness · Psychological intervention · Advanced cancer · Psychological support · Experience · Qualitative

## Introduction

A focus on the psychological needs of those with advanced stages of cancer is pertinent given increasing global cancer incidence and mortality every year. Figures available in

2018 from the World Health Organization [1] for the overall cancer incidence were 18,078,957 cases worldwide with 9,555,027 deaths.

People with advanced cancer frequently experience mental distress with fear for the future, shock, worry, hopelessness, and anger, having to cope with physical symptoms of cancer such as pain, appetite loss, and fatigue [2], as well as dealing with side effects of medical interventions like surgery, chemotherapy, and radiotherapy [3–5]. Patients with cancer can feel a sense of loss, altered roles, difficulty in achieving goals, and concern for the distress of loved ones [6]. Anxiety and depression are prevalent in those with cancer [7–9]; therefore, psychological interventions become relevant to address the impacts generated by the disease [10–12].

Palliative interventions, advance care planning, and support services are well established for people with advanced

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cancer in the last few weeks of their life [13–15]. However, patients with advanced cancer who are not yet at that stage often experience significant emotional turmoil [8, 9, 16]. Notably, though, there is a lack of research into the psychological support needs of those with advanced cancer who have not yet reached the palliative or end-of-life stage [17]. One reason for this gap in research is likely to be related to difficulty recruiting vulnerable advanced cancer populations [18, 19]. If they are not under hospice treatment or at the end of life, they may be left to cope with their terminal illness for many months, or even years, with no psychological support.

In this context, we developed a novel mindfulness-based intervention package, called Coping with Cancer Mindfully (CCM), designed to provide psychological and emotional support to adults with advanced cancer [20]. The CCM intervention was an adapted brief mindfulness-based programme utilising core principles of mindfulness-based stress reduction (MBSR) [21] to assist participants to learn mindful coping skills, acquire an acceptance stance, and reflect about meaning in their lives through the practice of mindfulness. It was designed to take into account pragmatic, logistic, and ethical needs of this vulnerable population [22, 23]. The adaptations included shortened sessions and treatment duration, individual instead of group sessions, provision of resources to increase accessibility (podcast, compact disc (CDs), or memory stick formats), no homework expectations, and home delivery to reduce burden and facilitate participation (for further details of the wider study, see [20]).

This paper reports the qualitative data from a mixed-method study that used a single-group pre-post-intervention design to test the CCM intervention [20]. For the quantitative analysis, see [24]. The research question relevant to this paper was “How do participants experience the CCM intervention in terms of the utility of the intervention itself and the extent to which it provides psychological support?”

## Methods

This qualitative study used thematic analysis to analyse semi-structured interviews eliciting patients’ experiences before and after participating in the CCM intervention.

### Study participants

Participants were adults (age > 18 years old) with a diagnosis of advanced cancer (stage III or IV) of any type, with an understanding of written and spoken English and an estimated life expectancy of at least 4 months. Exclusion criteria were those with severe neurological and auditory impairment, acute exacerbation of illness, current acute psychiatric disorders, or current hospitalisation.

### Study procedures

Participants were recruited from public hospital oncology services and other cancer-related service providers in Christchurch, New Zealand.

Potential participants were screened by a research nurse, and if interested, they were contacted by a principal investigator (F.F.Z.) and provided with information and consent forms. Data collection started in November 2016 and ended in January 2018.

The four 30-min CCM sessions were delivered on a 1:1 basis in participants’ homes by the CCM facilitator (F.F.Z.), who is a clinical psychology graduate (Br), trained in MBSR, with 3 years of experience working with hospice patients in the UK. After a brief explanation of the content, participants listened to one of the pre-recorded sessions each week. They were free to listen to the audios between sessions.

### Pre- and post-intervention interviews

Semi-structured interviews were conducted by the principal investigator. At baseline, questions focused on their prior expectations regarding the mindfulness intervention, on how they were feeling emotionally, and if they had felt the need for psychological support on facing advanced cancer. Questions at post-intervention focused on the extent to which they experienced any change in their thoughts, actions, and life perspectives (see Table 1 for the qualitative questions-prompts).

Interviews were digitally recorded and transcribed verbatim by a professional transcribing service. Pseudonyms were attributed to preserve anonymity of the participants.

### Data analysis

Thematic analysis methods were used to identify codes, concepts, and patterns, analysing and synthesising material to form themes from the data [25].

The computer software NVivo (version 11 for Macintosh) was used for coding, although a manual process was used to identify concepts. Codes identified were sorted into categories and collated as themes [25, 26]. Once themes were no longer generated (saturation), refinement was deemed complete [25]. The process of analysis involved two authors reading the full interview transcripts and discussing the emerging patterns. Subsequently the themes were reviewed independently in a process of validation. To ensure trustworthiness of the data/process, regular meetings were conducted between the three authors for review of the data analysis, listening to the recorded interviews, coding, reviewing categories, and the emerging themes.

