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Constructing an intervention to foster posttraumatic growth in people living with a life limiting illness and receiving palliative care: Participatory action research

Melanie R. Lovell [a,b,1,*], Kerry N. Warner [a,c,2], Peter Archer [d,3], Rebecca McCabe [a,4], Philip J. Siddall [a,5]

[a] HammondCare Palliative Centre, Greenwich Hospital, Sydney, NSW, Australia
[b] Sydney Medical School-Northern, University of Sydney, Sydney, NSW, Australia
[c] School of Clinical Medicine, University of New South Wales, Kensington, NSW, Australia
[d] HammondCare HealthCare and Hospitals, Greenwich Hospital, Sydney, NSW, Australia

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ABSTRACT

Objectives: People living with cancer and other life limiting illnesses often experience spiritual and existential distress. This distress may be linked to trauma related to the disease, treatment or preexisting posttraumatic stress, which may be exacerbated. Interventions based on posttraumatic growth have proven to be successful in promoting psychological, spiritual and existential wellbeing in people suffering chronic pain and spinal cord injury. This project aimed to design and develop an intervention to promote psychological and spiritual well-being in people with a life-limiting illness receiving palliative care by drawing on the principles of post-traumatic growth.

Methods: Action research cycles, based on a participatory health perspective to include those living with life limiting illness and/or practitioners associated with their care in all stages of the study, were used to design and develop an intervention based on posttraumatic growth principles. People experienced in delivering palliative care services in hospital and/or community settings (N = 30) and those suffering life limiting illnesses and receiving palliative care (N = 9) participated in this study. Two pilot programs were run.

Results: Participatory action research, used iteratively in two pilot programs, was employed to design and develop a novel intervention based on posttraumatic growth suitable for use in the palliative care context.

Conclusions: This intervention developed using a posttraumatic growth framework has the capacity to improve the lives of people living with a life-limiting illness while receiving palliative care.

1. Introduction

People diagnosed with cancer and other life-limiting diseases experience psychological distress, including significant numbers of patients who experience posttraumatic stress disorder [1,2]. Many are referred for palliative care to address complex needs. Posttraumatic stress symptoms have been shown to worsen in palliative care settings due to increased reliance on others for personal care, social isolation and increased use of medication [3]. Thus, the importance of alleviating symptoms of psychological distress in people undergoing palliative care cannot be minimised.

1.1. The phenomenon of posttraumatic growth

People living with life limiting illness, especially at the end of life, often experience significant distress. The response to stress and trauma

* Correspondence to: PO Box 5084, Greenwich, NSW 2065, Australia.
E-mail address: mlovell@hammond.com.au (M.R. Lovell).
[1] 0000–0002-1407–2748.
[2] 0000–0003-1236–8198.
[3] 0009–0007-9469–5964.
[4] 0009–0002-9057–8780.
[5] 0000–0002-5491–8795.

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is not necessarily unidirectional. Inner conflict, struggles and reflection following trauma may lead to reframing of a person's situation with the potential for positive psychological change [4]. The idea that people experience positive change through suffering and adversity is common in many religious and philosophical traditions.

In the field of positive psychology, this is known as the phenomenon of posttraumatic growth [5], and is defined as "positive psychological change experienced as a result of the struggle with highly challenging life circumstances". Posttraumatic growth encompasses five key domains [5]: 1. A greater sense of personal strength and the discovery of inner resources, including self-efficacy, problem-solving capacities, determination, wisdom, and compassion for the suffering of others [6–8]; 2. A greater appreciation of life and changes in perspective, goals, and priorities, such as valuing life more, appreciating small things, and prioritising relationships [6–10]; 3. A stronger relational connection with others or a higher power [10–13]; 4. An identification of new possibilities or opportunities [8,11,14]; and, 5. A stronger sense of meaning and purpose in life, including making sense of trauma and engaging in meaningful activities to the benefit of others [7,14,15].

