A critical exploration of a collaborative Kaupapa Māori consistent research project on physicianassisted dying

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ABSTRACT

AIM: This paper critically explores the research approach undertaken by Māori and tauiwi researchers working alongside kaumātua within the context of physician-assisted dying. We critically explore the collaborative process we undertook in framing the research context and discuss the rewards and challenges that emerged.

METHOD: The research this critical discussion draws on undertook a qualitative Kaupapa Māori consistent research approach and drew on the principles of an Interface Research approach. The paper focuses on the collaborative approach taken between the 10 researchers involved in the study.

RESULTS: Challenges identified within the collaborative Kaupapa Māori consistent research process included: determining appropriate authority and representation of researchers and participants; maintaining clear communication; time and logistical management. The key strengths that emerged from this research design were: establishing a culturally safe and robust research process; an ability to build and maintain relationships between researchers and participants; and the opportunity to develop academic research skills between researchers and participants.

CONCLUSION: Collaborative Kaupapa Māori consistent research approaches to research can enable accountability, control and representation throughout the entire research process. Given the rich research results achieved and personal rewards gained from this study design, we would advocate for the application of such approaches within health research contexts.

aua e kaiponutia ngā taonga a ō tātou tūpuna. Tukuna mai ... Mā konā ka mau tonu ai ā rātou kōrero, ka mahue iho ai hei koha ki ngā uri e tipu ake nei, kei moumou te hari atu ā ngā kaumātua ki (Te Reinga) ā ka mahue kupu kore mātou ngā mokopuna.

(Do not over-zealously hold on to those treasures of our ancestors. Hand them over ... so that their stories will be captured and left behind as a bequest to the next generations, and not wastefully taken by the elders with them to the departing place of spirits (Te Reinga) leaving the grandchildren with nothing).¹

Rapua tō Atuatanga i roto i tō Māoritanga. Rapua tō Māoritanga i roto i tō Atuatanga. Kaumātua (respected older Māori men and women)² occupy an important position within whānau (family) and Māoridom, conducting Māori rituals and traditions, and supporting and "protecting interests of Māori people here and in the future".³ They are the kaitiaki (guardians) of tikanga (customs and protocols) surrounding dying and death. They carry the important responsibilities and obligations within the Māori world.

Medical practices that hasten death are legally permissible in a number of countries around the world,^{4,5} with many other countries—including Aotearoa—discussing the issue from legal, ethical, political, social and medical perspectives. A doctor administering a lethal dose of medication



at a patient's explicit request, or a doctor prescribing or supplying a patient with the lethal means to end their own life,6 are two practices generally referred to as physician-assisted dying (PAD). In both cases the doctor acts on the explicit request of a competent patient, death is intended and the patient dies as a result of the medication and not from the underlying condition. [Competency refers to both the mental and cognitive capabilities required to accomplish an action. It is also a legal term, although that is not our intended meaning in using the term here.] Despite being illegal in Aotearoa, such practices do occur,⁷ and a number of surveys and studies show public support for them in qualified circumstances.8-10

Although societal support for PAD by predominately Pākehā (New Zealanders of European descent) in Aotearoa is clear,^{9,10} very little is known about the reasons individuals or broader social and family groups have for supporting or opposing such practices and the implications such reasoning may have on decision making at the end of life. Even less is known about what Māori think about such practices. While two small qualitative studies have contributed to our understanding of PAD in New Zealand,^{11,12} more research is needed.

The absence of Māori perspectives and understanding of PAD within the literature is concerning as the views of Māori must be heard within informed discussion about PAD because (possible) future legislation in this area has significant implications for Māori and health professionals caring for Māori at the end of life. Implications include; access to information about PAD, access to health professionals willing to assist in PAD, appropriate knowledge of tikanga around the dying process, support and guidance for those who want an assisted death and support for whānau at this time.

Additionally, given historical violations and injustices towards Māori in Aotearoa, all researchers have obligations and responsibilities under Te Tiriti o Waitangi (the Treaty of Waitangi)¹³ to include Māori in research that is of paramount importance to Māori. There is no doubt that medical practices that hasten death have significance to Māori as "the events surrounding times of serious illness, dying and death and grieving are among the most sacred and important in Māori life".¹⁴

The aim of our research was to explore older Māori individuals' attitudes and beliefs towards medical practices that hasten death, such as PAD.15 We were interested in exploring the views of kaumātua for several reasons: as the kaitiaki of tikanga and tribal knowledge, they have important perspectives and responsibilities around the dying process. Moreover, many would have experienced illness, and the dying and death of others and cared for whanau at the end of life. They may also have thought about their own mortality. Held in high esteem. kaumātua are nurturers and leaders.2 thus their attitudes and beliefs towards PAD provide an important foundation of knowledge and a critical starting point for exploring PAD within Māori communities.