**Table 1** Qualitative questions-prompts

Pre-intervention question prompt list	Post-intervention question prompt list
<ul style="list-style-type: none"> <li>• Cancer Can you tell me what do you wish to accomplish/achieve with this mindfulness training?</li> <li>• Can you tell me if you felt any need or importance to express your concerns, feelings or emotions since you have received the diagnosis of your illness?</li> <li>• After you received the diagnosis of your illness, did you receive any kind of psychological support service by your health care system? For example: Counseling on facing incurable cancer, a conversation with a specialist in Psycho Oncology or with a staff about the psychological and social aspects of cancer? Could you tell me about what kind of service did you receive?</li> <li>• Do you think that receiving emotional support would be any help for you, after having the diagnosis of your illness? How?</li> <li>• Can you tell me what gives life meaning/significance for you?</li> <li>• Can you tell me what is worthwhile or fulfilling for you?</li> <li>• Is there anything else you would like to ask or add, any kind of final thoughts or things you would like to follow up that I have not asked you?</li> </ul>	<ul style="list-style-type: none"> <li>• Can you tell me if you accomplished/achieved what you wished with this mindfulness training? How did this work out for you?</li> <li>• Can you tell me if you experienced any changes in thoughts or actions since you started participating in this mindfulness training? What were the changes you have experienced?</li> <li>• Can you tell me if you have experienced any changes about your meaning or purpose in life?</li> <li>• Can you tell me if do you think this mindfulness training was helpful/supportive for you? In which way it was or was not helpful?</li> <li>• Is there anything else you would like to ask or tell?</li> </ul>

## Results

Table 2 presents participants' characteristics and cancer-related information. Twenty participants opted in to the study. The mean age of the sample was 55.6 years; they were predominantly female. Thirty percent had stage III and 70% had stage IV cancer, and 65% were currently receiving treatment for cancer. Participants had been diagnosed with cancer between 6 months and 10 years prior to this intervention, with the majority in the previous 5 years.

### Thematic analysis of pre- and post-intervention interview data

After analysis, all themes identified in participants' interviews were incorporated within an overarching concept of *vulnerability*. It was apparent that participants fluctuated between two different perspectives/states of this vulnerability; that of being vulnerable with a *fighting attitude*, we defined as *vulnerability in battle*, and being vulnerable in a calm manner, defined as *vulnerability in peace*.

Figure 1 illustrates the theorised process of pre-post-changes in relation to the participant's reported experience of the CCM intervention.

### Vulnerability in battle

In the left column, the meta-theme of *vulnerability in battle* has ten themes characterising how the CCM participants felt at baseline. Participants described being in a position of vulnerability related to their advanced cancer diagnosis, when they talked about feeling devastated and frustrated, struggling with *independence issues*, and questioning "why." Some did not know, at baseline, what

to respond when they were asked about what was fulfilling or meaningful to them; some did not answer the question; rather, they changed the subject.

They reported feeling guilty, not accepting and not wishing to accept their advanced cancer condition, but wanting to cope better with their current situation. Some of the participants reported that they had expectations of feeling emotionally better, and they hoped the CCM intervention would help them to feel calm, free from anxiety. Others had an open mind and curiosity in relation to the CCM intervention, with no major expectations.

Most of the participants reported at baseline that they had experienced a *traumatic diagnosis*, in the way that they were told they had advanced cancer, raising feelings of *shock*, and that they were not able to process the information received from their oncologists at the time of diagnosis.

Some participants were told their lives were now short. However, a number had lived for many years after their diagnosis (e.g., Ashley, diagnosed as terminal 20 years ago; Darcy, 11 years ago; and Lee, 7 years ago). They were facing *uncertainty* about the time they had left, about different treatments and which ones to choose, about taking or not taking holidays depending on their health status, and when to make a will. These dilemmas meant that their lives had changed drastically, and they were having to adapt to what they referred as a "new reality of being sick."

In facing so many changes in their lives, some participants adopted a *fighting attitude* as a result of the *fear* and anger, arising from their advanced cancer diagnosis. They felt vulnerable under the threat of a life-threatening illness, as if they were "in a battle" (see Table 3 for quotes illustrating the meta-theme *vulnerability in battle*).