1.2. The process of posttraumatic growth

Posttraumatic growth does not occur automatically or in everyone after the experience of trauma [4]. This does not mean that the trauma must be outwardly and severely traumatic. Importantly, the trauma must be severe enough to force a challenge of our core beliefs - the way that we think about the world and our place in it [16]. Posttraumatic growth is more likely to occur if an event or situation is disruptive enough to push one towards personal reflection and rumination [17,18]. Growth also does not happen because of the event itself. Personal struggle with the event's circumstances and sequelae contributes most to posttraumatic growth [3]. Those who are more naturally resilient cope better with a challenge and may experience less change in adversity [19]. Although the numbers vary in different contexts and ways that posttraumatic growth is defined, studies show that around 60 % of people who experience trauma report positive change [20]. In studies examining psychological outcomes following a diagnosis of cancer, it has been reported that 53–95 % report some experience of growth [21–24].

1.3. Posttraumatic growth in palliative care settings

Some studies examine the experience of posttraumatic growth in people with and surviving cancer [25–29] and other life-limiting conditions [30,31]. Less is known about the experience of posttraumatic growth in palliative care settings [32]. Current evidence indicates people with more advanced cancers experience stronger positive growth than those with less advanced disease, suggesting the greater the perceived threat, the stronger the relationship between stress and growth [33]. Although participants found a life review intervention helpful, no changes in posttraumatic growth were detected after the intervention [34]. Brief semi-structured individual psychotherapy sessions (CALM: Managing Cancer and Living Meaningfully) over six months showed reductions in depression, death anxiety and improved spiritual wellbeing but no significant improvements in posttraumatic growth and satisfaction with life [35]. Researchers also suggest that posttraumatic growth could be facilitated by cognitive strategies used for resilience training, and the development and use of positive reframing and coping skills or religious coping for those so inclined [6,36,37]. Some approaches use specific exercises or tasks believed to foster some of these factors, such as mindfulness exercises, written or spoken self-disclosure, and appreciation interventions, although these have not been tested on those with a terminal illness [15,38–40].

In summary, despite the potential usefulness of interventions to foster posttraumatic growth, there is currently limited research exploring such interventions in the palliative care setting. Using a participatory action research approach, this project aimed to design, develop and implement an intervention that promotes psychological and spiritual well-being in people with a terminal illness by drawing on the principles of posttraumatic growth. This paper outlines the development process and the resulting intervention that was piloted in two groups of people living with a life limiting illness.

2. Methods

2.1. Methodology

This project employed an action research methodology, based on a participatory health research perspective seeking to actively involve those living with life limiting illness and/or practitioners associated with their care in all stages of the study alongside the research team [41]. This perspective recognises the strengths and insights arising from lived experience, and emphasises the value of collaboration and democratic decision-making for everyone taking part in the research process [42–45]. Its goals are transformative, intended to bring about change for the better in the lives of those whose life or work is the focus of the research [46,47]. Our participatory action research employed an iterative, cyclic process of planning, action, observation and reflection focused on generating practical knowledge [47–49] to construct and revise an intervention based on posttraumatic growth aimed at improving the lives of people living with life limiting illness and receiving palliative care. Reporting of the intervention is in line with TIDieR guidelines [50].

2.2. The participatory action research process

The project was led by a multidisciplinary research team comprising a pastoral care coordinator, a physiotherapist, a pain physician, a palliative care physician, and a research fellow. Team members either had clinical and research experience in the delivery of programs that seek to foster posttraumatic growth in other contexts, or clinical and research experience in the palliative care setting or healthcare.

The process of program development was democratised at every stage to include key stakeholders to ensure the program was informed by grounded practice and likely to be sustainable. This project consisted of a preliminary design stage, and a subsequent stage involving the recruitment of participants and pilot program delivery over iterative cycles of action, observation, reflection and planning.

The preliminary design stage consisted of development of the pilot program content undertaken by the research team and formation of an advisory group (see Table 1), which operated for the life of the project, to provide general counsel and participate in key decisions such as the mode and timing of delivery, program content, recruitment, and the

Table 1
Program stakeholders.

Advisory group (some with multiple roles)	(n = 9)
Health professionals with clinical experience in palliative care	3
Academics with research experience in the area of spirituality and disability and palliative care	4
Representatives from a national palliative care support organisation	2
Senior leadership of an organisation involved in the delivery of palliative care	3
A person currently living with a terminal illness	1
Consultation group workshop participants	(n = 21)
Nurses	4
Social workers	1
Palliative care researchers	4
Pastoral care workers	9
Physiotherapist	1
Bereavement counsellor	1
Dietitian	1

program's long-term future. A single workshop with a 21 member stakeholder consultation group was conducted with researcher and clinician representation (see Table 1).

