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‘Let us enjoy the fruits of our own labour, we have our own solutions’ Creative co-design methods and narratives of Māori whānau with chronic pain

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ABSTRACT

Chronic or persistent pain disproportionately affects Māori and their whānau (family and significant others). Our previous engagement with Māori living with persistent pain has identified significant barriers for Māori to accessing primary, secondary, and tertiary services. This paper describes the insights obtained from Māori living with persistent pain by using a creative art-based data collection method as part of a co-design process to understand how they would like to be supported in their pain management journey. We used brainstorming discussion sessions and a creative art session to encourage divergent thinking and to stimulate innovative ideas for better pain management support for Māori. The creations showed a deep connection to taiao (nature) and the support of whānau as sources of strength. Connecting with other whānau living with pain in a safe space (i.e. community setting or a marae (community meeting place)) was an aspiration. Existing mainstream services were viewed as deficit-focused with an overwhelming support for Māori-led solutions delivered kanohi-ki-te-kanohi (face-to-face). Creative activities can be used as a culturally appropriate research method for both generating rich insights into the lived experiences of Māori living with persistent pain and how to deliver culturally responsive pain services.

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KEYWORDS
Art-based method; chronic pain; equity; health service delivery; pain management

Background

Māori – the Indigenous population of Aotearoa New Zealand (henceforth Aotearoa) report a higher prevalence and disproportionate burden of chronic or persistent pain (Ministry of Health – Manatū Hauora 2024). An in-depth phenomenological study exploring persistent pain experiences of Māori individuals and their whānau (family and

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significant others) has identified barriers to accessing pain management services at primary, secondary, and tertiary levels in Aotearoa (McGavock 2011). Experiences of racism and lack of culturally appropriate care were cited as main barriers to receiving optimal care (McGavock 2011). These findings were substantiated by a subsequent study interviewing kaiāwhina (Māori community health workers) for their perspectives in supporting Māori individuals and their whānau during primary, secondary, and tertiary care consultations (Devan et al. 2021a). The kaiāwhina study identified pain management in primary care was predominantly through pain medications. Lack of explanation regarding the nature of persistent pain, lack of acknowledgement of rongoā Māori (Māori traditional treatments), and lack of referral to specialist services including tertiary pain services were cited as further barriers for Māori whānau in accessing pain management services (Devan et al. 2021a). These findings suggested that the current way of delivering pain management services at primary, secondary, and tertiary levels in Aotearoa are not meeting the needs of Māori (Lewis et al. 2021; Devan et al. 2021a).

Co-design or action research is increasingly used to design and develop health services and interventions that better meet the needs of end-users (Slattery et al. 2020; Goodwin and Boulton 2024). The participatory and flexible nature of co-design makes the approach well suited to developing health services that meet the needs of under-served communities and address health inequities (Cram 2010). A recent review has however identified a lack of clarity in definitions used to describe co-design studies. There is limited evidence on the impact of the co-design research process in improving inequities for Indigenous populations (King et al. 2022). Since technology can enhance access to and uptake of health services, our research team has previously co-designed an online version of a group-based pain management programme – iSelf-help (Perry et al. 2022). This programme was developed by a participatory action research (PAR) group involving researchers, clinicians, people with lived experience of persistent pain, and members from the Māori community living with pain. The iSelf-help programme was designed to support the general population of people with persistent pain with cultural considerations for Māori (Devan et al. 2021b). In-person pain management programmes are very limited in Aotearoa, so iSelf-help was designed to enhance access to this type of service. Māori researchers from Tū Kotahi Māori Asthma and Research Trust (Tū Kotahi) were part of the PAR team and were responsible for ensuring that the iSelf-help programme was culturally appropriate for Māori users. It was pre-decided that the content of the iSelf-help programme would mimic the in-person programme as the aim was to compare the clinical and cost effectiveness of iSelf-help in reducing pain-related disability compared to the in-person programme using a non-inferiority randomised controlled trial (Hale et al. 2021).

Although the iSelf-help online programme was informed by PAR methods, process evaluation showed that it did not adequately meet the needs of Māori whānau (Devan et al. 2021b). Access to iSelf-help required a referral from a general practitioner or medical specialist to pain management services. However, none of our Māori participants in the PAR group who were consulted in the research had previously been referred to such services. Further investigation showed that the Wellington regional pain management service which operates from two main Wellington hospitals (Wellington and Kenepuru) had very few patients who identified themselves as Māori. So, while iSelf-help was designed to be culturally appropriate for Māori patients, the barriers that prevented

Māori from accessing a tertiary pain management service in the first place were not addressed. This highlights how well-intentioned research can fail to address inequities in access to specialised health services (Devan et al. 2021b).