**Table 2** Participants' characteristics and cancer-related information

Characteristics	N	%
Gender		
Male	5	25
Female	15	75
Age		
30–40 years	3	15
41–50 years	2	10
51–60 years	8	40
61–70 years	5	25
71–80 years	2	10
Race/ethnicity		
New Zealand European	14	70
Māori	1	5
Cook Island Māori	1	5
Other (European and Middle Eastern)	4	20
Marital status		
Not in a relationship	1	5
Married	15	75
Divorced	1	5
Widowed	2	10
Separated	1	5
Living situation		
With family	18	90
Other	2	10
Education level		
Primary	1	5
Secondary	9	45
Tertiary	7	35
Post-graduate	3	15
Cancer stage		
III	6	30
IV	14	70
Cancer type		
Bowel	4	20
Breast	3	15
Lung	2	10
Lymphoma	2	10
Bone	1	5
Cervix	1	5
Colon	1	5
Skin	1	5
Gallbladder	1	5
Kidney	1	5
Ovarian	1	5
Pancreatic	1	5
Throat	1	5
Treatment* (self-reported)		
Currently on cancer-related treatment	13	65
Currently off cancer-related treatment	5	25
Missing data	2	10
Time since diagnosis		
Less than 6 months	5	25
7 months–1 year	6	30
1–5 years	4	20
5–10 years	1	5
10+ years	2	10
Missing data	2	10

\*Cancer treatments received during the CCM intervention were chemotherapy or radiation therapy

## Changes reported at post-treatment

As participants' diagnosis did not change, they continued to feel insecure about their future, but their state of vulnerability was rather different post-intervention. From an initial position of being vulnerable *in battle*, participants reported that new skills were potentially acquired or reinforced by the CCM intervention and that they came into contact with a number of experiences which involved learning about themselves. The process that participants passed through was a transition to another position or a *state in time*,<sup>1</sup> one of feeling vulnerable but in peace having approached an inner resolution to varying extents, largely by post-intervention.

## Vulnerability in peace

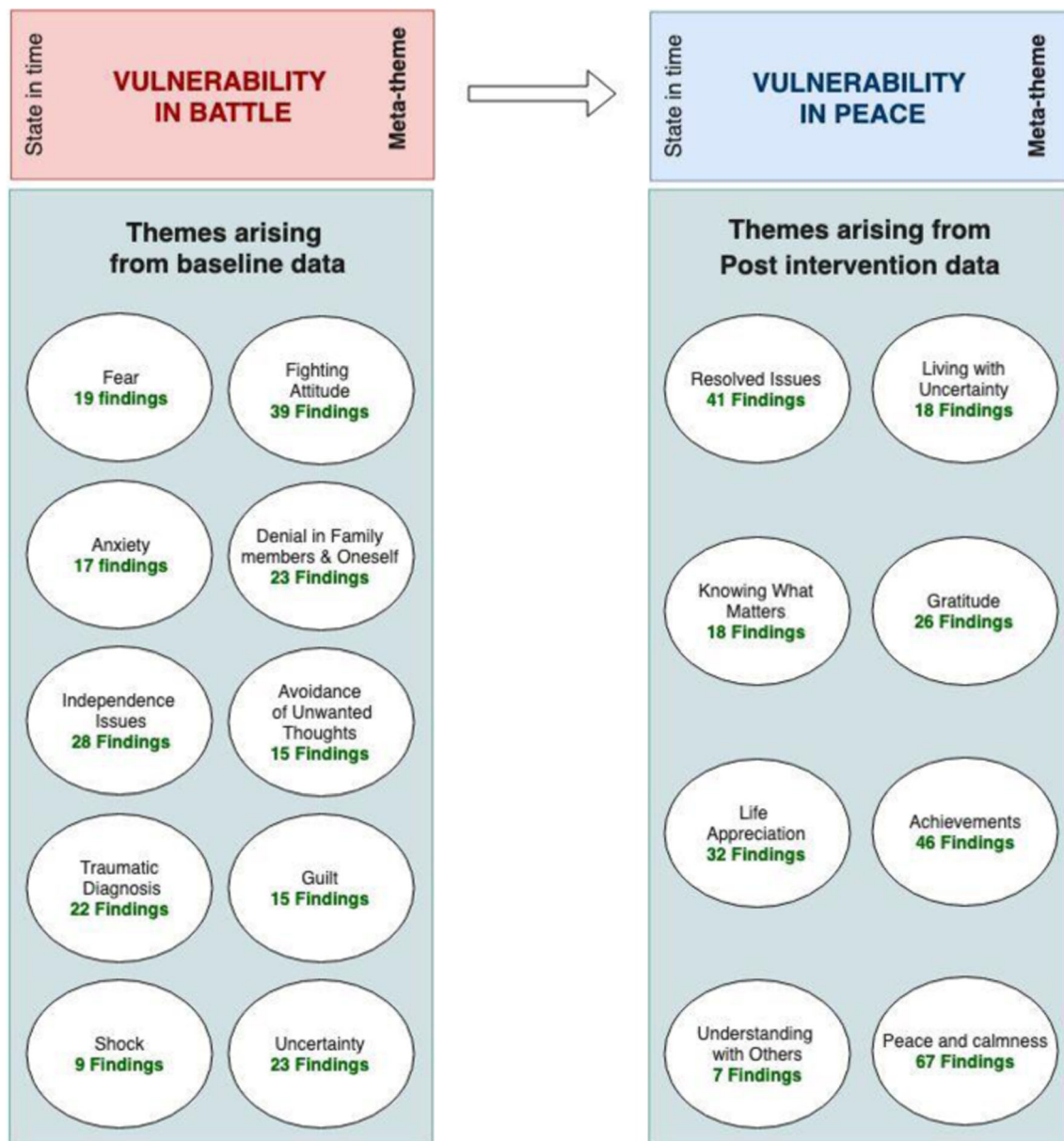
The second meta-theme, *vulnerability in peace*, comprised eight themes (see Fig. 1). It is comprehended as a *state in time* for participants: given their current circumstances, they could feel frustrated at times and face disappointments, therefore being in fluid state, being vulnerable, although more settled and even reconciled.