The purpose of the stakeholder consultation group was to explore the key underlying concepts of posttraumatic growth, hope, meaning and purpose to inform program content, and discuss program names, language, structure and delivery mode. Participants were given an overview of previous interventions that used the same underlying concepts and principles but delivered in different settings (chronic pain and spinal cord injury). The pilot program content and method of delivery was then finalised by the research team in preparation for the second stage.

In the second stage, two pilot programs were delivered - the first with four participants, the second with five participants. Program participants were recruited after presentations about the proposed program were made to staff members of community-based and inpatient palliative care services, who then referred potential participants to the research team. All potential participants were receiving palliative care services. These people were contacted by phone or email by research team members and provided with information and sufficient opportunities for discussion to make an informed decision to voluntarily provide written consent to participate in the program. No remuneration was offered other than to pay transport costs to the program venue if required. Nine out of thirty-three people contacted chose to participate. Participant demographics are recorded in Table 2. All participants provided written informed consent. Approval for research was granted by the Northern Sydney Local Health District Human Research Ethics Committee (Project no. 2022/ETH02214). Local governance approval was obtained from HammondCare Australia.

The setting for the research project was metropolitan Sydney, Australia. Data were collected in semi-structured interviews after the finish of each program by a clinician researcher with experience in qualitative research. All interviews were recorded, transcribed and deidentified. Transcriptions were analysed to identify factors that enabled understanding and participation or posed problems for participants in program delivery, thus providing an important part of ongoing program development for each action cycle [51]. Observational field notes were also collected during every program session to provide data for reflective feedback by the project team after each session and for cyclical program evaluation. Additional data were collected from all participants using the following measures pre and post-delivery of the intervention: Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale (FACIT-Sp-12); Palliative Care Outcomes Collaboration Symptom Assessment Scale (SAS); Hospital Anxiety and Depression Scale (HADS). Further qualitative interpretation of the transcripts was used to evaluate how outcomes associated with meaning, purpose and hope were experienced by participants after delivery of the intervention. All data were collected between March and December 2023.

Table 2
Pilot program participants.

Participants		Number (n = 9)
Age (years)	50–60	1
	61–70	2
	71–80	4
	81–90	2
Average age (years)	71	9
Gender (Self-declared)	Male	4
	Female	5
Diagnosis (One person with both cancer and respiratory disease)	Cancer e.g. breast, lung, prostate	8
	Respiratory disease e.g. bronchiectasis	2
Educational Level	Secondary	2
	Tertiary	5
	Postgraduate	2
Employment Status	Retired	6
	Part-time work	1
	Casual work	1
	Unemployed	1
Home situation	Living alone	1
	Living with another person	8
Needs personal assistance	Yes	5
	No	4

3. Results

3.1. First design stage

3.1.1. Pilot program content

The program was based on the five posttraumatic growth domains and explored themes the research team identified as important to people with a life limiting illness following from a scoping review of the literature [32], advice from the advisory group, and research team members' past experience in delivering similar programs based on posttraumatic growth in different contexts (see Table 3 for the program structure and content). Program content was explored in weekly, two hour long, face-to-face small group sessions for six weeks. Sessions were designed for participants to have substantial time for reflection, and to join in structured activities and facilitated group discussions, as well as having a 'restorative' break for morning tea.

3.1.2. Stakeholder consultation

Following preliminary content development, the proposed program

Table 3
Embrace program overview.

Session Structure	Purpose	Content
1. What is our aim?	Introduction to the whole program	Creating a safe place and establishing ground rules. "Getting to know you" through sharing stories. Basic introduction to the Positive Psychological Change framework and to the Kintsugi metaphor/ image.
2. What changes are you facing?	Exploring loss, grief, and adjustment	Identifying some of the changes being faced and the impact on the participant's life through reflection and use of photo-language cards/images. Adjustment Process Continuum. Strategies to promote wellbeing – Wellness Flower and possible actions.
3. What keeps you going?	Exploring meaning and purpose	Reframing hope as persistence in the face of disappointment. Identifying sources of meaning and purpose. Working on an "I am…" list.
4. What matters most?	Contemplating changing priorities	Introduce Ira Byock's [52] "Four things that matter most". Personal Core Values Exercise to begin naming priorities and actions.
5. How can I make a difference?	Recognising how participants can still make a contribution	Acknowledging the challenges but also the strengths and skills participants still have. Making a difference as participants affirm who is important to them and what strengths participants bring to their relationships.
6. Where to from here?	Personal reflection on what each participant has learned	Bringing and sharing about 2–3 objects that express the participant's feelings about their current situation. Celebrating and appreciating each other as the group concludes.

