Original Article

"Beyond Feasibility": A Qualitative Study of Patients, Their Whānau (Family) and Staff Perspectives and Experiences of a Non- Pharmacological Delirium-Prevention Intervention in Two Aotearoa/New Zealand Hospices

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Abstract

Context. Delirium is prevalent in the hospice population. Despite causing significant distress to patients and families, delirium is under-recognised. There is a need to better understand delirium prevention and outcomes in this population including people's experiences of delirium-prevention strategies in different cultural contexts.

Objectives. To determine whether the "PRESERVE Aotearoa" delirium prevention intervention was feasible and acceptable for Māori (indigenous peoples of Aotearoa/ New Zealand) and non-Māori patients with advanced cancer, their families (called *whānau* in this paper), and clinical staff.

Methods. A qualitative semistructured interview substudy of a cohort PRESERVE Aotearoa feasibility study codesigned with a Māori partner to ensure inclusion of Māori-centred values. The study was underpinned conceptually by He Awa Whiria (braided rivers)—combining Western and Māori knowledges. Data were analysed using Hopwood and Srivasta's framework.

Results. Twenty-six patients and their whānau, 21 clinical staff and five researchers from two stand-alone hospices in the North Island, Aotearoa/New Zealand. Finding showed that, for the most part, participants considered the study interventions feasible and acceptable. Inductive analysis resulted in four themes highlighting the importance to whānau of their participation in the study: benefits of learning about delirium; the affirmation of the caregiver role and whānau-centred care; valuing fundamentals of care; and research as legacy.

Conclusion. This qualitative study found that it is feasible and acceptable to study multicomponent nonpharmacological delirium-prevention interventions in Aotearoa/New Zealand hospice inpatient units. The study also highlights the value of Māori-centred approaches and whānau involvement in these settings. J Pain Symptom Manage 2024;67:327–336. © 2024 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/)

Key Words

Hospice, delirium, palliative care, research qualitative, feasibility studies, Māori people

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Key Message

This article describes the qualitative sub study of a delirium-prevention feasibility study. The results show that not only are delirium-prevention strategies feasible in the hospice setting, but that making delirium and its prevention strategies explicit as part of the study and partnering with Māori colleagues meant that whānau were able to contribute to patient care in ways hereto-fore not realised. These findings highlight that study design should consider cultural context for First Nations people including how best to ensure interventions are equitable and accessible as well as aligning with palliative care philosophy.

Introduction

Delirium is a serious neurocognitive condition with a prevalence of one in three people admitted to a palliative care unit.¹ An episode results in poorer outcomes, including increased falls, pressure injuries and mortality.² During advanced illness, delirium adds to overall symptom burden and distress, complicates the clinical assessment of other symptoms, and impedes communication.³ In inpatient palliative care settings, the predominance of hypoactive delirium combined with lack of routine screening and uncertainty about which screening tool to use contributes to its underrecognition.^{1,4} Once recognised, root causes of delirium are not always reversible and there are no effective pharmacological palliative interventions.^{5,6} While antipsychotics and benzodiazepines have long been prescribed palliative interventions for patients with delirium, there is increasing doubt about their efficacy and safety. 6,7

New approaches to delirium in palliative care are therefore called for. Prevention is one of the most promising areas of enquiry, as nonpharmacological strategies to optimise natural sleep, hearing, vision, hydration, communication, orientation, mobility and family partnership have reduced delirium incidence in a range of hospital settings.⁸ A recent Australian phase two cluster randomised controlled trial of these strategies (the "PRESERVE pilot study") found they were feasible and acceptable in palliative care units, and hence worthy of a definitive trial.^{9,10} However, simplification of the PRESERVE intervention and more authentic involvement of patients and their families were identified as essential, moving forward.^{9,10}

Building upon learnings of the Australian trial, this team undertook a single arm cohort study of a modified multicomponent nonpharmacological deliriumprevention intervention in two hospices in Aotearoa/ New Zealand. The study aimed to determine whether the "PRESERVE Aotearoa" intervention was feasible and acceptable in this setting for Māori (indigenous people of Aotearoa/New Zealand) and non-Māori patients with advanced cancer, their families, and clinical staff. In this study, we used the word $wh\bar{a}nau$ to primarily denote family, while remaining mindful that in its fullest sense, $wh\bar{a}nau$ encompasses the patient, staff, community, and others.¹¹ The PRESERVE Aotearoa study used both quantitative and qualitative methods, with this paper reporting the qualitative component.

