Behind the label: Complexities of identifying Māori whānau in an away from home hospital transfer

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This paper highlights two methodological issues that arose for a group of Māori researchers during the first few months of a Māori CoRE funded project. The issues were in relation to defining 1) the evolving construction of Māori whānau in New Zealand, and 2) an away from home hospital transfer. Through the process of reflexive practice about our knowledge constructs the research team highlight some of the complexities that we as indigenous researchers had to navigate when working within a cultural context. We describe the details of the Hospital Transfers project and reflect on the learning experienced during the pilot interview phase of a three year project.

Keywords: Māori whānau, away from home, hospital transfers

Introduction

The most consistent and compelling inequities are reflected in health outcomes between Māori and non-Māori in New Zealand (Ajwani, Blakely, Robson, Tobias, & Bonne, 2003). As a consequence efforts to improve service delivery to Māori across a range of health settings have been employed (Ellison-Loschmann & Pearce, 2006; Cormack, Robson, Purdie, Ratima, & Brown, 2005). However, understanding the extent to which implementation is effective in a specific setting, prolongs sustainability, and promotes dissemination into other settings (Damschroder, Aron, Keith, Kirsh, Alexander, & Lowery, 2009) still remains a challenge. Both whānau, and the communities with which they identify, play a key part in the development of culturally appropriate, high quality hospital and health services for underserved populations (Stellefson, Diparine, & Stopka, 2013; Dutta, 2007; Wallerstein, Oetzel, Duran, Belone, Tafoya, & Rae, 2008).

Hospitalisation can be stressful for patients, for whānau, and for friends and support people (McBride, 2017a; Robson & Harris, 2007). When unwell whānau members are removed from the familiar context of their everyday lives, the world around them can become strange and feelings of vulnerability often arise (Masters-Awatere et. al, forthcoming; McBride, 2017b). There are also many challenges for whānau (relations) who wish to remain self-determining and included in the hospital care equation, from "big picture" structural, ethical, legal, socio-cultural challenges through to more personal challenges concerning the financial and the practical aspects of providing care (Cram, 2014; Cram, Smith & Johnstone, 2003; Dow, 1999). One of the most significant of these perhaps, is for whānau to entrust a loved one into the exclusive context of the hospital environment.

We begin this paper by presenting the context of hospital care and hospitalisation in New Zealand. We argue that very little is actually known about the process of hospital transfers in New Zealand. Even less is known about the experience of Māori and their whānau when whānau members (i.e. patients) are required to travel away from home to receive hospital care. We then introduce our study which seeks to shed light upon the hospital transfer process for Māori and their whānau. The Hospital transfers: whānau involvement in the healing equation Project focuses specifically on hospital admissions that involved transfers into Waikato Hospital within the last 12 months. The focus of this paper is to highlight two methodological issues that arose during the pilot phase of our study. Clarifying the nature, boundaries and extent of the two issues (what counts as a hospitalisation "away from home", and who exactly are the "Māori whānau" that we talk about in relation to "Māori whānau engagement during hospitalisation") was a crucial step prior to our entering the field to conduct the project interviews. How we have made sense of these two issues and the implications of them for the full study are explored and presented within this paper.

Background

Internationally, there has been growing concern that health research has not been able to reduce health inequities despite the strong evidence-base for improving health. For example, a systematic review that included, New Zealand, Canada, Australia and the United States of America, has identified the lack of uptake of scientific findings by clinical and community practitioners to be significant for the lack of impact on improving health and reducing health disparities (Gibson & Segal, 2015). The importance of translational research has identified issues of context and external validity as central to the problem of the utilisation of evidenced-based practices. As such, recognition of the importance of stakeholder knowledge and participation in research, translation, dissemination and implementation of research findings is essential (Barkin, Schlundt, & Smith, 2013). Strategies that facilitate the incorporation of whānau knowledge and experience in the care equation are more likely to be successful for both Māori and the health services themselves. Both whānau, and the communities with which they identify, play a key part in the development of culturally appropriate, high quality health services for underserved populations (Stellefson, Diparine, & Stopka, 2013; Dutta, 2007; Wallerstein, Oetzel, Duran, Belone, Tafoya, & Rae, 2008). In this paper we advocate for strategies that actively support whānau and their communities to partner with health services. So we asked, what would culturally appropriate health services for Māori entail?