The Stanford University's 5-stage design thinking process (Plattner 2013; Interaction Design Foundation – IxDF 2016) has been used previously in Aotearoa to develop culturally appropriate health interventions for Māori (Te Morenga et al. 2018). Our current study aims to build on from the learnings of the iSelf-help project and use a design thinking approach (i.e. co-design) to develop a Māori-centred pain support programme working in collaboration with end-users (i.e. Māori whānau who live with persistent pain). The five stages of design thinking are **(1) Empathise** – understanding the users' problems, **(2) Define** – clearly outlining the users' problems and their needs, **(3) Ideate** – brainstorming to stimulate innovative and novel ideas and solutions to the identified problems; initially, this stage can involve *divergent thinking* to stimulate multiple innovative and novel ideas (Puccio and Cabra 2008) and at later stages, this can involve *convergent thinking* to refine multiple perspectives and create more focused ideas, **(4) Prototype** – starting to create the best possible solutions, and **(5) Test** – piloting the solutions with real users. The five stages of design thinking are non-linear, and they can be adapted based on the unique research context (Interaction Design Foundation – IxDF 2016).

Art-based methods utilise any form of art (e.g. creatives, storytelling, theatre) in producing, interpreting, and communicating new knowledge (Boydell et al. 2012; Hammond et al. 2018). Art-based methods can be used to build connections, stimulate creative problem solving, and provide a forum for voicing the views of historically marginalised communities (Hammond et al. 2018). In Aotearoa, creative activities and metaphors have been previously used to understand Māori communities' aspirations for hauora (health and wellbeing) (Te Morenga et al. 2018). This paper describes the insights obtained from Māori living with persistent pain by using a creative art-based data collection method as part of a co-design process to understand how they would like to be supported in their pain management journey. We report the first three phases (Empathise, Define and Ideate) of a 5-stage design thinking co-design process that informed the development of a community-based Māori-centred pain support programme. Phases 4–5 (Prototype and Test) were described in another paper (Davies et al. 2024).

Methods

A participatory co-design approach (Te Morenga et al. 2018) was used where Māori participants with persistent pain were meaningfully involved in the planning phases of the project to inform the development of a Māori-centred pain support programme (Slattery et al. 2020).

Kaupapa Māori (research principles) and tikanga (norms) were followed in all aspects of the research process (Smith 2021). Māori kaupapa takes a holistic approach, where participants are seen as part of a community as opposed to an individual, and takes a strengths-based approach recognising their existing pain management skills (Goodwin and Boulton 2024). Tikanga Māori was followed to create a safe space for participants to engage in the whole process, this includes the use of karakia (blessings/prayers), mihi (formal introductions) and whakawhanaungatanga (the process of establishing relationships), sharing healthy kai (food), specifying the shared values of openness and being non-judgemental, and allowing everyone to speak and being empathetic. Our theoretical understandings of persistent pain also informed the research process, where persistent pain is viewed from a biopsychosocial perspective, and pain perception is shaped by an interplay of biological, psychological, and sociocultural factors (Nicholas 2022).

Our Māori community partner (CD), from Kokiri Marae Trust (Kokiri) – a Māori Health and Social Service provider located in Te Awakairangi (Hutt Valley), invited Māori whānau, who were current recipients of marae services and known to be living with persistent pain, to be part of this co-design project. Adults (older than 16 years) living with persistent, non-cancer pain who self-identified as Māori and their nominated whānau members were invited to participate. Persistent pain was defined as recurrent pain lasting for more than 3 months (Treede et al. 2019). Seven participants accepted the invitation, and a 2-hour co-design workshop was subsequently held at Kokiri Marae in Lower Hutt, Wellington.

Our research team included an early career pain researcher with experience in co-design and qualitative methodology (HD), a senior Māori health researcher with experience of participatory co-design (LTM), and a senior Māori community health researcher (CD) from Kokiri. HD had met some of the whānau during the previously described iSelf-help project. LTM and a Māori postgraduate student research assistant had never met the whānau and, therefore, whakawhanaungatanga (introductions and relationship building) was a critical first step.

The research team consulted with Ngāi Tahu (a Māori iwi (tribe) with an existing tangata whenua (local Indigenous people) relationship with the University of Otago) prior to the commencement of the study. The University of Otago Human Ethics Committee – Health approved the study protocol (H19/124).

Initial hui (meeting)

In line with the Empathise (Stage 1) and Ideate phases (Stage 3) of the design thinking process, the purpose of the initial hui (meeting) was to actively listen to participants' kōrero (discussion) and facilitate divergent thinking. The hui started with a brainstorming discussion session followed by a creative art session to generate novel ideas and new insights for better pain management support for Māori whānau (Dam and Teo 2019).

Brainstorming session

The hui was opened by our community partner – CD, Kokiri with a mihi whakatau (semi-formal welcome) to create a culturally safe space for all researchers and participants. The research aims and processes were described and written informed consent to participate was obtained from all participants. LTM led the co-design process with HD facilitating the session and a Māori postgraduate student research assistant recorded summary notes from the hui.

At the beginning of brainstorming session, LTM explained to the participants that as people with lived experience of managing persistent pain, they were considered the most valuable experts in the room, and that all the people in the group could contribute equally to determining the direction and outcomes of the research. This was a crucial step in instilling trust and confidence in the participants and have them engage fully in the process.