Participants still *live with uncertainty* but reconciled and with a decided mind-set, reported as feeling *peace and calmness*, and *gratitude*. Though the participants were not cancer free, they still spoke of feeling gratitude, being “lucky” for still being alive. They were grateful for their life and consequently they felt *life appreciation* since they transitioned to this more settled internal perspective in the way most of the participants perceived their life. They spoke of the need to be more *understanding with others*, reported some *resolved issues and achievements*, such as having hard conversations about their cancer, a walk up a mountain, cooking a new dish, or going back to their home town to visit their parents, among other things. Participants related *knowing what matters* to them, i.e. what was meaningful in their lives. They planned holidays with the important people in their lives, making time for what uniquely mattered to each one of them, once they knew or reaffirmed who or what was significant in their lives. Some reported at post-intervention to have noticed how much some family members were important to them, and also how much they loved gardening or going for walks and lots of other simple things in life that they found were fulfilling to them.

They demonstrated having reached a position of reconciliation although this state was not always constant. The feeling of calmness and sometimes peacefulness, facilitated by the CCM sessions, contributed to participants moving forward with their lives (see Table 4 for exemplar quotes from participants related to the meta-theme of *vulnerability in peace* and the above themes).

<sup>1</sup> State in time: This term denotes how participants were feeling at the time of interviews, although their state may not have remained static.





**Fig. 1** Theorised process in the experience of the CCM intervention. The number of findings is the frequency of reports presented to illustrate their weight within the dataset (Guest et al., 2012)

### The experience of the CCM intervention

The majority of participants reported at post-intervention that the CCM intervention was *supportive* and *positive*. They related it to a positive experience or approach that matched their way of thinking when being optimistic. Quotations illustrating participants' experience of the CCM intervention are in Table 5.

Two participants however reported difficulties in acquiring an acceptance stance; Liam for example at post-intervention stated that he was "not thrilled at having to let go" of particular thoughts related to his cancer.

For some participants, the CCM sessions helped them to brush away several issues in their life, that is, issues that had

lost relevance. They concluded that the sessions were relaxing to listen to and made them reflect about things they had never thought of, or emphasised before, for instance, times that they had been courageous in the past. They described the intervention as an interesting "learning curve" experience.

A number of participants reported using the CCM sessions as *a source of readily available support*, whenever they felt they needed that.

At each CCM session, all participants had been asked if they had questions about the previous CCM sessions, but no specific monitoring or review of practice was undertaken by the facilitator. The fact that the participants were not asked if they had done their "homework" in practising the CCM sessions was

**Table 3** Illustrative quotes related to the meta-theme of *vulnerability in battle* and the themes arising from baseline data