Holistic, whānau-centred care approaches have long been integral to Māori conceptualisations of health and wellbeing (Durie, 2001; Lange, 1999). For Māori, the care of the unwell has always been the concern of whānau and community. Established knowledge systems relating to health and wellbeing, and long-standing practices for both promoting good health and responding to illness have been recorded (Durie, 2011; Waitangi Tribunal, 2001). Māori recognise the importance of relationships between peoples and their broader environments to health and wellbeing (Durie, 2011; Mark & Lyons, 2010). Colonisation introduced an orientation towards Western notions of medical science and "care" that re-ordered the structure and provision of that care.

New Zealand hospitals

In New Zealand publicly-funded hospitals are large healthcare institutions with specialised staff and technologies where people are referred for care; or present for acute care in the case of emergencies. Twenty District Health Boards (DHBs) are situated around the country to plan, fund, and provide, health and disability services to their regional populations. Within each region there are differing levels of hospital services with specialisation between hospitals and across the DHBs (Ministry of Health, 2017a). The distribution of services can be dependent upon population size. However, the drive to centralise care has resulted in different levels of specialist services being available at different hospitals. This means that the provision of secondary and tertiary care services¹ often necessitates referral and transfer to settings beyond where patients usually live; in other words, patients are transferred to a large secondary or tertiary hospital in another town or city, where they can receive more specialist care (Butt, Singh, Farrant, Kyle, Gilkison, Fancourt, Hill & Mosquera, 2013; Freebairn, 2012).

The two figures presented here show the DHB boundaries, most of which span over one hundred kilometres (Figure 1) and likely include at least one sub-acute or secondary hospital (see Figure 2). As can be seen in Figure 2, there are only five tertiary level hospitals in the North Island. While the majority of DHB regions have at least one secondary hospital facility within their boundary, residents in Auckland, have three high level tertiary hospitals within the metropolitan area. When these two maps are considered with regards to Māori population distribution, the impact of a hospital transfer on a whānau who live in a region that requires a two-hour drive to the nearest subacute or secondary hospital can become apparent.



Figure 1: DHB regions throughout New Zealand. Source: Report of the Controller and the Auditor-General (2003; p.33)



Figure 2: Location of levels of hospital services in the North Island Source: Ministry of Health (2017a)

Transfers between facilities

Inter-hospital transfers and intra-hospital transfers are often referred to as the relocation of patients either between units or wards, or from one hospital to another (Mascia, Vincenzo & Cicchetti, 2012; MacKenzie, Smith, &

Primary level services mainly deal with internal medicines and include general practice. Secondary care services are recognised as having 5-10 clinical services, with 200-800 beds, and often referred to as provincial hospitals.
 Tertiary care services are highly specialised services and technical equipment. They can range from 300-1,500 beds.
 (Mulligan et al, 2003, cited in Henser, Price & Adomakoh, 2006)

Wallace, 2007). A common reason for such transfers noted by Kulshrestha and Singh (2016) was as a result of there being "few centres [that]... provide super-speciality care, non-availability of speciality beds and funding of medical treatment" (p. 451). In New Zealand, transfers can occur between different facilities within a DHB region, as well as to facilities outside the DHB of usual residence, depending on the reason for transfer.

Due to the geographical size of some DHB regions, even hospital transfers within a DHB's geographic boundaries could constitute an 'away-from-home' hospitalisation from a whānau point of view. While some data on inter-district flows (or the flow of patients between their DHB of usual residence and another DHB to receive a health service) are available (National Health Board, 2014), there is limited routinely published information that provides detail on patterns of transfer between hospitals or receipt of hospital care outside one's usual place of residence, particularly data disaggregated for Māori. However, given the differential distribution of the Māori population by region and DHB, it is likely that these patterns of hospital transfer and care differ between Māori and other population groups.

Issues to do with hospital transfers

In England and Wales, as many as 75,000 patients a year may be affected by relocation stress that is brought on by a hospital transfer (Cullinane & Plowright, 2013). Mackie and colleagues (2014) refer to the hospital transfer process for relatives as a journey that "was disorientating as the need to travel away from home forced many into unfamiliar surroundings" (p. 179). The stress evoked from transferring to another hospital facility, or being relocated away from familiar surroundings, causing emotional distress was referred to as relocation stress by Carpento (2006) who considered relocation stress as, "a state in which a person experiences physiologic and/or psychological disturbances as a result of transfer from one environment to another" (p. 356).