Methods

This paper describes the research approach undertaken by Māori and tauiwi (non-Māori) researchers working with kaumātua within the area of PAD. We explore the process we undertook in framing the research context within a Kaupapa Māori consistent research approach as well as drawing on the principles of an Interface Research methodology.¹⁷ We also discuss the rewards and challenges that emerged during the project thus far. The discussion focuses on the collaborative approach taken by the ten researchers within the study and the reflective process undertaken throughout the research process. Our ropū rangahau (research group) were consulted about this paper and had a role in writing it.

Kaupapa Māori consistent research framework

At its heart, a Kaupapa Māori research framework recognises the significance of affiliations "and the responsibilities [of the researchers] to ensure the project delivers its intended outcomes to Māori communities".¹⁷ Such an approach "stems from a Māori worldview".¹⁸ Despite contested debate around the appropriateness of involvement of tauiwi within Kaupapa Māori research,¹⁹ control and ownership of the research process by Māori is central to Kaupapa Māori and is by negotiation of all involved in the research.^{18,20,21} As the lead researcher was tauiwi, a Kaupapa Māori consistent research approach was taken



meaning the principles of Kaupapa Māori remained central to the research. This was the approach we took in the research.

Interface Research principles

According to Durie,¹⁶ four principles underlie learning and research at the interface of indigenous knowledge and science: 1) Mutual respect, 2) Shared benefits, 3) Human dignity and 4) Discovery. These principles were central to our research approach, underpinned the commitment of the researchers and kaumātua to the study and formed the foundation of our rōpū rangahau (research group).

In the beginning

The research focus of one of the authors (R8 see Table 1) explores the reasons New Zealanders support or oppose PAD with a particular focus on the ethical dimension. Several studies had been completed, 10,11,12 however, the voices of Māori were largely absent. To overcome this, the principal author approached a leading Māori academic for advice and was referred to the second author of the paper who is a Māori health researcher (R9) and who agreed to take part in the collaborative Kaupapa Māori consistent research study.

No research has explored Māori perceptions and views about PAD. Yet research has shown the importance and significance of tikanga around the dying process, particularly as it relates to whānau and their decision-making responsibilities,²² especially those of kaumātua. It was clear to both

researchers (R8 and R9) that we needed to explore Māori views of PAD if we were to understand the challenges and implications of PAD for individuals, whānau and health professionals at the end of life. Given that kaumātua speak with authority and are the experts on most things in Te Ao Māori (the Māori worldview),²³ it was appropriate and necessary that we sought their guidance in developing and collaborating on a research project that explored the views of Māori on PAD, especially in terms of ensuring that everyone involved was safe, empowered and respected for what they brought to the research table.

Links with kaumātua within Te Kupenga Hauora Māori (Māori Leadership within the Faculty of Medical and Health Sciences) resulted in a group of seven kaumātua (Table 1) being prepared to listen critically to the proposed research outlined by the two researchers (R8 and R9). At this point in the research process, the role of the kaumātua was as kaitiaki, providing guidance and expertise in developing the project further.

Our first research hui (meeting) was in early October, 2012. At that hui, background context of the topic of PAD was discussed. Coincidentally at that time, the issue of PAD was being politically debated within Aotearoa, and a bill to permit PAD was sitting in the parliamentary ballot.²⁴ This added a certain gravity and significance to the research hui, as it strongly highlighted the possibility of PAD becoming legally available in Aotearoa in the future.

Table 1: Researchers working in the study.