From the start, all whānau were encouraged to share their views on their pain experiences and their aspirations of holistic pain management via open discussion and writing on Post-it® notes. A summary of the brainstorming discussion was captured visually with words and illustrations on A0 sheets. Although we had a short list of guiding questions, the discussion followed the lead of the participants based on what they considered to be the pertinent issues. Visual summary notes captured by the research assistant on A0 sheets were also used as a guide to stimulate further kōrero (discussion) and for whānau to draw connections between various aspects of pain they had highlighted.

Participants gathered for a shared kai (meal or food) after the brainstorming discussion session. Kai is an important aspect of tikanga Māori (norms) often used to build and extend the whanaungatanga established during the earlier sessions (Mead 2016).

Creative art session

After the shared kai, a creative art session was used to gain further creative insights from participants. Whānau were provided with a range of creative craft materials including beads, sticks, coloured pipe-cleaners, foam shapes, magazines with natural imagery to create a visual and/or tactile representation of their experiences of living with persistent pain and their aspirations for pain management support services. These creative materials were chosen by LTM based on a previous co-design project (Te Morenga et al. 2018). Initially, whānau were reluctant and unsure about the purpose of this kaupapa but we explained that the purpose was not to create a masterpiece but to use this process as a way of exploring and communicating their experiences and ideas. Participants had the choice to work individually or in groups depending on what they felt most comfortable with.

As they worked, the researchers (HD and LTM) made notes to record the discussions occurring about their creations and the ideas underpinning them. Māori community partner (CD) also took part in the creative art session as a participant to provide a community health provider perspective. When their creations were completed (7 whānau participants with persistent pain and 1 Māori community provider), participants were asked to describe their artwork and its meaning, and these stories were captured audio-visually with camera phones by the research team. As they recounted their stories, the researchers actively listened to what participants were saying and asked probing questions to gain more insight into how they could be better supported in their pain management journey. All discussions were subsequently transcribed by an independent transcription service.

Data analysis

Participants' verbal kōrero from the initial hui was analysed using a reflexive thematic synthesis approach focusing on participants' pain characteristics, impact on their whānau, holistic management approaches and barriers to accessing pain care. This will be reported as a separate paper.

For the current study, data (summary notes, cues, transcriptions, videos, and stories from the creations) from both initial and follow-up hui were analysed by LTM, HD, and CD. The researchers critically reflected on the data via multiple meetings following the hui. CD being a participant of the creative art session provided an *insider* perspective to the reflexive discussions about the overall data collection process and the descriptions of the creative art shared by Māori whānau. HD and LTM subsequently developed an Empathy map, Point of View (POV) statement, and How Might We (HMW) questions. These correspond to the Define phase (Stage 2) of the design thinking process (Dam and Teo 2024).

An *empathy map* was created to describe our participant's thoughts, feelings, desires for, and needs from a pain management service. An empathy map is typically used to articulate user needs and preferences and to inform design decisions (Plattner 2013; Dam and Teo 2024). A four-quadrant *empathy map* was used to capture what participants said about pain, what their needs were in terms of pain management support, what we observed as to how they engaged in the initial hui, and the insights generated from the initial hui.

A *Point Of View* (POV) statement was created to define who our participants were, what they needed in relation to pain management support, and why they needed this. The purpose of developing a POV statement is to clearly define a deeper understanding of the user and their needs as a meaningful and actionable problem statement (Dam and Teo 2024).

The POV statement and empathy map were then presented to the rest of the team for further discussion and consensus. This resulted in developing specific 'How Might We (HMW)' questions to stimulate further discussion and generate feasible ideas for addressing needs in the follow-up hui (i.e. solution-focused) using a strengths-based approach (Dam and Teo 2024).

Follow-up hui

Approximately two months after the first hui, we held a 2-hour follow-up hui in a local community room. LTM, HD and CD facilitated the follow-up hui and all seven whānau from the first hui participated in the hui. The participants were presented with a summary of the findings including the empathy map, POV statement, and HMW questions for further brainstorming and convergent thinking to synthesise the ideas (Interaction Design Foundation – IxDF 2016). The follow-up hui discussion was designed to build on their feedback, sense-check the findings, and for participants to offer further suggestions on how their aspirations for pain management could be met. Similar to our brainstorming session in the initial hui, the kōrero was captured mainly by writing on Post-it® notes.

Results

Initial hui

The brainstorming discussion session stimulated ideas and conversations about pain experiences and solutions to pain management as shown in Figure 1. These were explored further throughout the creative art session. The researcher reflections and