In addition to psychological stress, the financial burden of an "away from home" hospital admission for both the patient and support people requires attention. Gott and colleagues (2015) conducted a qualitative study on the financial impacts faced by family and whānau carers in the palliative care context. However, aside from this sole study very little New Zealand research on the burden carried by support people during a hospital admission has been conducted. Given the rates of hospital admissions for Māori (Ministry of Health, 2017b) and indeed the inequity of health outcome experienced by those who do seek hospital care (Oetzel, Scott, Hudson, Masters-Awatere, Rarere, Foote, Beaton & Ehau, 2017) the experience of Māori during a hospital transfer represents a large gap in our knowledge.

The Hospital Transfers project

The Hospital transfers: whānau involvement in the healing equation Project (hereafter referred to as the Hospital Transfers project) arose from this identified gap. This three-year study is funded by the Māori Centre of Research Excellence Ngā Pae o te Māramatanga (NPM) under NPM's Mauri Ora or Human Flourishing theme. Research conducted under this theme recognises the challenges and opportunities that lie ahead for Māori whānau, hapū (larger family), iwi (extended family) and communities and, rather than taking a deficit or victim-blaming approach, seeks instead to embrace and build on practices that sustain, strengthen and liberate communities (Ngā Pae o te Māramatanga, 2017). The research question that guides the overall study is: *How can whānau maintain active engagement in the care of their whānau member when they need hospital care away from their home base?*

In the research project we intend to explore whānau decision-making processes about key supports for the patient; negotiation of the distance between home and the hospital where a whānau member has been transferred to; whānau unfamiliarity with the different town, city or region; unfamiliarity with the hospital and its staff; how whānau remain active in decisions regarding the care of their whānau member; and how whānau seek help and advice, and access the support services to which they are entitled. The overall study investigates how whānau navigate caring for their whānau during the process of a hospital transfer. This paper focuses on the pilot interviews and the team reflection upon two key methodological issues that have implications for future project work.

Methodology

Our team are committed to undertaking research that both benefits Māori communities and centres Māori aspirations for health and wellbeing. In the design and execution of the study we are guided by Kaupapa Māori theory (Pihama, Cram & Walker, 2002; Ormond, Cram, & Carter, 2006). Key to our approach is a focus on research practices that recognise and facilitate self-determination (Alves, 1999). In order to enact our commitment of transformational change (Grande, 2003; Lather, 1991; Smith, 1997), we remain mindful of how whānau (as patients and support people/relatives) are involved in the healing equation before, during and after the transfer process.

Pilot phase interviews

Our literature review revealed a dearth of literature regarding hospital transfers in the New Zealand context and a similar paucity of literature exploring indigenous patients' hospital transfers away from home. Of the published research in the area of hospital transfers, much was focused on the perceptions of the staff and patients whilst very little information was obtained from the perspectives of the relatives or support people who often travel with the patients. The lack of information gathered from relatives or other support people was highlighted by McKinney and Deeny (2002) and Odell (2000) who provided detailed descriptions of 'patients' experiences without considering the experiences of their family members. The experiences of families, or their support people appear absent from research regarding hospital transfers.

Given the paucity of research evidence looking at the experience of families in the hospital transfer care equation, guidance on the conduct of such a study was equally limited. Thus, our team took the prudent approach of conducting a series of pilot interviews to both test our processes of recruitment into the study and the interview protocols themselves.

Four, face to face, semi-structured interviews focusing on whānau experiences of hospital transfers and hospitalisations 'away-from home' were conducted. The primary focus of these interviews was to identify ways in which whānau engaged in the hospital care process during their whānau member's transfer and hospitalisation away from home, with particular attention to the medical context. The interviews also highlighted whānau perspectives on the engagement that occurred between whānau and various medical teams.

A number of inclusion criteria were adopted for these interviews, namely hospitalisation and transfer had to have occurred in the past 12 months; the participant had to be 18 years of age or older on the day of the interview; the patient had to have been admitted to hospital for a period of at least 24hrs; all participants had to be of Māori descent, and they had to have been transferred to a hospital which was 'away from home' (out of the city/town they are associated with), and away from their usual place of residence.