Methods

Design

We undertook a qualitative interview study of the feasibility and acceptability of a multicomponent nonpharmacological delirium-prevention intervention that was modified for hospice settings and cultural appropriateness for Māori. The study is reported here according to Consolidated criteria for reporting qualitative research (COREQ).¹²

Context

Aotearoa/New Zealand is an island nation in the Southern hemisphere with a population of just over five million people. Māori are 16.5% of the people, and ethnicities of the remaining is European (70.2%), Asian (15.1%), Pacific Islander (8.1%) and Middle Eastern, Latin American and African (1.5%) (2018 figures).¹³ There are significant health inequalities in Aotearoa/New Zealand, with Māori having a higher incidence of cancer and chronic disease and poorer outcomes, including significantly lower life expectancy than the general population.^{14,15} Despite this, Māori are underrepresented recipients of palliative care, currently reported to be just 13% of people using Aotearoa/New Zealand hospices services.¹⁶ This underrepresentation may stem from many Aotearoa/New Zealand palliative care services reflecting a European background and culture; although, there are signs that Māori trust and engagement in hospice care is increasing through positive experiences and services responsiveness to whānau. 17 Moving towards equity is supported by the New Zealand Palliative Care Strategy,¹⁸ which recommends that palliative care services have policies, linkages and coordinators focused on meeting the specific needs of Māori.

Study Settings

The study was conducted at two hospice inpatient units in Aotearoa/New Zealand. Hospices in Aotearoa/ New Zealand are not-for-profit, partly charitablefunded organisations that provide free inpatient and at-home care to patients with life-limiting conditions and their families. Most patients (64%) cared for in these settings have a cancer diagnosis.¹⁹ Te Omanga Hospice in Lower Hutt serves an urban population of approximately 157,000 people, of whom 18% are Māori.¹⁵ The inpatient unit is a new purposebuilt facility with eight beds, although bed numbers were reduced to four between March and August 2020 during the COVID-19 pandemic (with research projects paused for a further six months). Patients are admitted to Te Omanga for complex symptom management or end of life care.

Waipuna Hospice serves Tauranga City and the Western Bay of plenty population of approximately 188,000 people, of whom 19% are Māori. The inpatient unit has nine beds, with one reserved for respite care. This unit was closed for some of the study period due to COVID-19: June to August 2020 before reopening with six beds, then closing again August to September 2021. Both hospice inpatient units are stand-alone, purpose-designed buildings, with single soundproof rooms and sliding doors opening onto private patios and gardens.

Participants

Participants of the cohort study were patients admitted to either of the two hospice inpatient units who were at least 18 years old, had a diagnosis of advanced cancer, an Australia Karnofsky Performance Status above 20, and able to consent. Participants of the qualitative study included patients who had received the PRE-SERVE Aotearoa delirium-prevention intervention, their whānau, and staff involved in any of the study processes.

Nonpharmacological Delirium-Prevention Intervention

The PRESERVE Aotearoa delirium-prevention intervention had six domains: (1) preserving a natural sleep pattern, (2) maintaining optimal vision and hearing, (3) optimising oral hydration, (4) promoting communication, orientation, and cognition, (5) optimising mobility and function, and (6) supporting family partnership, with each domain incorporating discrete strategies (Appendix file). The intervention started immediately after patient consent was obtained and lasted for seven days. Whānau and staff were encouraged to document all prevention interventions on specially designed forms that were placed in patients' rooms, which also acted as a prompt to undertake the strategies. Delirium screening using the Nursing Delirium Screening Scale (NuDESC)²⁰ and certain orientation strategies (e.g., clocks, information whiteboards) were instituted throughout the units (i.e., not just for consenting patients) during the study.

Ethical, Cultural, and Conceptual Considerations

A Health and Disability Ethics Committee New Zealand approved the study on 31 July 2019 (HDEC number 19/STH/102) and research governance approval was obtained from both study sites. Tailoring of the study and intervention for the Aotearoa/New Zealand hospices was informed by local ethical, health policy and cultural considerations, as well as by learnings about the need for simpler and more family-inclusive processes from the related Australian study.^{9,10}

A long-standing relationship between one site (Te Omanga) and Kokiri Marae (a large Māori health provider with expertise in codesigning innovative research projects) helped form a new partnership between CD, a Kokiri Marae Māori researcher, and others in the research team.²¹ With leadership and guidance from CD and Kokiri Marae, we sought to honour Māori values so that whānau would feel culturally safe and their participation would be *mana* enhancing. Mana enhancing is a way of engaging with others that cares for their emotional, spiritual, physical, and intellectual dimensions.^{22,23}

We drew on Te Ara Tika guidelines,²⁴ as well as *He Awa Whiria* (braided rivers).²⁵ *He Awa Whiria* is a metaphor for the drawing upon both *mātauranga* Māori (Māori knowledge) and non-Māori ways of knowing.²⁵ The Māori concept of *whakawhānaungatanga* (creating and strengthening relationships) also underpinned our ways of working, together as the research team and with whānau and staff of the hospice units.

CD codesigned the information and data collection resources for the study. The resources were trialled with a small group of whānau from Kokiri Marae prior to study commencement (Fig. 1). Modifications included a Patient Room Form (Fig. 2) with graphics and simplified wording to support whānau understanding and engagement with the delirium-prevention intervention. Further, for the "promote communication, orientation, and cognition" domain, whānau were encouraged to share their stories and memories, bring in *taonga* (treasures) from home to stimulate patients and their whānau to talk, reminisce and share what was happening for them.