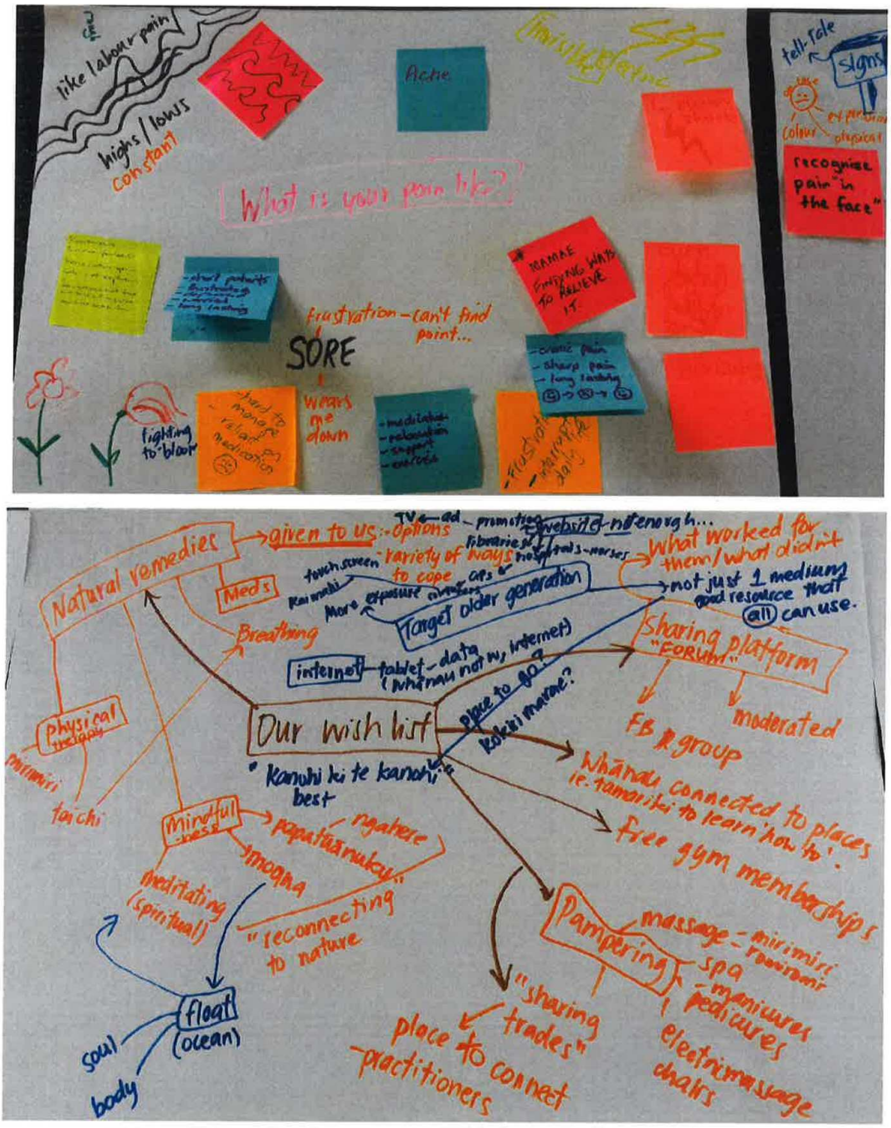


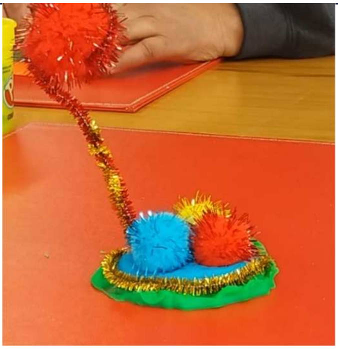
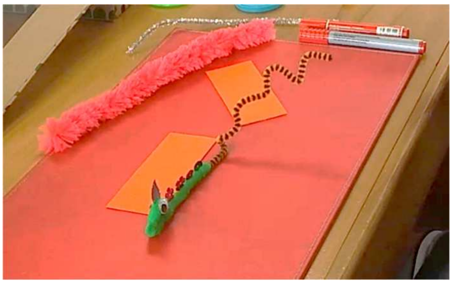
Figure 1. Visual summary from the brainstorming discussion session capturing participants' pain experiences and ideas for pain management.

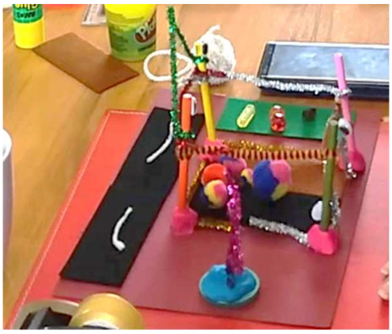
interpretation along with supporting participant quotes during the creative art session are described below.

Beyond words to communicate pain

Using an art-based method in the creative art session gave whānau new ways to express the experience of living with persistent pain and communicate creative solutions to pain management (Table 1). They were quite hesitant to start their creation but were soon busy, laughing, talking, and encouraging each other. A rich conversation about persistent pain emerged. Connection to taiao (nature) was portrayed as a source of comfort

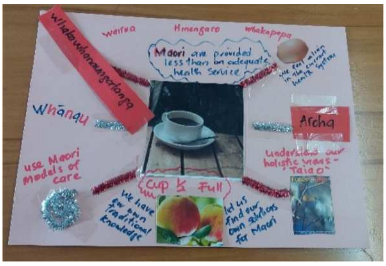
Table 1. Descriptions of participants' creations and narratives.