was presented at a stakeholder consultation workshop. Participants were informed about the beneficial use of posttraumatic growth in interventions employed previously in the settings of spinal cord injury and chronic pain and asked to provide feedback about its use in the setting of palliative care.

The value of contemplating new ideas about hope and personal growth for people living with life limiting illness was acknowledged by workshop attendees. However, they stressed program facilitators need to be aware of likely divergent views held by program participants concerning hope and the possibility of personal growth in the circumstances of palliative care.

The working name of the program - 'Fostering Hope' - was disputed by attendees because of their concern about the dangers of offering false hope. The necessity for careful explanation by facilitators and encouragement of open discussion during sessions was highlighted as consideration of personal growth may seem too challenging or irrelevant for program participants. Workshop participants commented how small, face-to-face group sessions are effective ways for participants to support, share and learn from one another when discussing deeply personal issues.

Most workshop participants considered the physical and psychological effects of life limiting illness would likely pose problems for people choosing to participate in this program. Thus, the length of program sessions, the duration of the program and the depth of content would need to be carefully planned in order to prevent undue fatigue; therefore, six sessions of no more than two hours each were advised. They recommended the provision of a course handbook for all participants, as some may be unable to attend all sessions or others become weary or lose concentration.

Following the consultation, the key change was the name of the program to 'Embrace' with the tagline 'Meeting the challenges of living with serious illness'. 'Embrace' was thought to be a positive and active term conveying the ideas of connection, support and hope which were keys concepts underlying the program. In keeping with this, the team chose a space for the delivery of program that was separate from the main clinical part of the hospital, was quiet, comfortable and homely, overlooking gardens to engender feelings of comfort and calm for participants.

3.2. Second design stage

Two team members delivered the two pilot programs; one team member with primary responsibility for delivering the content, and the second to facilitate and encourage group participation and discussion. All facilitators were very experienced in small group work, often having facilitated programs using concepts of positive psychological change in people living with chronic pain or spinal injuries, or having in-depth experience of providing palliative or pastoral care and dealing with the many emotions associated with a life-limiting illness. Guided discussion with participants, focused on their concerns during each session, was prioritised over detailed delivery of content. Participants were given a folder containing slide printouts for each session to use during and review after each session.

Participants from both pilots agreed the duration of the course and session length were appropriate. Being part of a small group over this length of time allowed participants to feel safe with confiding personal stories and to allow their emotions to be expressed. The time for a tea break was both necessary and appreciated to afford a few moments of rest. Overall, the program was found to be enjoyable and worthwhile.

3.2.1. The first participatory action cycle

All four participants enjoyed being in the company of other people living with a terminal illness, even though they recognised their individual journeys were different. The honesty of open discussion, the development of trust in each other, and how humour arose in these conversations were very much appreciated.

The content of the program was the source of most recommendations for change by participants. Some found it difficult to relate to the central concept of posttraumatic growth, especially identifying their illness as a traumatic event, and relating the concept of growth to their particular circumstances. Instead, they saw it as ongoing trauma which would culminate in death, thus not allowing for a period "post" illness. This was also observed by the research team.

Based on participant feedback, mention of posttraumatic growth was minimised in the second pilot and instead referred to by the phrase within its definition: "Positive psychological change" [5]. This captured the concept in language more accessible for participants. The team decided to highlight a picture of broken Japanese pottery repaired with golden seams, *kintsugi*. It illustrated metaphorically how life still has value and beauty when coming to terms with the adversities one faces to live with meaning and purpose as people persevere and heal despite brokenness.