Possible participants were approached through researcher personal networks and four participants were recruited who met the selection criteria. The four whānau members comprised of two patients and two support people. The four whānau members resided in different areas of the Waikato; ranged in age from 22-87 years, identified as male or female, and incorporated different whānau member relationships (partner, daughter, and grandchild). Data was collected from kanohi ki te kanohi (face-to-face) interviews, which lasted between 30 and 90 minutes. Interviews were transcribed verbatim and the process of analysis was conducted using thematic analysis. Themes were collated based on similar responses or common findings when comparing the data from both the patients and support people.

In addition to undertaking a relatively straightforward thematic analysis of the pilot data however, through a process of reflexive practice, we also realised we needed a deeper and more nuanced examination of at least two of the terms we had been using in our study. It is to the results of this reflexive practice that we now turn.

Reflexive Practice

Academics in psychology (Robson, 1993; Waldegrave, 1993), and particularly in community psychology (Nelson & Prilleltensky, 2005; Riger, 1990) have argued for the explicit positioning of research that involves working in community settings at the broader social research level (Crotty, 1998). Unfortunately, explicitly stating the researcher's values in research has yet to be accepted and is positioned on the fringes of psychological research (Marie & Haig, 2006).

Indigenous researchers similarly have long been advocating for a reflexive commentary on the epistemological tensions inherent in research across power differentials (Bevan-Brown, 1998; Cram, McCreanor, Smith, Nairn & Johnstone, 2006; Smith, 1999). The arguments posited for reflexive practice challenge researchers, and psychologists doing research work, to move beyond simply being the distanced-passive observer towards being an engaged-active participant. Such approaches produce a richer, more in-depth description of the research activity (Ashworth, 2003; Crotty, 1998; Etherington, 2004; Neuman, 2000) that allows us to learn from our experiences with participants to be more reflexive in our work.

The processes employed by our research team as we make sense of our data highlights a reflexive approach consistent with the principles of Kaupapa Māori Methodology and which recognises the two worldviews that we, as Māori researchers straddle, i.e. Mātauranga Māori and the dominant models of Western social science. We lay out the dynamics and tensions inherent in working with these two worldviews in an attempt to make visible the underlying complexities and hidden ideologies of power and control that are generally attached to research, yet are rarely voiced. We would argue that as long as health inequity persists, programmes must be examined for their cultural responsiveness and engagement.

In coming together to discuss and analyse our pilot data, our research team reflected on the myriad interpretations of what "away from home" means for Māori, and the evolving notion of what it means to be Māori whānau. What initially appeared, when we developed the research question and study design, to be seemingly innocuous labels of "away from home" and "Māori whānau", were shown through the pilot interviews to instead encompass layers of meaning. Our reflections on these two terms; how we have made sense of them, and their significance for the wider study are presented here as results from our pilot interview phase. Pseudonyms have been used in this section to protect the identity of the participants involved in our study.

Results

Through reflexive practice we identified two methodological issues that required an in-depth discussion to unravel our own individual assumptions. We then to achieved an agreed understanding that reflected our intended approach; that to defining "Māori whānau" and the criteria for "away from home".

Defining "Māori whānau"

For the purposes of this study, and to align with the broader Kaupapa Māori underpinnings, the team took a deliberately inclusive approach to the term "whānau". At the outset we determined that in order to identify whānau members who had been involved in the care of a loved one during a hospital transfer away from home for the purposes of an interview, we would rely on self-identification by the whānau member. Whānau then, for the purposes of this project, include anyone that is considered or identified as whānau by the person hospitalised and/or their whānau.

The concept of whānau, in and of itself has been problematic for politicians, policy-makers, statisticians and demographers alike; those required to count people in order to account for the needs and services those people require. For example, Massey University's longitudinal study, Te Hoe Nuku Roa, has used "household" as a proxy for whānau (Boulton and Gifford, 2011). Despite the flaws in ascribing a household with the same attributes as a Māori whānau, in the absence of reliable whānau data, Te Hoe Nuku Roa household data was, for many years, used to inform the development of social policy for Māori (e.g. Cunningham, Durie, Fergusson, Fitzgerald, Hong, Horwood, Jensen, Rochford, & Stevenson, 2002).