Recruitment and Consent

Recruitment posters were displayed in public spaces of the hospice units at both sites. In keeping with the concept of whakawhānaungatanga and considering that many patients were acutely unwell on admission, clinical staff first attended to the immediate needs of patients' and whānau. established trusting relationships with them before introducing the PRESERVE Aotearoa study, verbally and with the Study Information Pamphlet, usually within 48 hours of admission. Unit-based research nurses (DG and AG) then introduced themselves and described the study in more detail to interested patients and whānau and obtained the written consent of those who wished to proceed. As part of study participation, patients and whānau were invited to participate in an interview at the end of the seven-



Fig. 1. Study information pamphlet.

day intervention. Māori whānau were offered the opportunity for a Māori researcher to explain the study and to undertake the interview. In keeping with tikanga (Māori customary practices), karakia (prayer) was an integral part of interviews with Māori whānau. Reciprocity was enacted by offering whānau interview participants a koha (gift) [a supermarket gift voucher] as acknowledgement of their contribution to the project.²⁶

Research nurses invited staff involved in the care of study participants to participate in an interview and

obtained the written informed consent of those who participated. Aligned with the feasibility and acceptability study aim, academic researchers within the research team (AC and AH) invited site researchers to participate in an interview about their experiences of the study and its implementation.

Data Collection

AG and VJ conducted audio-recorded interviews at Waipuna hospice, DG, KB and CD at Te Omanga hospice and site researcher interviews were conducted via



Fig. 2. "Delirium prevention strategies" form for patients' rooms.

Zoom. Whānau were interviewed in patients' rooms and staff were interviewed in a variety of nonclinical staff spaces. Interviewers kept reflective notes following interviews.

Data Analysis

The ethical, cultural, and conceptual approach described above underpinned data analysis. A

contracted transcriber transcribed the data verbatim, except for Māori interviews which were transcribed by CD. KB and DG coded the transcribed texts, with CD overseeing and contributing to coding of Māori interviews. This first level analysis was deductive and semantic, directly addressing the question of feasibility and acceptability of the research and explicit content of data. Then, during a series of meetings with the wider research team (KB, DG, CD, VJ, AH, AC, AG) wherein codes were critically discussed and reviewed through an inductive process, we identified latent content of these data. Rigor was maintained by multiple coding and cross analysis of themes and by honouring whānau voices. The core analysis team met fortnightly for 10 months via Zoom to review, refine and finalise themes using Hopwood and Srivasta's analysis framework; in particular, by repeatedly asking the question: what are these data telling us?²⁷

Te Hurihurihanga (Reflexivity)

Te Hurihurihanga was an iterative process where we reflected at each stage of the research to ensure our interpretations most closely reflected whānau voices. By melding our varying expertise and broad skills from both Māori and Western research perspectives (He Awa Whiria), we were able to listen more attentively to each participant and each other.²⁸ The authors are the sitebased research (and registered) nurses (DG and AG), palliative medicine specialists who were the principal site investigators (KB and VI), an experienced Maori researcher (CD), and palliative care nurse academic researchers (AC and AH). All authors identified as female except DG and were based in Aotearoa/New Zealand at the time of the study, except for AH who was in Australia. AH was a leading investigator of the PRESERVE pilot study and thus brought comprehensive insights into its Australian processes and findings to the team. AC led the study until 2021 when she returned to Australia, after which time VJ became a coprincipal investigator. CD has strong links with the local Māori community and long-standing experience and expertise in qualitative research.

Findings

Forty patients enrolled in the PRESERVE Aotearoa study (20 at each site) between May 2021 and May 2022, with 51 interviews (22 at site 1 and 29 at site 2) conducted during this period, averaging 13 minutes in duration (range 2–67 minutes). Twenty-six interviews were with patients/whānau, 21 with clinical staff, and three with site researchers. Eight (20%) whānau participants were Māori and no patients identified as Pacifika.

First, the deductive semantic level of analysis showed that study processes, measures, and intervention were for the most part considered feasible and acceptable by participants. Patient and whānau participants expressed how straightforward the study processes were and how comfortable they felt, views that were shared by hospice staff:

"No, no, I've been happy to take part in it. And it hasn't been intrusive in any way" (Patient 02/02)

"It was very easy. There were no hard questions or anything that made me feel uneasy." (Patient 01/20)

"Some families were really keen to do it. I don't know that I saw any family that wasn't. I didn't get any bad feedback from family at all" (Staff 01/01).

Although, some staff questioned the additional burden the study may place on patients, as evidenced by those who did not want to participate:

"We have asked some patients who have just said 'no, it's just too much, I just can't do it, I can't think about it'." (Staff 01/05)

For some patient participants, despite being user friendly, the relevance of the study to their circumstances was unclear:

"Most of it was... user friendly enough. It's just I didn't think it particularly applied to me." (Patient 02/08)

While for others, the "tick boxes" were considered too simplistic and limiting. For instance, a whānau member expressed how they wanted to contribute more information:

"I wanted to write down more things, but I thought I don't want to confuse the situation." (Whānau 01/07)

The inductive latent analysis generated four themes: (1) Learning about delirium; (2) Whānau-centred care and affirmation of the caregiver role; (3) Revaluing the fundamentals of care; and 4) Research as legacy.