Participants stated more time was needed for broad, open discussion; that the language used by facilitators should be simplified to improve understanding of important program ideas, and the objectives of each session should be made clearer. Thus, the language used was refined; the volume of the presentation material was reduced, and a decision made to encourage a full exploration of topics arising from participant discussion in the second round. Example quotes are included in Table 4.

3.2.2. The second participatory action cycle

The five participants had a similar experience to the first group in terms of taking part in a trusting, supportive group that enabled each person to communicate openly in a safe environment to foster personal reflection on how to live with meaning and purpose.

Employing *kintsugi* as a metaphor to facilitate speaking of positive psychological change was very successful in place of the term 'posttraumatic growth'.

Presenting the program aims and content in a more simplified manner for each session was also successful. Participants agreed they had time for useful discussion to prompt self-reflection about matters most important to each, such as prioritising which choices to make, or how to more easily discuss their demise with family and friends. Nevertheless, the amount of content remained a problem. Participants recognised the need to cover as much as possible and enjoyed the content that was delivered but stated sometimes it felt a bit rushed.

This was something the research team felt should be managed in future programs by identifying what was most important to participants during delivery of the program. Rather than removing content, allowing scope for facilitators to respond to participants' needs was deemed necessary for successful implementation. Examples of quotes are included in Table 5.

Table 6 summarises both action cycles outlining the changes made to improve the program and its delivery.

4. Discussion and conclusion

4.1. Main findings/results of the study

Our results demonstrate the effectiveness of using participatory action research to develop and design an intervention for people living with life limiting illness receiving palliative care. Alongside the reflective assessments undertaken by the research team, participants shaped this intervention through recorded interviews used as resources to guide the development of content exploring the concept of posttraumatic growth and its practical application.

The concept of posttraumatic growth was used successfully in the development of two other programs in different contexts, and the literature attests to the relevance and importance of this concept in those who have experienced various types of trauma including a diagnosis of cancer [9,13,32,53–55]. It was not known how well people in the palliative care setting would relate to this concept when participating in

Table 4
First participatory action cycle - qualitative comments.

"It's making me more aware of I'm not alone, that other people are going through this. It's part of life. People have to deal with challenges and struggles." (Anika*)
"You might think about changing the name [referring to posttraumatic growth] there. … [the program is] really focusing on this getting up and getting on with life." (Anika)
"And the philosophy. I didn't know how to tackle that." (Billy)
"Well, the whole concept of the forum is to talk about the positives of dealing with a terrible situation. But it's not completely a contribution unless the four of us were talking about the negatives as well. … There's more pluses in getting the positives and the negatives out in total than just talking about the positives." (Charlotte)

* All names are pseudonyms

Table 5
Second participatory action cycle - qualitative comments.

"I just think at the end of every session that I kept thinking about it, and thinking about it more and important things that you talk about and things that we think about, so very cool." (Heath*)
"The simplicity of it [Kintsugi] that then something can be broken and then can be put together and it can still be functional and beautiful without being perfect … you can still have a functional life and you can still get a lot out of your life and give a lot out of your life." (Freddy)
"I don't know whether I'd change it. … I really came away feeling like I still have hope, but hope is re-framed I suppose. … it made me think about what I really want to do, what's important to me to do now." (Gabrielle)
"I think it's a hard one that the course seems a little bit at times skimming over material. That's a hard one because you can't really make it much longer, and then you get the thing that you're going to start cutting things out and that would be a shame as well because it was all such good information." (Freddie)

* All names are pseudonyms

a program of this nature. Participatory action research allowed us to design and develop a novel intervention based on posttraumatic growth.

Feedback from participants at the end of the program indicated that the concept of positive psychological change was a useful way to reframe living with hope and the potential for growth in the face of severe illness in the palliative care setting. We used the language of "positive psychological change", which is contained within the definition of the posttraumatic growth phenomenon [5], rather than the term 'posttraumatic' because its connotation suggested an isolated traumatic event in the past to our participants. Instead, the challenges the participants faced were ongoing; nevertheless, they still saw the potential for growth in the context of palliative care. Overall, the content of this intervention was viewed positively by participants to promote their psychological and existential well-being.