Meta-theme and themes	Illustrative quotes from participants
Vulnerability in battle	“What I’m taking is something that is a lot of pain and grief for not a lot of gain but some. I do not know. Perhaps you could tell me the extra things about the meaning of life” (Liam, pre-intervention).
Traumatic diagnosis	“I want to get rid of this anger” (Blair, pre-intervention). “[The doctor] did not know when I’d be able to get the operation and then having delivered all this at speed ... there was not a shred of empathy. He said, depending how fast [it will spread] maybe [you have left] about six months or so. He was brisk” (Alison, pre-intervention). “[When received the diagnosis] I just cried and cried and cried. Wanted to be on my own ... when I heard the word ‘terminal’ I thought I could die tomorrow, it was very scary” (Lindsay, post-intervention).
Denial in family members and oneself	“[I’ve [been through] lots of very aggressive treatments, my oldest daughter just goes crazy when I [had treatment] so I do not tell her [anymore] because [she just thinks], dumb dad, people die from it! [And I say] so they have ... And [people] can see at times when you are struggling and you have lost weight, so they see it as a facade or reality but they do not see the inner side [of it] which is [me] the patient. If they could possibly just step away from that mind-set” (Lee, post-intervention). “I think my daughter is always slightly under the influence of alcohol, it’s the only way she can deal with it, my bloody cancer” (Lindsay, post-intervention). “When I [have to] face something that I do not like I just avoid it, I do not go for a try, I just avoid, that is who I am” (Alex, pre-intervention).
Independence issues	“Walking has been a big thing for me. Physical stuff [that cannot be done anymore]. I do have to learn to slow down and accept [the situation]” (Mel, pre-intervention). “I pulled over and said [to my husband] you’ll have to drive, I cannot drive any more. It was the most extraordinary feeling that there I was, living this apparently normal life at the time but I could just feel life draining away” (Alison, pre-intervention). “I do not like asking people to do things for me because that’s like my job to do that but she did not mind. [My sister] said no, that’s fine...” (Jess, post-intervention).
Fighting attitude	“[It is] just, basically my desperation to survive. I have cancer and I do not have a future. That’s my first thought of the morning. [Then] I’ve got to spend the day trying to snap out of that” (Alex, pre-intervention). “Yeah, what the hell, you know. Everything was going perfect and then boom...And it [the cancer] is still in your body, it honestly sucks. The world sucks” (Gale, pre-intervention).
Fear	“I did not know how much time I have. It’s just so much it’s too much to process (Frankie, pre-intervention). I think this pain may be ... it makes me feel afraid and emotional. Sorry about crying that much, I do not know where that came from” (Jude, pre-intervention). “When I got the diagnosis as terminal ... I could die tomorrow, it was very scary. But I never talk about it. I get very tearful and emotional, it is hard. But sharing is good actually” (Lindsay, pre-intervention).
Anxiety	“I think I struggled because of the kids. I used to think oh my god my kids are going to grow up without me. Yeah I struggled big time. I’m scared of death” (Jude, pre-intervention). “My kids and my wife, we separated about a year and a half ago because it was just all too much for them, so there’s more than just cancer, there was a whole lot of reasons ... being on that journey for so long” (Lee, post-intervention).
Avoidance of unwanted thoughts	“And after having chemo I could not handle it mentally and physically” (Jude, pre-intervention). “I just want to survive ... I just resolved to not accept it and get well” (Alex, post-intervention). “I cannot really think at the moment [about what is meaningful in my life], these are very hard questions” (Gale, pre-intervention).
Guilt	“I do not know. Perhaps you could tell me the extra things about the meaning of life” (Liam, pre-intervention). “One of my grandchildren, I had custody of. But had to give her back because I got sick (Jess, pre-intervention). I said to my daughter, I do not want to be a gibbering, crying mess, you will not want to come and see me if I’m crying and emotional” (Mel, pre-intervention). “‘At the start when I first got my cancer, I just expected life to carry on the way it was and I felt I did not really learn the lesson because then, I got secondary cancer from it [now advanced cancer]’ (Darcy, pre-intervention).
Shock	“When they gave us the diagnosis, it was a huge shock because all I had was a lump under my arm. I was physically fit” (Mel, pre-intervention).
Uncertainty	“Apparently, I had only another, you know very limited time left. And let us do this stuff while I’m still functioning well” (Alison, post-intervention). “Like one surgeon will say ‘well you will not be going back to work at all’ then someone else will be like, no you have got to go back to work. And it’s like well, you get stuck and financially it’s like what do you do? It’s kind of hard” (Charlie, pre-intervention).
Expectations regarding the CCM intervention	“I just want to feel better emotionally” (Alex, pre-intervention). “Hopefully relaxation. Knowing how to deal with my situation that’s what I’m after (Kelly, pre-intervention). I just want to have techniques to help me just accept what’s going on. To accept any changes that suddenly happen that I wasn’t expecting” (Jo, pre-intervention). “I guess, expect just calmness really, just to be able to calm the mind” (Lee, pre-intervention). “I want to accomplish having no anxiety and no pressure” (Darcy, pre-intervention). “I just want to feel better about what’s going on” (Gale, pre-intervention). “I’ve got an open mind about it really. I’ll just wait and see what comes” (Andrew, pre-intervention).