Learning About Delirium

Making delirium-prevention strategies explicit as part of the process of completion of the study data-collection had several effects not anticipated by the research team. For many whānau being part of the study was the first time they had heard about delirium and therefore the educational component of study participation was critical for them. Through the provision of explanations and clear graphics explaining the strategies on the introduction pamphlets and patient room form, whānau were able to assimilate important information about delirium and its prevention.

"We've had a lot of whā nau come in the room and we don't know what the delirium is. So, the nice little blurb at the top is great in terms of a nice explanation... and they look at it because of the butterfly catches their eye.... But you know by having this information in the room, supported us as a whā nau to start doing the things to prevent the delirium. But we wouldn't have had a clue if that wasn't in the room." (Whā nau 01/01 Mā ori).

Whānau found the visual prompts a useful trigger for the prevention strategies and an aid to their awareness of what might cause delirium. Staff and whānau expressed that prevention strategies were things that might easily be taken for granted.

"Just more aware of what is needed. Yeah, it was simple, things that we would normally done, but because we had to tick them off, we made sure each day... I mean, somethings we take for granted; being reminded is quite good." (Whānau 01/14). "These are things I sort of do automatically anyway." (Patient 02/04).

"I think all these things are actually important in helping to prevent delirium, especially in people who are already unwell. I sort of think that these are things that we should be doing, delirium or not." (Staff $01/02 \text{ M}\overline{a}$ ori).

Whānau-Centred Care and Affirmation of the Caregiver Role

Whānau who read study materials and became actively involved in the recording of delirium-prevention strategies for data-collection purposes expressed how they felt affirmed in their carer role (whakamana) as integral members of the care team:

"Like when you're working with the nurses, and I'm learning too, all the time, when there's an opportunity to learn to do something better. . . Family feel helpless, 'cause they don't know how to care, they've never done it before. These are little ways that they can feel a part of helping." (Whā nau 01/07 Māori).

Where a patient had several whānau, the patient room form ("tick box") could provide a mechanism for sharing information and supported a shared approach to preventing delirium, as this family member of a patient expressed:

"The whānau knows to do the ticks as well, 'cause we're all here at different times. But I think it's important that the whānau really contribute and support the stopping, the prevention of the delirium." (Whānau 01/01)

Clinicians expressed that the study processes and prevention strategies facilitated a heightened awareness of whānau-centred care including bringing significant items from home to the patient's bedside, as this staff member conveys:

"One is just encouraging family members to bring photos or books they like, or something that relates to them, into their room, to make it their own." (Staff 02/09)

Whānau welcomed prevention strategies as giving permission to share stories, food, and bring in patient belongings to create a familiar environment that fostered whānau wellbeing. From a patient's perspective, having familiar treasures/taonga from home helped their reminiscing of happy memories:

"It encourages me to remember the memories...to remember the good times." (Patient 02/18 Māori)

Patients valued the whānau-centred approach. For the patient quoted below, discussion about deliriumprevention strategies provided a mechanism to talk openly about other significant matters, express their feelings and, in turn, include and support whānau:

"It's probably in a way made me open up a bit more about how Γ m feeling with family.... From that aspect I think it made them feel part of it too." (Patient 01/02)

For clinicians, making delirium-prevention strategies explicit often drew their focus towards a whānau perspective. For the staff member below, the study provided further opportunity to support whānau agency by optimising cognitive function and independence:

"If you keep taking away all these things, like if someone comes in and we go 'here's your meal...oh no don't make your bed, we'll do that'...and everything gets kind of taken away-...your world kind of goes, becomes smaller and smaller... I think anything that we do that widens that for people, I guess that's how I see the delirium project." (Staff 02/13)

For another member of staff, the social engagement strategy was a prompt to continue to "see" the patient as a person, promoting their intrinsic value even if they developed delirium:

"And it's a nice reminder to keep engaging with them as people, even if those cognitive changes are occurring. Because just to keep them orientated and to have a sense of value about themselves, you know, they're not being written off." (Staff 01/08)

Revaluing Care Fundamentals

Explicit conversations about delirium and the prevention strategies led some patients and whānau to apply their new knowledge beyond the study and the hospice environment:

"It's not just for someone who is ill. It just gives you encouragement to think about what you're doing at home as well." (Whānau $01/16 M\bar{a}$ ori)

Clinicians also noted the potential impact of whānau knowledge about delirium being translated into the care at home:

"And I love that this project really involves families and improved peoples' understanding of delirium and prevention. Because again, families take that back home with them." (Staff 02/14)

Patients and whānau also found that the strategies promoted *taha tinana* (physical well-being) for themselves in their daily lives at home, reinforcing self-care strategies that might otherwise be overlooked:

"For myself, my children, and everybody really, because we all have such crazy lives and sometimes, we forget about the simple things of life, like regular drinking, or you know sleeping, making sure we have good sleep." (Whānau 01/16 Māori).