	Whānau story #1 – **The importance of being able to come together to care and to share**. This participant's artwork, named 'The Heart' was about how she found comfort and relief from being able to share her story of pain with other Māori women who also experienced persistent pain but in different ways. She used different coloured and shaped beads to represent the different ways people experience their pain conditions. An enclosure in her artwork symbolised the importance of having a '*safe space*' to connect with other whānau with pain.
	Whānau story #2 – **The importance of hearing what Māori are saying**. The participant shared a story of an experience at a meeting about how health services could better support Māori living with cancer. She felt that the meeting organisers (i.e. mainstream health providers) did not ask the right questions so therefore the solutions would not provide Māori with the support they really needed. When she raised her concerns about this process, they were disregarded, and she was left feeling angry and upset. The artwork conveys how she feels that Māori are still *'in that box, looking at them [Pākehā health system], waiting for answers'* waiting for the services that they want and need.
	Whānau story #3 – **Pain is a rollercoaster of good and bad days** – The participant created a rollercoaster illustrating waves of highs and lows, representing the good and bad days of living with persistent pain. On the bad days (the lows) she wants to be in her own space and the best way whānau can help on these days is to let her be alone. It's only on the good days (the highs) that she is amenable to accept help from her whānau and pain specialists.
	Whānau story #4 – **Whānau need help knowing how to be supportive** – This participant created a sculpture of a taniwha (a supernatural being in Māoridom) with a wiggly tail. She used her creation to tell a story about how she likes to be supported by her whānau and to connect with other Māori experiencing persistent pain. She thought whānau would benefit from learning how they can support others when they are feeling *mamae* (pain) and *pōuri (sadness)*. This could include bringing them to hui like this one. The creation led to a group discussion about the importance of having a supportive whānau when managing persistent pain.



Whānau story #5 – **Nurturing** – In addition to identifying whānau and community as essential supports, this participant talked about how nurturing ourselves with meaningful healthy traditional activities such as growing good food with our children and whānau can help keep the pain at bay by focusing on positive life-giving activities.

Whānau story #6 – **Power of the whānau collective** – A string of paper dolls was created to represent the value of being connected with your own whānau and an extended support network including other people experiencing persistent pain.



Whānau story #7 – **Mana motuhake – Māori self-determination**. This participant's artwork entitled 'A cup half-full' told the story of how our mainstream health services are not safe spaces for Māori and Māori are not provided with the holistic services that work for Māori. In describing the work, the participant explained '*let us enjoy the fruits of our own labour, we have our own solutions*'.

Whānau story #8 – **Self-reflection** – The participant created a rainbow from pictures of plants and flowers to represent the multi-faceted experience of pain that the individual needs to reflect on to understand how to live with it. She linked this with the Māori concept *wairuatanga* (spirituality), which has been eroded by colonisation through the loss of land and natural environments.

(Figure 1) and featured in most of the creations (Table 1). The support of whānau (close and extended family) was described as a source of strength. One whānau member recollected the importance of involving her mokopuna (grandchildren) at the time of her breast surgery and dealing with mamae (pain),

> I had my mokos with me when I had my breast off; and I had treatment and the nurse would come, the district nurse would come and do the dressing, and I always had them in the room so that they could see. My moko girl, she was three then; she went to kindy. She went and told them that, 'My nan's got a special mamae', you know 'cause she was part of it. I'd let her see the dressing, both her and my moko boy. It was for them to know what's going on, why I'm at home, why I'm just lying there and doing nothing, and not cooking for them. So that's a way for them to deal with it too and be part of it, it's important.

Share and care with each other

Connecting with other Māori experiencing persistent pain in safe spaces where they can listen, share, and learn from each other was an aspiration. As one whānau described from her creation (Whānau story #1, see Table 1),

> Kia ora. My one is a heart, it's about everybody has a heart and it's good that we can all come together to share, and to care, to help each other through our journey of pain. There's all of us together, and some we'll just send up to heaven, but most of us will be left here to support and tautoko, and awhi each other. And with our pain journey, there's different types of pains; different types of pains for different types of people, it's an honour and a privilege to be here to share and care with each other, and 'cause that supports me as well, in my health and wellbeing.

The process also generated deep, critical kōrero on the impact of historical racism and colonisation on Māori wellbeing (Table 1). Existing mainstream health services were described negatively as being overly focussed on the deficits of the individual and not designed around Māori values of collectivism, or incorporating strengths-based, whānau-focused, Māori-led health care solutions to support their community.

Expressing in our own way

The creative arts session enabled the participants to support each other's creations as a group. A whānau participant shared that their creation came out of being inspired by another creation in the group (Whānau story #8, see Table 1),

> I didn't know what I was looking at, but I enjoyed looking at (X's creation) and colours; and what came to my mind was a rainbow. And so, I just started collecting all the different colours in there; and for me, the pain journey is about connecting, reconnecting to what that pain is all about, what my journey is all about. And some of it is dark and some of it is light. And at the end of it, just looking at all the different colours that reflect that journey. I chose the pictures because we were descent of Māori, represented nature and then it just, it represents colour. We all come from that rainbow of colour.

When specifically queried about the usefulness of doing this art-based activity to stimulate kōrero on pain management, one participant enthusiastically suggested 'This (Creative arts-session) could be an activity as part of the programme. All of us expressing in our own unique way'. There was an overwhelming tautoko (support) for this suggestion from other whānau participants.