Research member	Principal roles	Gender	Tribal affiliation/s
R1	Kaumātua	Male	Ngāti Wai, Te Kawerau ā Maki, Ngāpuhi
R2	Kaumātua	Female	Ngāpuhi
R3	Kaumātua	Male	Waikato, Waiōhua
R4	Kaumātua	Female	Ngāti Mahanga, Te Ākitai
R5	Kaumātua	Male	Te Rarawa, Te Aupōuri
R6	Kaumātua	Female	Te Rarawa, Te Aupōuri
R7	Kaumātua	Female	Ngāti Mahanga, Ngāti Te Ata
R8	Principal investigator	Female	Tauiwi
R9	Co-investigator	Female	Kāti Māmoe, Kāi Tahu
R10	Research assistant	Female	Tūwharetoa



During this initial hui, kaumātua discussed personal experiences of dying and death; the lessons they had taken from such experiences and their own perspectives of any practices that hastened death—medical or otherwise. This hui was also an opportunity for kaumātua to question us as researchers about our motives for the research and what we brought to the study in terms of expertise and skills. This process led to R8 and R9 undertaking critical self-reflections of their positionality in regards to who they were to undertake the research in terms of their ethnicity, their engagement with and understanding of Te Ao Māori, and their academic skills and practices. Such processes of positionality have been argued by Mahuika²⁵ to be essential to ensure that Kaupapa Māori research is kept critical and anti-colonial. The relationship with our kaumātua was central to ensuring that the research progressed in an ethical manner. We were cognisant of the need to work to create a safe space where everyone could be honest and open about the research being undertaken, especially given its controversial and challenging nature.

Over the following 18 months, the researchers and kaitiaki kaumātua met many times, clarifying, modifying, questioning and seeking feedback on each step of the research process. During this collaborative period, the role of our kaitiaki kaumātua changed to that of researcher kaumātua, culminating in our ropū rangahau. Our focus was on mutual respect, sensitivity, trust and continual reflection of how we engaged together. This approach guided our ropū rangahau and upheld the Māori principle of Āta,²⁶ which relates specifically to the building and nurturing of relationships (how we behave and engage together). As the rōpū rangahau, it was decided that the views of our kaumātua about PAD would be sought in a focus group interview and that the discussion would be recorded and used for research purposes as the first point of data collection for the study. Furthermore, our ropū rangahau was involved in recruiting participants for subsequent focus group interviews, the thematic analysis of qualitative data and the dissemination of the research findings. Although holding dual roles of researcher and participant has been criticised as an

extremely subjective research method,²⁷ it is common to some social science research approaches such as ethnographic participant observations²⁸ and autoethnography.²⁹ Such approaches perceive research as a socially conscious act that "seeks to describe and systematically analyse personal experience in order to understand cultural experience".²⁹

Our research ropū felt this structure would provide a normative and privileged cultural viewpoint of PAD that would form a strong foundation on which to build our Kaupapa Māori consistent research as we expanded our study focus to include younger Māori and older Māori and from a broad range of iwi (tribe) and hapū (sub-tribe). All members of the research ropū were cognisant of the challenges that would arise: our kaumātua were not representative of all kaumātua across Aotearoa, thus the information that was shared and disclosed at the hui, and the findings that emerged, could not be generalised for all Māori. The research findings are reported elsewhere.¹⁵

Results and discussion

The challenges

At the first hui, three challenging questions arose that required honest consideration by the authors:

- Who were we to undertake this research?.
- What skills could we contribute to the research? and
- How do we (Māori and tauiwi researchers) navigate the research process together?

We were asked 'are you the right people to do this research?', a question that drove to the heart of what the research aimed to do, how it would proceed and who was involved in its implementation, analysis and dissemination. Our response was that we may not be the most qualified people to undertake the research, however, we each bring unique skills to the table (as a medical ethicist (R8) and medical anthropologist (R9). We were also determined to provide a 'voice' for Māori that is currently absent from the political and research contexts surrounding PAD. Thus a collaborative approach was adopted where everyone in our ropū rangahau was involved with all aspects of the study, yet each of us also held speciality roles which



were respected. At the heart of the questions asked by kaumātua lay the historical context and the 'colonizing gaze'³⁰ that could not be dismissed—a past dominated by colonialisation, marginalisation, violation and oppression—and a present that "continues to harbour and maintain profound inequities in health, education and employment outcomes between Māori and non-Māori".³¹

Linked to the past lay a further challenge concerning whether tauiwi should be involved in the research at all. Within the literature, opinion is divided on the role tauiwi should play in the advancement of Kaupapa Māori research. 19,21,22 It has been argued that Kaupapa Māori research should be undertaken by Māori alone to ensure that Māori ways of knowing, understanding and being, remain academically rigorous, thus promoting a 'pure' Kaupapa Māori approach to research. 33,34 In contrast, Barnes has argued that there is a space for tauiwi within Kaupapa Māori research where tauiwi can align with key principles of the approach while ensuring that the research is "controlled by Māori, for Māori and is of direct benefit to Māori".20 Furthermore, as Kerr notes, what is important is the right attitude: those who support "the indigenous desire for self-determination should be welcome to join...it is this right attitude that we are looking for and trying to foster".35 Such a view is also shared by Barnes: "making the commitment to build and sustain relationships over a long period and being prepared to walk alongside Māori groups...".20 The ropu rangahau were in agreement that we all have a role to play, including tauiwi, and that we were all in this space together.