From the staff point of view, prevention strategies reinforced care fundamentals. Given the hospice culture of holistic person-centred care, staff felt permitted and legitimised in attending to the social engagement strategy in their role focussing on the person, rather than on associated tasks:

"And one of the good things about doing the research in the hospice is that we put a value on spending time and having a chat with our patients; and that chat is not just a casual thing. It might seem casual, but it has a purpose." (Staff 01/ 08).

Whānau appreciated staff being able to combine strategies in a holistic way, rather than isolating them as separate tasks: "and they are always asking 'would you like a drink?"... And they'll sit and have a conversation with her about anything in everyday and the flowers." (Whānau 01/01 Māori)

The ease of access to the outdoors, sunlight and gardens helped the exposure to natural light and facilitated the strategy to promote movement:

"It's good to see family engage in all these things. One is exercise; that's something that I've asked family for help with. It's perfect having sliding doors onto their own patio and then out into the wider garden. So, family can take their family member with them." (Staff 02/08)

Despite hospice staff being able to integrate the prevention strategies into patient care, for some patients the explicit focus on the strategies came across as reverting to a task focus:

"Telling me over and over again that, you know, maybe you need to go outside and go for a walk... I don't need reminding every five minutes." (Patient 02/01 Māori).

Research as Legacy

Whānau commonly expressed altruistic reasons for contributing to the research, for example:

"And if I can help, you know, other families and patients in the future, yeah that's a really good thing." (Whānau 01/ 07 Māori).

"If it makes a difference for other people and makes a difference to their quality of life, then Γ m happy to have been involved." (Patient 02/20)

Staff expressed that research participation remained important for some patients and a sense of purpose was important, even in the last days of life:

"I think people are quite happy to be able to try and do something to help other people in the same situation... They are quite excited to be involved in a research study and may even be a bit disappointed that they don't have more to do than this." (Staff 02/11)

Discussion

Our findings show that research into delirium prevention is feasible in an inpatient hospice setting in Aotearoa/New Zealand, even with a vulnerable patient population. The study processes were not only feasible and acceptable to participants, but also provided a mechanism to build meaningful relationships (whakawhanaungatanga). For patients, talking about delirium prevention encouraged sharing of concerns with their whānau. For whānau, their involvement in the study, administering and documenting prevention strategies, allowed for a proactive caring role, centring them in the care team and placing value on their contribution. The sense of teamwork for hospice teams and whānau was enhanced by shared resources and orientation boards including space for messages. Working in partnership with whanau to meet physical care needs has been described as fundamental to the provision of palliative care in inpatient settings.²⁹ For hospice staff, delirium-prevention strategies were aligned with fundamentals of care more broadly and validated spending social time with patients and whānau. This mana or dignity-enhancing approach to care has been identified as fundamental to caring³⁰ but is often in danger of being eroded by limited time and stressors for staff in the care environment.³¹ Participants valued the deliberate inclusion of this mana-enhancing approach in patient care plans.

Although palliative care affirms patient and whānau as the unit of care,³² this study helped to reinforce a whānau-centred approach to care. As well as centring whānau within the care team, there was also a sense for them of belonging in the hospice space, encouraging decoration of patient rooms with personal belongings and sharing *kai* (food). Creating a personalised environment for patients at end-of-life has been shown to improve patient and caregiver satisfaction³³ and create opportunities to engage patients on a personal level around illness and meaning.³⁴ For hospice teams, the central role of whānau led to consideration of how best to include whānau in the hospice approach to care, looking to actively share the caregiving role.

Alongside sharing care, making knowledge explicit and sharing this was fundamental to adherence to prevention strategies. In part, sharing knowledge created opportunity for whanau to participate more fully in patient care, but also led to information sharing within the whānau and a shared, systematic approach to delirium prevention. Whānau also noted that they applied the knowledge they had gained from the study to their own self-care. Prompts and resources for the self-care of whānau caregivers are invaluable, as limited confidence in self-care negatively impacts on caregiver stress.³⁵ For staff, the knowledge and care approach prescribed by the study was relevant to the care of the wider inpatient population which may support the suggestion that care of this nature to prevent delirium is "fundamental."

A further finding was that whānau and staff members often conveyed delirium-prevention strategies using language such as "basic" and "everyday care." At the same time, however, staff participants also expressed that these strategies were good reminders for care. This suggests that staff are not always able to implement the fundamental care they aspire to provide and challenges the normative assumption "we do this all the time."

Although a selection bias has been identified in the literature, whereby patients at end-of-life or with serious illness have often been excluded from delirium-prevention studies,³⁶ the opportunity to contribute to the care of future patients was seen as important for both patients and whānau in this study. Altruism and awareness raising have both been identified as benefits

for patients participating in palliative care research with Chatland et al.,³⁷ also noting that research can provide a forum for caregivers to reflect upon and validate the caregiving role. In fact, there was an eagerness noted by staff for more activities related to the study and a hunger for opportunities to "give back."