Drawing on these findings from brainstorming discussion and creative arts session, the empathy map (Figure 2) summarises the participant experiences of persistent pain and their need for pain management. The healing nature of taiao (environment), holistic solutions to pain management (rongoā) and the importance of whānau support were highlighted as important.

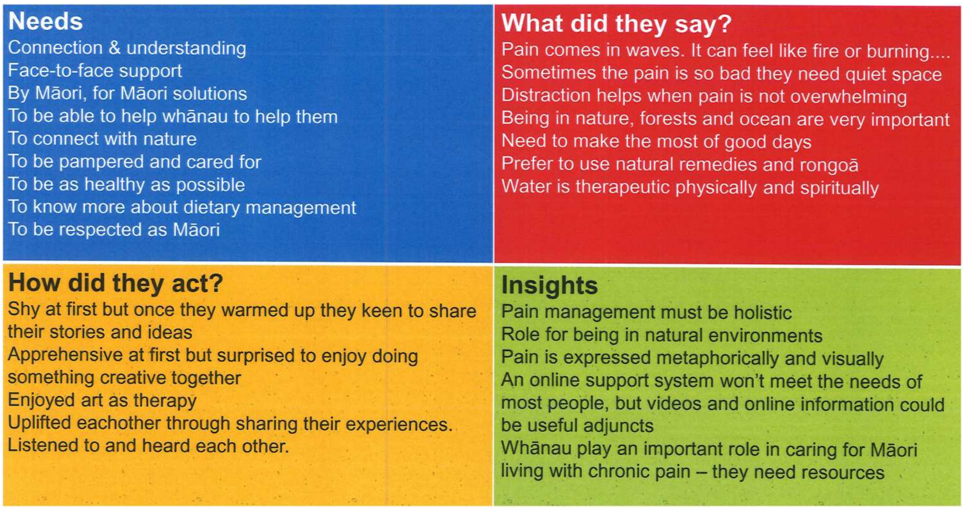
Drawing on the experiences of the participants, a generalised POV statement was created (Table 2) describing their aspirations for a kaupapa Māori pain management service that prioritises kanohi-ki-te-kanohi (in-person) group-based interactions to better meet their needs compared to existing hospital-based services.

Based on the empathy map and POV statement, three HMW questions were derived from the initial hui:

- How might we deliver a cost-effective pain management support service that all Māori can access and that meets their needs?
- How might we ensure that the service caters to people of all ages, genders, and degree of Māori cultural identity?
- What would this service look like and what would it do?

Follow-up hui

In the follow-up hui, the research team presented the empathy map, POV statement, and the three How Might We (HMW) questions for further brainstorming. The whānau participants clearly described what they wanted to support them: a 'kanohi-ki-te-kanohi' (face-to-face) pain support group similar to a cancer support group – Te Mauri, run in their own spaces like at Kokiri, at the right times (see Figure 3 for visual summary). They also asked for a marae-based pain clinic run at the Kokiri facilities to make it possible for their community to access much needed pain services (Figure 3). They emphasised the importance of taking a whānau-centred approach to the delivery of support services rather than a service which only involves the individual experiencing pain. Finally, they reminded us of the service providing 'mana' enhancing care where respect and trust are core elements (Figure 3).



Needs
Connection & understanding
Face-to-face support
By Māori, for Māori solutions
To be able to help whānau to help them
To connect with nature
To be pampered and cared for
To be as healthy as possible
To know more about dietary management
To be respected as Māori

What did they say?
Pain comes in waves. It can feel like fire or burning....
Sometimes the pain is so bad they need quiet space
Distraction helps when pain is not overwhelming
Being in nature, forests and ocean are very important
Need to make the most of good days
Prefer to use natural remedies and rongoā
Water is therapeutic physically and spiritually

How did they act?
Shy at first but once they warmed up they keen to share their stories and ideas
Apprehensive at first but surprised to enjoy doing something creative together
Enjoyed art as therapy
Uplifted eachother through sharing their experiences.
Listened to and heard each other.

Insights
Pain management must be holistic
Role for being in natural environments
Pain is expressed metaphorically and visually
An online support system won't meet the needs of most people, but videos and online information could be useful adjuncts
Whānau play an important role in caring for Māori living with chronic pain – they need resources

Figure 2. Empathy map created based on participant experiences from the initial hui (meeting).

Table 2. Point of View (POV) Statement for Māori living with persistent pain.

Who	What	Why
People who self-identify as Māori and live with persistent pain and their whānau	A kaupapa Māori (by Māori, for Māori) pain management support service that reaches everyone who needs support and prioritises kanohi-ki-te-kanohi group-based interactions	Existing hospital services are extremely limited. A successful online pain management service has been helpful for Māori users but because this requires users to have WiFi access and to be profient Internet users it does not meet the needs of all Māori. In addition an online service is relatively individually centred and not the preferred mode of service delivery for Māori users. Moreover, although the information provided in the online support tool has been tested for cultural appropriateness with Māori users it is probably not culturally optimal.