Positive psychological change emphasises the process of personal transformation (growth) involved in self-reflective struggle with the vulnerabilities to the self that arise from a life threatening diagnosis, negative life events or highly stressful circumstances [32,53,56]. Posttraumatic growth in people receiving palliative care is reported to be greater in younger people, greater elapsed time since diagnosis, and in women [32]. Interestingly, some studies show depression is negatively correlated with posttraumatic growth in palliative care patients [53] and in a meta-analysis in oncology patients [57]. In the clinical context, while posttraumatic growth may lead to a more fulfilling and meaningful life, this does not necessarily translate to an individual being carefree or feeling good [56].

Using appropriate language and the metaphor of *kintsugi* helped to ground the concept of positive psychological change, making this program relevant and engaging. The utility of this metaphor has been recognised when dealing with grief and loss [58,59] and living with cancer [60]. *Kintsugi* is the Japanese art of repairing broken ceramics with metallic threads; it draws from the principle of *wabi-sabi* to re-value and appreciate the fragility and beauty of imperfections [61]. Thus, in the palliative care context, despite recognising how one's life changes dramatically with the diagnosis of life-threatening disease, like a ceramic pot broken into pieces, by acknowledging these changes and simultaneously re-piecing them together one may live positively with meaning and hope; just as metallic threads are used in Kintsugi pottery to rebuild the broken pot, one creates a renewed, imperfect but still beautiful whole. This metaphor allowed our participants to crystallise for themselves how the repair work of embracing changes redefines new and transformative ways [59] to live in spite of the difficulties of living with life limiting illness.

4.2. What this study adds

This study describes the development of a novel intervention, based on the principles of positive psychological change drawn from posttraumatic growth, designed to improve the psychological and spiritual wellbeing of people suffering from a life limiting illness receiving palliative care. This intervention promises to have widespread application across cultures and to our knowledge, there is no other intervention specifically developed with these criteria in mind to alleviate the suffering and stress often experienced by this group. Participant outcomes with larger numbers of participants need to be evaluated and analysed to confirm the intervention's effectiveness. Further research may also help to evaluate feasibility and acceptability using different modes of delivery and in different but related groups, e.g. developing an online intervention to reach people living in remote and regional areas and addressing the needs of informal caregivers of people living with life limiting illness using an intervention based on the principles of positive psychological change.

The involvement of stakeholders from rural and regional communities and from culturally and linguistically diverse communities by including patient groups and staff delivering palliative care services would further develop the Embrace intervention to meet the needs of rural, regional, and other groups. In the Australian context, Aboriginal and Torres Strait Islander peoples must be involved as stakeholders in any discussion of how best to meet the needs of their people living with life limiting illness and receiving palliative care; including their choice to decide if or how an appropriate Embrace intervention should be developed, and to fully participate in the design, development and management of any associated research program.

4.3. Limitations and implications for practice

The intervention was only tested in two small groups. Often, potential participants felt limited by their ongoing chemotherapy or current state of health to be available in person. The program was designed for up to ten people; however, the small numbers were perceived by participants to be advantageous in creating small, trustworthy groups. The face-to-face delivery of this intervention meant online participation was not available to those who might have otherwise attended.

An online program may enable other people to choose to participate. However, interestingly, face-to-face participation was felt by participants to enable greater honesty in offering personal narratives without family and carers being present. This may pose a problem for online delivery of this program and is an important implication to be

Table 6
Summary of program action cycles.