A household however is not a whānau. The boundaries that shape, quantify, demarcate and a define whanau from other collectives, whether these collectives be a "nuclear" family or an "immediate family" (Statistics New Zealand, 2012), mean that what constitutes a whanau is often likely to be as unique to each whānau as one hapū is to another hapū. In our study, we sought to uphold the rangatiratanga of the whanau who participated, meaning it was up to each whanau to define for themselves the membership and composition of their own whānau. In supporting the principle of rangatiratanga it was equally important that we acknowledged that not every whānau would necessarily be whakapapa-based (Bishop & Glynn, 1999). So-called kaupapa whānau, those collectives who come together around a common aim or objective could, for the purposes of our study, be the main support network of a participant transferred away from their home.

Our intention for an inclusive approach to the concept of a Māori whānau, did not however easily translate into the documentation required for an ethical review application. With a focus on individual rights (Code of ethics review group, 2008) the ethical review application templates and forms highlight a preference for the development of information sheets and consent forms that would be signed by consenting individuals, rather than by collectives, such as a Māori whānau.

The recruitment information sheet, in contrast, sought Māori whānau who were willing to talk about their experience of hospitalisation away from home. To be included in the study potential participants (whether they were a patient or a whānau support person), had to self-identify as Māori and a hospitalisation away from their usual home had to have occurred in the previous 12 months. The inclusion criteria for the study were seemingly straight forward respecting the ethical obligations to provide potential participants with freedom of choice to participate, respect for their dignity as a person and informed consent.

As a team we had decided from the beginning that the patient's consent had to be received before we spoke with whānau support. This process would eliminate the problem of potentially interviewing a whole host of whānau support only to find that the original patient did not want their story told. Even if a patient did not wish to be interviewed themselves, we developed a consent form so that patients could let us know that they were willing for whānau to talk about the experience even if the patient themselves did not wish to participate. It was at this point that complications began to arise. When we began to approach support people to participate in the study, we found, of course, that not all support people were Māori.

Two examples, related to this methodological issue have been drawn from the results of our pilot interviews, illustrating the complexity we uncovered. Tama was transferred from his local hospital to a tertiary hospital for surgery. He is a young man in his early 20s who has just left home to attend university and has visions of asserting his independence. During the University break he returned to his hometown where he injured himself playing sports for a local team. He put off the surgery as long as possible before being admitted and then transferred to the larger hospital. Not wanting to cause his whānau unnecessary concern, Tama drew upon his Pākehā partner Jane's support during his hospital admission and post-operative care at home.

The research team had to consider whether Tama and Jane's feelings and actions constituted that of a Māori whānau in order to determine if it was appropriate to include Jane's data in the collection of narratives we intended to gather from whānau. That type of decision was not appropriate for us to make, and would have been unethical. On the basis of our description of support, Jane filled that role for Tama. However, we did not apply for ethical approval to interview non-Māori – we had only sought approval to interview Māori. Could then we reasonably be expected to include Jane's data in our dataset?

Another example came from 83 year old Atarangi who experienced a hospital transfer from her home to the nearest tertiary hospital within her DHB region, 163kms away. Hana and her sister Hera, as mokopuna (grandchildren) to Atarangi, wanted to remain involved in supporting their grandmother. Atarangi's first language is te reo Māori, and her grandchildren are competent enough to engage in her native tongue. Hera and Hana's mother (Sophie) is Pākehā and does not speak Māori. Furthermore, Hera and Hana's father, Matiu, (Hinerangi's son), whilst Māori, does not have the same level of ability or confidence to maintain sustained conversations in te reo as his two daughters.

The centrality of whānau, however defined, to Māori wellbeing is well-recognised (Durie, 1998; Mark & Lyons, 2010). Providing for whānau to be actively engaged in the care of a loved one, in whatever way they collectively determine is appropriate for their whānau, supports whānau ora aspirations for self-determination and participation in decision-making (Boulton & Gifford, 2014). As a research team, and upon reflection of our own whānau compositions, we felt that it would have been inappropriate for us to dictate to Atarangi and Tama who could be part of their whānau for the purposes of our research. During one of our analysis discussions the research team tried to think of a way to present visually the complex nature of whanau. After different attempts to capture whānau in a simple way we determined that a portrait would



Figure 3: Depiction of a Māori whanau comprising Māori and non-Māori

be an effective way to depict a whanau.

Figure 3 below, sketched by artist Sharron Masters-Dreaver, is based on members of the first author's family and is presented as a visual example of a Māori whānau comprising different ethnicities and who still love each other.