Our study confirms that whānau, who are already engaged in the caring role, are eager for information and education about delirium. We postulate that whānau could therefore assist in the recognition and the prevention of delirium in our patients and have a key role in the management of delirium. Our study also adds a Māori-centred approach to the investigation of delirium prevention. The involvement of the local Māori community in helping to develop resources for this project may have led to the better uptake in participation than in the Australian trial, especially among Māori whānau, with these comparative findings to be published elsewhere.

Implications for Practice, Policy, and Research

Transfer of knowledge about delirium prevention by whānau from the inpatient setting to home was noted to be a potential benefit of the study and warrants further investigation. A similar study in the community, investigating whether delirium-prevention strategies are achievable in the home setting may be the next step for our research team. The local Māori community are keen to be involved in a Kaupapa Māori-led approach (for Māori by Māori) to such a community research project.

Strengths and Weaknesses/Limitations of the Study

We collected data from two hospice sites on the North Island of Aotearoa/New Zealand. We are aware that those participants who had a positive experience with the study and with the nonpharmacological delirium-prevention strategies might have self-selected to be interviewed.

Conclusion

This qualitative study indicates that it is feasible and acceptable to study multicomponent nonpharmacological delirium-prevention interventions in Aotearoa/ New Zealand hospice inpatient units. It also highlights the value of Māori-centred approaches and whānau involvement in these settings.

Author Contributions

Conceptualisation and coleading of the study (AH, AC); study coordination (AC, VJ); data collection (CD, KB, DG, AG, VJ); data analysis (DG, KB, CD, VJ, AC, AH, AG); manuscript drafting (CD, KB, AC, AH, VJ,

DG, AG); and manuscript revision (CD, KB, AC, AH, VJ, DG, ML, AG).

Research Ethics and Patient Consent

Health and Disability Ethics Committee (Health Research Council of New Zealand Ethics Committee) 19/STH/102.

Data Management and Sharing

Raw data appear in this manuscript as deidentified participant quotes. The corresponding author can be contacted for further information.

Disclosures and Acknowledgments

The authors gratefully acknowledge the contributions of patients, whānau caregivers, staff and volunteers at the participating sites; members of Kokiri Marae who codesigned and produced study documentation and community members who provided feedback in the documentation design process. Figs. 1 and 2 shown in this article were developed by Kokiri marae and this rauemi (resource) remains under the protection of Kokiri marae as kaitiaki (guardian) for this research study. We also thank Associate Professor Melanie Lovell for reviewing an earlier version of this manuscript, and the Australian PRESERVE investigator team [Agar, M., Phillips, J., Lam, L., Kochovska, S., Brassil, M., Noble, B., Kurrle, S., Cumming, A., Caplan, G., Chye, R., Le, B., Ely, E.W., Lawlor, P., Bush, S., Maree Davis, J., Lovell, M., Cheah, S.L.] for their review of documents and ongoing support and advice to the PRESERVE Aotearoa study team. We also thank the Palliative Care Clinical Studies Collaborative for their in-kind support to the study. This study was funded by the Cancer Research Trust, New Zealand. The authors have declared no conflicts of interest with respect to the research, authorship, and/or publication of this article.

References

1. Watt CL, Momoli F, Ansari MT, et al. The incidence and prevalence of delirium across palliative care settings: a systematic review. Palliat Med 2019;33:865–877.

2. National Clinical Guideline Centre for Acute and Chronic Conditions. Delirium: diagnosis, prevention and management, NICE clinical guideline 103. 2010. Available at: https://www.nice.org.uk/guidance/cg103. Accessed July 21, 2023.

3. Agar M, Bush SH. Delirium at the end of life. Med Clin North America 2020;104:491–501.

4. Webber C, Watt CL, Bush SH, et al. The occurrence and timing of delirium in acute care hospitalizations in the last

year of life: a population-based retrospective cohort study. Palliat Med 2020;34:1067–1077.

5. Leonard M, Raju B, Conroy M, et al. Reversibility of delirium in terminally ill patients and predictors of mortality. Palliat Med 2008;22:848–854.

6. Finucane AM, Jones L, Leurent B, et al. Drug therapy for delirium in terminally ill adults. Cochrane Database System Rev 2020;1:Cd004770.

7. Nikooie R, Neufeld KJ, Oh ES, et al. Antipsychotics for treating delirium in hospitalized adults: a systematic review. Annals Intern Med 2019;171:485–495.

8. Burton JK, Craig LE, Yong SQ, et al. Non-pharmacological interventions for preventing delirium in hospitalised non-ICU patients. Cochrane Database System Rev 2021;7(7): CD013307.

9. Hosie A, Phillips J, Lam L, et al. A multicomponent nonpharmacological intervention to prevent delirium for hospitalized people with advanced cancer: a phase II cluster randomized waitlist controlled trial (the PRESERVE pilot study). J Palliat Med 2020;23:1314–1322.