Stage 1	Stage 2			
Design and development factors	Pilot one: Observation	Pilot one: *Key changes for pilot 2*	Pilot two: Observation	Pilot two: *Reflection and finalising program changes*
Posttraumatic growth - concepts of hope and growth require careful explanation and discussion	Posttraumatic growth: The word 'posttraumatic' did not resonate with participants.	*Posttraumatic growth was rearticulated as positive psychological growth. Full explanation and discussion of the illustration of Kintsugi pottery to highlight how despite life's adversities one can still live with meaning and purpose.*	Positive psychological change and the metaphor of kintsugi were received well by participants.	*Important to continue the emphasis on positive psychological change and kintsugi to illustrate this.*
	The notion of spirituality was interpreted by participants as religion, and rejected on this basis.	*The language of living with meaning and purpose was used in place of spirituality.*	Change in language to focus on meaning and purpose well received.	*No further change.*
Facilitation	Aims of each session need to be clearly stated.	*Reformulation of content for each session to articulate aims clearly, and to review aims at the end of each session.*	Participants had a better sense of plan for each session, and the structure of the program.	*No further change.*
	Time should be made to allow for discussion of previous session.	*Time provision allowed.*	Timing worked well to enable participant feedback and reflection at the start of each session.	*No further change.*
	Presentation of content on slides needs to be simplified – too much and too complex.	*Content carefully revised and reduced.*	Participant engagement with presentation was better, although perhaps still too much content.	*No further change in content to allow choice of material to suit participants' needs in future programs.*
	Looseleaf booklet with course material was useful but needs to be printed as a book.	*No change to be made while program under development.*	Looseleaf booklet with course material was useful but needs to be printed as a book.	*Book to be printed for program roll-out. Online resource material should be made available for reference and future use. by participants.*
Participant safety	Participants felt safe during the program. The importance of confidentiality was stressed to all participants to enable full and frank discussion. That participants may feel strong emotions during or after each session was acknowledged by facilitators and provision was made for ongoing care if necessary.	*No change*	Participants felt safe during the program.	*No change. Baseline instruction about confidentiality within the program sessions must be maintained.*
Using small face to face groups	Worked well. Good group interaction and cohesion. Participants felt safe to disclose personal narratives.	*No change.*	Worked well. Good group interaction and cohesion. Participants felt safe to disclose personal narratives.	*No change.*
Necessity for break during session	Short break for coffee, cake and chat was enthusiastically endorsed by participants. This provided a rest period and the opportunity to get to know one another better on a more general, social level.	*No change. The break within each session was determined by participants' readiness to continue. The participants continued to engage well with program materials after the break without obvious signs of fatigue.*	Short break for refreshments and general chat very much enjoyed.	*No change.*

considered in the practical delivery of this intervention.

Our intervention was conducted by very experienced facilitators familiar with the concept of posttraumatic growth and delivering programs based on this in other contexts. Facilitators guided discussion to enable participants to learn from each other and refrained from giving advice. Emotion was acknowledged and validated. Group members spontaneously supported each other. We would recommend future facilitators have a background in group facilitation and at least one facilitator with experience in palliative care.

The time constraints associated with designing a program of no more than 6 weeks duration in 2 hour blocks meant it was not possible to cover every topic in-depth, especially considering the need for participant breaks for rest and refreshment during each session. We chose to prepare material on topics we felt were important and likely to be of interest to our participants, however, we did streamline our presentations and group discussions to address the concerns our participants raised or issues needing more time for reflection. The provision of a formal booklet and/or online resource should be available to all participants to access the full scope of the program and for future reference. This would be based on Embrace program content and provide ways to obtain further information for personal use e.g. community resources and online resources.

4.4. Conclusion

Participatory action research has been proven to be an effective method to develop a new intervention to address existential and spiritual distress in people living with life limiting illness in the palliative care context. Lessons drawn from the psychology of posttraumatic growth have been combined with the careful development of program resources focused on living with meaning and hope in the face of life limiting illness. Involving stakeholders from those living with life limiting illness and those who provide care for these people has led to the production of a practical and useful program.

Using the metaphor of Kintsugi and highlighting the language of positive psychological change improved participants' understanding of the key concepts of our program. Our novel intervention has the potential to be an effective way of promoting psychological and spiritual wellbeing for people with life limiting illness undergoing palliative care. We anticipate this intervention will be both feasible and sustainable to

deliver based on our use of participatory action research methods for its design and development.

CRediT authorship contribution statement

Melanie R Lovell: Writing – review & editing, Visualization, Supervision, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Rebecca McCabe:** Writing – review & editing, Methodology, Conceptualization. **Peter Archer:** Writing – review & editing, Resources, Investigation, Formal analysis. **Philip J Siddall:** Writing – review & editing, Writing – original draft, Investigation, Formal analysis, Conceptualization. **Kerry N Warner:** Writing – review & editing, Investigation, Formal analysis, Data curation.

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Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Melanie Lovell reports financial support was provided by David and Judith Taylor Foundation donation to the HammondCare Foundation. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

Data from this project is stored securely on a password protected share drive. Due to the sensitive and personal nature of the original interview material it is not freely accessible.

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