Outcomes from the hui

As a result of the co-design hui, we were able to identify two community-based solutions to pain management – (1) a 6-week kanohi-ki-te-kanohi community-based support programme focusing on the wellbeing of whānau living with persistent pain, (2) an outpatient pain clinic based at Kokiri Marae led by a pain medicine specialist from the Wellington tertiary pain management service. The outcomes from pilot-testing these community-based solutions for Māori whānau living with persistent pain and the guiding tikanga principles were recently published (Davies et al. 2024). Some key tikanga Māori principles guiding these initiatives included: adopting a whānau-centred, strengths-based approach,

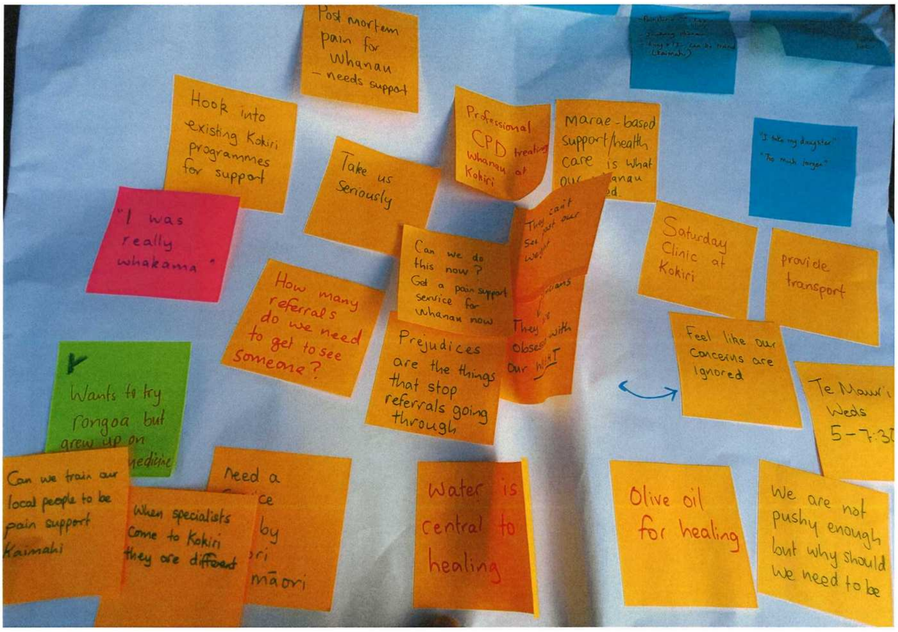


Figure 3. Visual summary from the follow-up hui on implementing a community based pain support programme and a Marae-based specialist clinic.

with opportunities for self-reflection and whakawhanaungatanga, using Māori metaphors to describe pain management, considering health and wellbeing holistically, drawing on whānau strengths, including rongoā Māori and mātauranga Māori (Māori knowledge and worldviews) (Davies et al. 2024).

Discussion

This study described the co-design processes and narratives shared by Māori whānau with pain from a creative art session designed to elicit stories about their pain experiences and their aspirations for pain management. Whānau felt the opportunity to use art-based methods via creative materials enabled them to express their ideas and to learn from and share with each other. The tikanga principles followed during the co-design processes helped to create a safe space for the art-based activity. Below we provide recommendations on using art-based methods as part of co-design processes from a te ao Māori (Māori worldview) perspective. The interpretations from this study may have implications for culturally sensitive qualitative data collection for other Indigenous populations and culturally and linguistically diverse communities with persistent pain.

Previous studies have used art and metaphors to understand Māori communities' aspirations for hauora (health and wellbeing) (Te Morenga et al. 2018). The Ola Ora app – mHealth app was co-designed with Māori and Pasifika communities to promote healthy lifestyles by providing nutrition and physical activity advice. During the app development process, participating Māori whānau were provided creative materials with the aim of understanding how technology can support hauora (health and wellbeing). These creative activities were guided by using the 'Te Hekenga Mai' story (the great migration story of Māori navigating the Pacific Ocean to discover Aotearoa) as a metaphor for navigating their current health challenges and how those challenges could be met by technology. Although the results from the randomised controlled trial did show some benefits of using the app, it did not show a clinically significant change. However, due to the participatory kaupapa Māori methodology, there was significant community uptake of the app following the study period (Mhurchu et al. 2019).

Using narratives and metaphors for communicating pain enabled whānau to share their stories of living with pain in a way that came quite naturally to them. Pūrākau (stories) are a 'traditional form of Māori narrative, and contain philosophical thought, epistemological constructs, cultural codes, and worldviews that are fundamental to our identity as Māori' (Lee 2009, p. 1). Pūrākau have previously been used as a creative activity to elicit palliative care journeys of Māori whānau using a digital story-telling method (Williams et al. 2017; Moeke-Maxwell et al. 2020). Although the digital storytelling method was created based on Western philosophy, it was culturally adapted to Māori communities due to similarities with pūrākau. Our research demonstrates the value of metaphorical approaches to understand the lived realities of Māori whānau and this is particularly useful for discussing conditions that can be difficult to articulate like persistent pain, an invisible, long-term condition.