10. Green A, Hosie A, Phillips JL, et al. Stakeholder perspectives of a pilot multicomponent delirium prevention intervention for adult patients with advanced cancer in palliative care units: a behaviour change theory-based qualitative study. Palliat Med 2022;36:1273–1284.

11. WTT Ara: The encyclopedia of New Zealand 2017, Available at: http://www.TeAra.govt.nz/en/whanau-maori-and-family/page-1. Accessed 7 June, 2023.

12. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007;19:349–357.

13. Environmental Health Intelligence New Zealand. Ethnic profile. 2023. Available at: https://www.ehinz.ac.nz/indica-tors/population-vulnerability/ethnic-profile/. Accessed April 19, 2023.

14. Robson B, Ellison-Loschmann L. Māori and cancer care in Aotearoa/New Zealand—responses to disparities. Eur J Cancer Care 2016;25:214–218.

15. Hutt Valley District Health Board Annual Report 2020-2021. Hutt Valley, New Zealand: Hutt Valley District Health Board.

16. Hospice New Zealand Facts & figures 2023. Available at: https://www.hospice.org.nz/what-is-hospice/facts-figures/. Accessed June 6, 2023.

17. Slater T, Matheson A, Ellison-Loschmann L, et al. Exploring Māori cancer patients', their families', community and hospice views of hospice care. Int J Palliat Nurs 2015;21:439–445.

18. The New Zealand palliative care strategy. Wellington, New Zealand: Ministry of Health; 2001.

19. Iupati S, MacLeod R, Stanley J, Davies C, Egan R. Community specialist palliative care services in New Zealand: a survey of Aotearoa hospices. New Zealand Med J 2022;135:36–48.

20. Gaudreau J-D, Gagnon P, Harel F, Tremblay A, Fast Roy M-A. Systematic, and continuous delirium assessment in hospitalized patients: the nursing delirium screening scale. J Pain Symptom Manag 2005;29:368–375.

21. Boyd H, McKernon S, Mullin B, Old A. Improving healthcare through the use of co-design. New Zealand Med J 2012;125:4–15.

22. Wi-Kaitaia M, Ruwhiu L, Eruera M. Development of the mana-enhancing paradigm for practice. In: Wellington, New Zealand: Oranga Tamariki—Ministry for Children, 2021.

23. Royal C. A modern view of mana. In: Joint conference of the Australasian Psychological Society and the New Zealand Psychological Society, Auckland: 2006

24. Hudson M, Milne M, Reynolds P, Russell K, Smith B. Te Ara Tika—Guidelines for Māori Research Ethics: A Framework for Researchers and Ethics Committee Members. Auckland, New Zealand: Health Research Council of New Zealand on behalf of the Pūtaiora Writing Group; 2010.

25. Martel R, Shepherd M, Goodyear-Smith F. He awa whiria — a "Braided River": an indigenous Māori approach to mixed methods research. J Mixed Methods Res 2021;16:17–33.

26. Mead HM, Mead SM. Tikanga Māori: Living by Māori Values. Wellington: Huia Publishers; 2003.

27. Srivastava P, Hopwood N. A practical iterative framework for qualitative data analysis. Int J Qual Methods 2009;8:76–84.

28. Macfarlane A, Macfarlane S. Listen to culture: Māori scholars' plea to researchers. J Royal Soc New Zealand 2019;49:48–57.

29. Bellamy G, Gott M. What are the priorities for developing culturally appropriate palliative and end-of-life care for older people? The views of healthcare staff working in New Zealand. Health Social Care Comm 2013;21:26–34.

30. Kitson A, Robertson-Malt S, Conroy T. Identifying the fundamentals of care within Cochrane systematic reviews: the role of the Cochrane nursing care field fundamentals of care node. Int J Nurs Pract 2013;19:109–115.

31. Conroy T, Feo R, Boucaut R, Alderman J, Kitson A. Role of effective nurse-patient relationships in enhancing patient safety. Nurs Stand 2017;31:53–63.

32. Steele R, Davies B. Supporting families in palliative care. Oxford Textbook of Palliative Nursing. New York: Oxford University Press; 2015. p. 500–514.

33. Sagha Zadeh R, Eshelman P, Setla J, et al. Environmental design for end-of-life care: an integrative review on improving the quality of life and managing symptoms for patients in institutional settings. J Pain Symptom Manag 2018;55:1018–1034.

34. Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. QJM Int J Med 2013;106: 1071–1075.

35. Hampton MM, Newcomb P. Self-efficacy and stress among informal caregivers of individuals at end of life. J Hospice Palliat Nurs 2018;20:471–477.

36. Hosie A, Siddiqi N, Featherstone I, et al. Inclusion, characteristics and outcomes of people requiring palliative care in studies of non-pharmacological interventions for delirium: a systematic review. Palliat Med 2019;33:878–899.

37. Chatland LE, Harvey C, Kelly K, et al. Research participation in palliative medicine-benefits and barriers for patients and families: rapid review and thematic synthesis. BMJ Support Palliat Care 2023;13:35–44.