**Table 4** Illustrative quotes related to the meta-theme of *vulnerability in peace* and the themes arising from post-intervention data

Meta-theme and themes	Illustrative quotes from participants
Vulnerability in peace	<p>“When I first heard about acceptance I can say [that I’ve] ignored it, and then a second time around when you came, [I] felt more like I need to accept my situation and not ignore it ... Accepting it now, feels like a weight that has been lifted off my shoulders. Emotionally I feel stronger now. [I] cope much better with it” (Casey, post-intervention).</p> <p>“I am not afraid anymore, I used to be afraid that the next breath would not come, and I am not afraid now ... I feel very peaceful, not angry or anything like that, not worried, even about [my husband], he will be okay” (Mel, post-intervention).</p>
Resolved issues	<p>“I have forgiven my brother ... [on the other day] during the last session [the CCM intervention session], I also pictured my grandparents here with me in spirit, they passed many years ago but we were very close and I feel quite emotional [she cried], I believe they are here with me right now, helping me going through all of it” (Charlie, post-intervention).</p> <p>“With acceptance comes forgiveness and either way” (Lee, post-intervention).</p> <p>“I told my son yesterday about my cancer, because I did not want him to hear from anyone else and he cried. You know, this 26 years old crying and then, [today] he was straight around here after work” (Jude, post-intervention).</p>
Living with uncertainty	<p>“I feel very emotional about telling my grandchildren about my cancer, as it is terminal and I do not look sick [so] it is hard for people to understand that, but I know I can die soon so [I’ll tell them], I’ve planned this conversation in my mind already [she cried for the first time]” (Kelly, post-intervention).</p> <p>“I’m always hoping things will come right. I have dark times too but I always come out of it thinking, oh that’s stupid just stop thinking like that. I do pull myself out of it” (Jess, post-intervention).</p> <p>“I definitely worried all the time about what [will] happen in the future for my daughter or my husband but then I say; okay, if we are together having dinner I will enjoy having dinner together and then when things change, we will deal with it, when it happens [not now]” (Ashley at post-intervention).</p>
Knowing what matters	<p>“Strangely enough because of the questions I listened to [in the CCM intervention sessions], I have been reflecting about my job, that it is meaningful for me and I made the decision that health permitting I am not going to retire in the near future” (Alison, post-intervention).</p> <p>“It is that, with these sessions [from the CCM intervention], you feel like okay I have a purpose in life, I can do things that makes other people happy so you do not feel yourself as a no one (Ashley, post-intervention).</p> <p>Last night I tried to think back in terms of how the meaning in life might have changed for me over the years ... I used to think, if you are famous then people will remember you. But with the CD [CCM intervention session] and then lots of thinking around that, what is it that you actually leave for others? You live with your family and you have an impact on them and on your friends or whatever other things you did. There’s all those little things that are important, rather than this big thing you achieved or the work you have done” (Frankie, post-intervention).</p> <p>“It’s just things like, walking on grass in bare feet. When you can you have got to do it” (Kelly, post-intervention).</p>
Gratitude	<p>“I think I’m lucky, some people do not even get to live this long with breast cancer, you know. God I’m in my 11th year since I was diagnosed, so” (Jude, post-intervention).</p> <p>“I appreciate all the good people in the world I would say. You value your life more than before. You do not take it for granted... and then you get well again because you have this feeling of that you can make it, you know” (Robin, post-intervention).</p>
Achievements	<p>“It’s helped me to handle things and it’s not just the cancer. In fact, to be honest, the cancer has gone, is not a problem to me now, what will be will be with the cancer. I cannot control that. The best I can do is be positive up here about it” (Blair, post-intervention).</p> <p>“I think it’s given me a clearer picture [of] what I need to do for myself. I need to learn to put how I feel sort of like aside and to be comfortable asking for help or for someone to do something for me. We’ve had some really good one on one times with my daughter ... we have definitely got closer” (Gale, post-intervention).</p> <p>“Sometimes I can react a bit with little things, last Saturday something happened, and if you take a few breaths, you can step away from it and reflect on it so that is useful to me. I mean it is something I’ve been trying to do” (Frankie, post-intervention).</p> <p>“I told my son yesterday about my cancer, because I did not want him to hear from anyone else and he cried. You know, this 26 years old crying and then, [today] he was straight around here after work” (Jude, post-intervention).</p>
Life appreciation	<p>“Okay I’m alive now, let us enjoy it and then when things will be different you know ... I am still living well” (Ashley, post-intervention).</p> <p>“Maybe it might be something I do not want but I cannot do anything to change it. I can only do what I can, yeah. Enjoy it while I am still here” (Jude, post-intervention).</p>
Understanding with others	<p>“I enjoy now the phone calls and even What’s App and Facebook to connect with others. I have more time now, I try to do it more, connect with them” (Frankie, post-intervention).</p> <p>“She still calls me the old bitch and whatever, but it’s just her, she does not come out with it in nasty tone so we have definitely got closer” (Gale at post-intervention).</p> <p>“It’s not so difficult with the younger one because she’s single. She’s very busy when I go up to see her concerts in Wellington, but I have the time” (Alison, post-intervention).</p>
Peace and calmness	<p>“The breathing is good, it’s just so calming, it just brings me right down and relaxes me, and I just feel so much calmer with everything that is going on around” (Jo, post-intervention).</p> <p>“I think, like talking to you and ... I think I’m calmer. I was actually scared of dying, and I just sort of, I do not know it’s really weird, [I feel like] I’m ok now” (Jude, post-intervention).</p> <p>“I now accept things and move on more quickly, have passed the worry and anxiety” (Jordan, post-intervention).</p>

appreciated. The duration of the CCM sessions was also viewed as satisfactory (see Table 5 for illustrative quotes).