A comprehensive scoping review of studies using art-based methods in Indigenous populations globally has suggested that art is a decolonising, non-Western way of eliciting lived experiences and Indigenous knowledge (Hammond et al. 2018). Of the 36 included studies from a wide range of topics including mental health, the commonly used art-based methods were photovoice, model making, and storytelling (Hammond et al. 2018). Images generated via photovoice fostered visual and oral storytelling which were perceived by participants as enjoyable and culturally appropriate (Jones et al. 2013). Similar to the findings from our study, they found art-based methods generated new knowledge, and provided new ways of expressing Indigenous participants' views, ideas, and emotions beyond words. Due to the group-based nature of art-based methods, participants also developed a sense of cohesion with similar others, generated new knowledge that was a result of mutual trust amongst the participants and researchers (Hammond et al. 2018).

Another study conducted with Aboriginal Australians found using art acted as a medium for embodying compassion and fostered a safe group atmosphere (Bennett-Levy et al. 2020). The results concur with our study findings as the creative art session provided a safe space for whānau to share their novel ideas as well as learn and share from each other in an enjoyable way. This was possible due to the tikanga principles followed during the co-design hui (e.g. karakia, whakawhanaungatanga, manaakitanga (kindness/hospitality)) by acknowledging participants as experts of lived experience of pain and shared kai. Further, the pre-existing relationship and trust with the participants helped to create a safe space as the whānau already knew the researcher (HD) and the Māori community partner (CD) who is well respected with about 30 years of experience in kaupapa Māori research.

Art and visuals were previously used as a discursive method to understand pain expression and communication in non-Indigenous populations. For example, pain expression via art workshops can be therapeutic for the person and art can be a medium to share, seek support and learn from similar others (Tarr et al. 2018). Similarly, using drawings to illustrate people's lives with pain was previously used in a Aotearoa-based group pain management programme as a way of communicating the changes in 'sense of self' before and after the programme (Henare et al. 2003, p. 514). Another thesis using drawings to capture longitudinal patient journeys before and after a pain programme, provided richer and deeper accounts of living with pain and changes to their sense of self (Nizza et al. 2022). A recent scoping review on art-based methods conducted in persistent pain populations highlighted the positive impact of using art-based methods to elicit lived experience of persistent pain and suggested the need for using such methods in a group-based format (Harasymchuk et al. 2024). Our experience concurs with the key findings from the review, where creative art session provided a non-verbal way of communicating and expressing pain.

Strengths and limitations

This was the first study to use art-based methods as part of a co-design process to gain insights on Māori whānau experiences of pain and their aspirations for pain management. We, however, acknowledge the following limitations. Firstly, although whānau engaged actively in the creative art session, they were initially surprised by what was expected of them. On reflection, some prior notice about the creative activity may have helped to prepare whānau with the co-design process. However, as whānau started engaging in the creative process, everyone supported each other with their creations, and it became an enjoyable group activity, and most whānau surprised themselves about their creation and the story they shared about it afterwards. Although we used craft materials, photos, and news magazines as part of our art-based method, future studies involving Māori whānau could be enhanced by using natural materials common in Māori art (e.g. seashell, harakeke (flax), feathers, and stone) that may generate additional cultural value and resonance.

Future research

Our research demonstrates the value and potential for using art-based creative activities to build deeper engagement and connection with Māori participants with persistent pain in co-design and participatory research. Whilst we used this approach to stimulate divergent thinking and to understand the needs, values, and health aspirations of our participants, this approach could also be integrated as a peer-support activity to facilitate whanaungatanga (establishing relationships) and a safe environment for whānau to communicate their thoughts and ideas on health issues that can be deeply personal and sensitive. Our experience from the current study has led to ongoing art-based research projects to elicit kaumātua (elders) experiences of receiving rehabilitation services and to gain insights on meaning-making of pain for Māori whānau living with persistent pain. Group-based pain management programmes delivered in the mainstream tertiary pain services often use group activities to build connections and to share lived experience of pain. Art-based activities have been included in some pain programmes in Aotearoa for decades (Henare et al. 2003); our research supports the value in expanding these activities further in clinical programmes.

Conclusions

Art-based activities for gaining insight on the lived experience of Indigenous populations is widely used, however to our knowledge, this is the first study to use an art-based method involving creative models as part of a co-design process in Māori living with persistent pain. The creations and narratives showed a deep connection to taiao and the support of whānau as sources of strength. Connecting with other whānau living with pain in a safe space i.e. community setting or a marae was an aspiration. Existing mainstream services were viewed as deficit-focused and there was an overwhelming support for Māori-led solutions delivered kanohi-ki-te-kanohi (face-to-face). Creative activities can be used as a culturally appropriate research method for generating rich insights into the lived experiences of Māori whānau with persistent pain. The insights gained provides much needed understanding of how existing services need to be adapted to be more culturally responsive to Māori, and address health inequities and meet the obligations of te Tiriti o Waitangi (the Treaty of Waitangi).

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