Domains	Strategies	Implementation
1. Preserve natural sleep	• Reduce noise outside patient rooms during 21:00- 06:00	Room curtains/blinds are open during the day Room lights are off or minimised at night
	• Normal day-night variation in room and unit lighting	The person spends time outside during the day
	• Exposure to natural light during daylight hours	The patient drinks no caffeinated tea, coffee or cola
	 Schedule care activities to allow uninterrupted sleep 	after 4pm
	during the night	The patient reports night-time sleep uninterrupted by
9 Maintain antinal	• Avoid caffeine after 4pm	noise or care activities
sensory perception	hearing aids and special communication	The patient nearing was assessed
	techniquesVision:	The patient wears functioning nearing aids
	teeninquesvision.	The patient wears their glasses appropriately
	• Assess need for visual aids (glasses, magnifying	The patient uses visual aids
	lenses)	1
	 If needed, ask family to provide for the patient 	
	 Assist with and re-inforce use of visual aids 	
3. Optimise hydration	Encourage oral fluids	The patient is encouraged to drink
	Physical assistance with drinks and meals, as required	The patient is assisted with meals
	Drinking aids, as required Realest and regrand to reversible course of poor oral	Drinking aids are provided e.g. straws, cup holders, cups
	intake within 94 hours e.g. nausea vomiting	Intervention for reversible causes of poor oral intake
	drowsiness, sore mouth.	are in place
4. Stimulate	Communication:	Interpreter is available and utilised
communication,	Interpreter and translation for people for whom	Orientating information is translated into the patient's
orientation and cognition	English is a second language.	native language
	Orientation:	The patient can see the time in their room
	Greet the patient by name	The patient can see the day, date and month in their
	Introduce self by name and role	room The metionst memoins in the same had leastion within the
	patient	unit
	Time aids in room e.g. watch, personal or wall clock:	The patient discusses current events
	wall, desk or electronic calendar	The patient reminisces and/or talks about their life and
	Update in-room whiteboards daily with date, day, place,	family
	reason for admission, team member names, schedule	The patient spends time in cognitively stimulating
	Minimise number of transfers to other beds or rooms	activities e.g. reading, puzzles, games, knitting, music
	within the unit	Cognitive stimulating activities are in the patient's care
	Cognition: Discuss current events with the patient	pian
	Encourage the patient to reminisce and talk	
	Encourage the patient to engage in cognitively	
	stimulating activities	
5. Optimise mobility	Minimise use of tethers e.g. intravenous line, indwelling	The patient is free of tethers
	catheter, drain, oxygen	The patient moves and/or exercises to their optimal
	Encourage and/or assist the patient to undertake	capacity
	physical activity throughout the day according to their	
	Level 0: No activity planned (state reason):	
	Level 1: Active range of movement exercises in bed	
	and/or sitting position in bed (e.g. regular bed	
	adjustment, assistance with re-positioning)	
	Level 2: Assistance to sit on the side of the bed	
	Level 3: Sitting out of bed in a chair, standing	
	Level 4: Walking (marching in place, independent or	
	assisted walking around room and unit)	
6. Family partnership	Ask family about the nation's baseline cognition	Family are asked about the natient's baseline cognition
o. runn, paratonip	Inform the patient and family about delirium risk	on admission
	Inform the patient and family about delirium	Delirium information brochure is provided to the
	prevention strategies and invite participation	patient and family
		Patients and family are verbally informed about
		delirium
		Patients and family are informed about delirium prevention strategies and invited to participate

Semi-structured interviews with patients and family caregivers/Whānau

Eligible patients and family caregivers/Whānau who are receiving care at the intervention sites will be invited to participate in a sub-study. This will involve semi-structured interviews focused on their experience of the intervention strategies (e.g. receiving information from staff about delirium) and study measures, and whether they found these to be feasible and acceptable. Interviews will be designed to be brief (approximately 20-30 minutes).

The researcher will describe the intervention strategies and delirium measures that the patient has received (as per case report forms). Questions will include:

- Were these aspects of care reasonable and possible?
- Were these aspects of care acceptable to you?
- Were these aspects of care acceptable to your family/Whānau?
- Do you have any suggestions about how these aspects of care could be better delivered?

All interviews will be digitally recorded and transcribed verbatim. Field notes will be completed immediately after each interview, noting relevant information not captured on tape and summarising key points.

Staff and volunteer interviews

Staff and volunteers who give informed consent will participate in an interview towards the end of data collection. The interview will focus on their views about the feasibility and acceptability of the intervention strategies and delirium measures which they were involved with.

Questions will include (with options for additional comments/free text):

- What aspects of the intervention and delirium measures were you involved with?
- Were these strategies feasible:

○ For your patients?

- \bigcirc In this setting?
- Were these strategies acceptable for patients?
- Were these strategies acceptable for family members?
- Were these strategies acceptable for staff and volunteers?
- Do you have any suggestions about how these interventions and delirium measures could best be delivered:
 - To your patients?
 - \bigcirc In this setting?