### The need for psychological support

For most of the CCM participants, nothing was provided to assist with the psychological discomfort and emotional pain and to cope with the uncertainty that they experience. Of the 20 participants interviewed, only three reported that had been offered psychological support for facing advanced cancer. For two participants, the support offered was from the local hospice (end-of-life care), considered unsuitable by the participants as their prognosis indicated they were not facing the last few days or weeks of their lives.

Participants reported that emotional *support would have been helpful*, and they recognised that talking to someone, as they were doing in the current study's interviews, would have been helpful at an earlier stage (see Table 5 for illustrative quotes).

### Discussion

This study addressed the question “How do participants experience the CCM intervention in terms of the utility of the

intervention itself and the extent to which it provides psychological support?”

At baseline, these participants with advanced cancer reported feeling vulnerable and battling their cancers, and were seeking help through the CCM intervention, in the hope of bettering their current situation. For most in this sample, the need for psychological support had been neglected despite having the diagnosis for many months and in some cases years.

Facing one's imminent death is arguably the biggest universal human dilemma. In this study, some CCM participants reported receiving the message (whether explicitly said or implied, or taken) that “there is nothing more that can be done.” While this may be true in terms of a cure, it is certainly not true regarding the provision of psychological and other support. The severity of the diagnosis makes support that could facilitate their psychological adaptation even more necessary, as confirmed in a recent systematic review of 52 studies which concluded that patients with advanced cancer have higher needs for supportive care when compared with patients with localised (early-stage) cancer [27]. Other studies have highlighted the importance of psychological/emotional support for this population [28–30].

Despite recognition that there needs to be more research on interventions to improve the well-being and coping of those

**Table 5** Illustrative quotes related to participants' experience concerning the CCM intervention

Themes	Illustrative quotes from participants
CCM intervention was supportive and positive	<p>“Because again like, [when] dealing with cancer or being very sick or [when I] cannot move, you need of course to remember your good moments in life ... It [the CCM intervention] was supportive for me [to remember that]” (Ashley, post-intervention).</p> <p>“[The CCM intervention] was supportive for me because everything, what I heard made it even clearer in me that this was the right way of thinking” (Robin, post-intervention).</p> <p>“Mindfulness was positive in my life, got me thinking” (Liam, post-intervention).</p>
A source of readily available support	<p>“That's why I like it [the CCM intervention session]. If I'm feeling anxious or if I cannot sleep or something I'll put it on [play the CD]” (Darcy, post-intervention).</p> <p>“So I thought, well I'll take the thing [the CCM intervention sessions in podcast format] with me and the headphones when I go to the hospital because I get very uptight in the hospital ... I get anxiety in hospitals and I have spasm attacks and all my muscles go into spasms ... [I thought] all I have to take is my phone and the headphones ... and I went into hospital” (Jess, post-intervention).</p> <p>“I say it is so good to have the four sessions you know, just on your iPad and you might pick a favourite one [anytime you want to]” (Lee, post-intervention).</p>
No “homework” and good length of treatment	<p>“I was glad that you did not monitor the home practice, I think that I have so many things to do between appointments and other things that I did not want to have one more thing to worry about, something that I had to do on the top of everything I already have. I did practise, in my own time, that was good” (Alison, post-intervention).</p> <p>“What I like about it [when I practice at home] is that it's got a start and finish point so in 20 minutes, it's just a good length of time” (Lee, post-intervention).</p>
Support would have been helpful	<p>“Psychological support would be helpful, I was devastated” (Ashley, pre-intervention).</p> <p>“There was no support or anything it was just there's the news [and], goodbye” (Alison, pre-intervention).</p> <p>“Support would be good just to put it into perspective. Yeah, I think that would be the main thing” (Jo, pre-intervention).</p>
Difficulties in “letting go”	<p>“I just want to survive ... I just resolved to not accept it and get well” (Alex, post-intervention).</p> <p>“I found the trusting of it, when it said let go, I found it difficult to get over that” (Liam, post-intervention).</p>



with advanced cancer [31–33], our study suggests that for some in this group at least, their psychological support needs have been neglected. There are several possible reasons for this oversight: (1) their needs are missed at a clinical level as they are not yet physically unwell enough for the end-of-life care; (2) they do not fit the criteria for support for cancer recovery services; (3) their distress level is not sufficiently obvious to warrant referral for psychological assistance; and (4) there may have been siloed thinking in some clinical services in the past, where the conclusion that “nothing more can be done” in terms of active cancer treatment stops consideration of other treatment possibilities such as referring on for psychological support. Instead, CCM participants were in a kind of “limbo” for many months and even years.