The challenges were not one-sided. Kaumātua were also very aware of the impact their authoritative voices have for Māori generally. This was poignantly expressed by one kaumātua who questioned her/their authority in speaking about PAD. She asked, 'who am I to do this [research]'? Another kaumātua expressed concern that he was not entirely comfortable about the research because of the wairua (spiritual) aspect for his mokopuna (grandchildren) and tamariki (children) in the future. However, he was committed to being involved because of the significance of the context (PAD) for all Māori, and the importance of Māori voices being heard within a society that has

traditionally ignored or dismissed all things Māori. He was also committed to ensuring that the knowledge that comes from the research would be available to future generations so that the stories would not be lost. As a consequence of this aspect of the research, it was agreed by everyone in the research rōpū that the verbal recordings and written transcripts would be securely archived, maintained and used within culturally appropriate processes approved of by kaumātua.

Finally there were challenges in terms of time and logistical management. All of our kaumātua were older in years with some experiencing poor health at times throughout the study. Finding time to meet together as a ropū was challenging, however, the commitment from everyone to work together meant we accomplished this. The ways in which information is communicated and knowledge transferred can also create challenges for everyone involved. Ensuring that relevant concepts were clearly understood, and that different dialects of Te Reo Māori were acknowledged and respected during the transcription and translation process, was central to making certain we were listening carefully to what was being spoken.

The rewards

As a rōpū, one of the most satisfying aspects of the research has been the building of our research rōpū as whānau and the nurturing of relationships with kaumātua. Central to the principle of Āta,²⁶ relationships define and sit centrally in how the research progressed. This was exemplified in a number of ways—many times it was more important to listen and hear than to talk.

Barnes proposes a descriptive framework as a "place to start in understanding the complexity of Pākehā engaging in kaupapa *Māori research*". ²⁰ Such a model positions collective relationships at its heart and invites Pākehā researchers to be upfront and reflective in their Kaupapa Māori research journey. He further states that "acknowledging the diversity of research thinking and doing among Māori and Pākehā is important if new knowledge and practice is to emerge, and be learnt from".20 One of the rewards (and challenges) of working within this Kaupapa Māori consistent research methodology has been continually reflecting on and questioning one's own values and intentions throughout the study.



As mentioned earlier, the two researchers came from different academic disciplines and research backgrounds—R8 from medical ethics (philosophy) and R9 from anthropology. Furthermore, R9 is Māori and R8 is tauiwi. Yet our differences were also our strengths in that we came to the research with different skills and abilities that complemented the focus of the study. Having the opportunity to return to the safety of the research rōpū and ask questions in order to clarify any queries that came from the interpretative process gave further depth and meaning to the analysis. We were also proud to have the trust of our kaumātua.

For the kaumātua, some of the most rewarding aspects of being involved in this research related to hearing each other's views and experiences, developing research skills and forming a close and trusting relationship with each other as a rōpū. They also enjoyed seeing how the learnings and knowledge gained by R8 and R9 resulted from their (kaumātua) participation in the research.

Conclusion

This paper has critically explored the Kaupapa Māori consistent research approach we took in exploring Māori attitudes and beliefs about medical practices that hasten death; the collaborative approach we embraced and the challenges and rewards that ensued. The four Interface Research principles were central to our study and formed the foundation of our rōpū rangahau.

Working together as a research rōpū and being committed to respecting the skills, insights and experiences that each individual brought to the study ensured accountability, control and representation throughout the entire research process. Given the rich research results achieved¹5 and personal rewards gained as a rōpū, we would advocate for the application of such collaborative research approaches within health research contexts.

Competing interests:

All authors report grants from Health Research Council during the conduct of the study. Dr Malpas is a member of the End-of-Life Choice Voluntary Euthanasia Society.

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