After receiving the CCM intervention, most of the participants demonstrated a change of perspective to a state of calmness despite their state of vulnerability. What specifically motivated the CCM participants to experience a shift of perspective indicating changes in their thoughts and actions, is not clear in interview responses. Participants’ actions may have been influenced by the CCM intervention which encouraged some reflections, and/or by the fact that they have a serious illness which has made them live their life in a more intense way as they were potentially faced with the end of life.

Chochinov et al. [6] noted that emotional reactions arise when people become aware of cancer’s progression. According to Hayes, Strosahl, and Wilson [34, 35], when people become aware of their values, they start behaving according to those chosen values, represented as committed actions. These committed actions are associated with an acceptance attitude, consistent with the acceptance stance encouraged in the CCM intervention. Participants’ shift of life perspective, thoughts, and actions indicates that their participation in the CCM study potentially served as an opportunity that they took to act differently and demonstrated how much they can do, despite the fact that they have an advanced disease.

The design and delivery of the CCM intervention endeavoured to avoid burden and minimise discomfort for participants in this intervention and the research project as well. These results indicated that the CCM intervention was experienced by the majority of CCM participants as a readily available, self-management tool of support due to its easy accessibility format and low-burden characteristics. Our 2018 systematic review highlighted that flexibility of facilitators in delivery and in the delivery settings as well as use of simplified (low-intensity) mindfulness-based interventions, is considered optimal in facilitating the participation of patients facing life-limiting cancers in this kind of treatment [36]. Recent studies support home-based delivery and the tailoring to meet individual needs are more suitable interventions for vulnerable populations [36, 37]. It has been suggested that low-burden psychological interventions could reduce the

number of hospital readmissions and could enable patients to better cope with their disease course at home [37, 38], and consequently patients are likely to benefit through feeling less anxious, reduction of distress, and to feel psychologically supported.

This short version intervention has pleasing utility as a therapeutic intervention given its flexibility of accessing the programme, brief duration, low burden, individual home delivery, and a valuable self-management resource to help these patients cope with further adversity.

### Study’s strengths

This intervention study provided emotional support to a vulnerable group seeking coping strategies to better adapt to their current situation. The development of a novel intervention with content and low-burden delivery aspects contributed to 100% adherence. Participants’ responses indicated that the CCM intervention was well received and experienced by this group as a readily available positive approach/tool of support, and most importantly, the delivery method reached these participants.

### Study’s limitations

This was a help-seeking sample and so these results may not generalise to the whole population with advanced cancer, many of whom may not require or seek help.

To reduce the burden on participants, the current study did not monitor the frequency of their home practice, so the extent to which the mindfulness practice contributed to the change is unknown. Although the pre-post-qualitative interviews are a strength, it is also possible that the baseline qualitative interview process itself may have contributed to the changes in participants’ reflective stance toward their situation. Social-connectedness bias could have occurred—participants were aware that this was the principal investigator’s PhD research and that she had developed the intervention and would be collecting and analysing the data, possibly leading to more positive responses about the CCM than if the researcher was independent from the treatment delivery.

### Conclusion

Findings from this study have provided understanding of how participants experienced the CCM intervention and their initial expectations to cope better with their current situation. At such an intense period in their lives, people with advanced cancer are likely to benefit from psychological support, even the ones who are not necessarily facing the last few days or weeks of their lives, as seen with the CCM sample. The analyses highlighted the presence and impact of vulnerability in

the face of the advanced cancer and for most, in the absence of appropriate support. After receiving the CCM intervention, most participants reported a shift of perspective that enabled better psychological adaptation.

From both an ethical and logistical standpoint though, brief patient-centred interventions such as the CCM (which take into account the limitations posed by their poor health) provide a greater opportunity for these unwell patients to receive psychological tools to meet the support needs identified by these participants.

## Recommendations

From a methodological perspective, the extent to which participating in the qualitative interviews about meaning in life contributes to change in participants' perspectives should be examined in relation to changed perspectives related to participating in the CCM intervention.

The current study's findings suggest that those with advanced cancer should be offered suitable options of psychological support that they can access at any stage post-diagnosis, including after they have had time to process the shock of the diagnosis.

Future research with those with advanced cancer should follow the brief, low-burden intervention aspects to ensure that participants receive the intervention, to improve retention in research studies.

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## Compliance with ethical standards

Ethical approval was obtained from the New Zealand Health and Disability Ethics Committee (16/NTA/75).

**Conflict of interest** The authors declare that they have no conflicts of interest.

**Informed consent** All participants signed a written informed consent form prior to complete registration and to start the CCM intervention sessions.

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