The pilot interviews raised methodological issues that required the team to consider its approach to two key issues within the research team – defining both Māori whānau and, the criteria for away from home. While the initial desire for an inclusive approach was expressed, the practicality for both the researchers and participants required reflexivity.

Defining the criteria for "away from home"

In our initial conceptualisation of this study, we determined that a hospital transfer as being "away from home" constituted some degree of travel and particularly moving between DHB boundaries. However when "home" is the usual place of residence that provides warmth, comfort and familiarity (Brookes, 2000), then any hospital admission may be considered, in the broadest sense, to comprise an "away from home" experience.

To illustrate this point we draw on an interview with an 87 year old kuia we've named Anahera. This participant noted that for her, what was important was that life at home continued to operate smoothly. Minimal disruption to her home life was more important to Anahera than either her engagement with the health clinician or with having a whānau member present during the hospital admission.

Here we share an excerpt from Anahera's interview, which shows a desire for her whānau to continue life and work as normal, and to look after her husband and the house whilst she was in hospital.

Interviewer: What helped you the most while you were in hospital?

Anahera: ... one of my kids must of taken us there [to the hospital... and then] probably looked after the home and their father. Helping him... They would have had to have done a lot of housework for their father... They always came home. There was always someone that could drive the car.

Interviewer: So they would drive home and then come back to you the next day?

Anahera: No not really ...I didn't want them to come. I wanted them to stay home and do some work. Pick me up when I am ready. Actually, I told them to stay home and do some work and look after the whānau. I wouldn't let them take time off work, they had to go to work.

Our interview surfaced a number of worries that preyed on Anahera's mind preventing her from concentrating on her own recovery and recuperation. These included concerns that her husband was being fed and not being left at home alone; that her house was not left empty and therefore prone to burglary; and that her children were not having to take time off work, thus losing valuable income, to sit with her while she was in hospital. Anahera managed the stress caused by being "away from home" by focusing her attention on making sure home would be the same as it was before she was admitted to hospital.

In response to the initial results of our pilot interviews, we decided it was important to clarify what an "away from home" transfer meant in the context of our research. Was it enough for a hospital admission to be an "away from home" experience for Māori patients and their whānau - or was something else required to constitute an "away from home" experience?

Another participant Marama, had to manage 80kms travel every two days for two weeks to support her elderly mother during her hospital admission at the nearest tertiary hospital. Marama repeated this journey on four separate occasions in the 12-month period prior to the interview. At the same time Marama also had to travel 142kms in a different direction, to support another whānau member as they prepared for surgery at a sub-acute hospital. Marama's family members both lived nearby to her home, but were transferred to different hospitals, in opposite directions.

For residents in metropolitan areas, a transfer to another hospital facility may only mean travelling across the city. This would appear more manageable for whānau support who may wish to return home between visiting hours. Whereas for people such as Marama, return travel, either 80kms or 142kms, required more planning and resources, particularly if it was required many times during a lengthy hospital stay.

While 85% of Māori live in urban areas (Kukutai, 2013), those who remain near the rural homestead can be transferred long distances to receive the specialist care they need. Field and colleagues (2008) observed patients feeling at home at their local hospital but having a sense of unfamiliarity when transferred, such as from a rural hospital to a metropolitan hospital.

In reflecting on this pilot data the research team came to the view that, for the Māori whānau we interviewed, any hospitalisation can be thought of as an "away from home" experience. Whether the hospital admission was within 10 kilometres or over 100 kilometres away, people's lives were going to be disrupted. Those whānau members who travelled to be with their loved one while they were hospitalised exhibited a strong desire to remain engaged during the hospitalisation. Irrespective of how near or how far their loved one was transferred, whānau managed themselves to deal with that hospitalisation for however long it was necessary, in the best way they could. When a hospital transfer is necessary, Māori whānau negotiate the activation of their internal support system to assess the availability, resources and time commitment required to remain engaged.

The Research approach

As researchers we are supported by a Research Whānau that includes health and research experts. The Research Whānau have expertise in Kaupapa Māori research methodology, qualitative methodology and methods, quantitative methodology and methods, ethics, medicine, and clinical practice. Given that the project navigates the two landscapes of health systems and whānau systems, the Research Whānau provide expertise and experience on health research policy, strategies and procedures, while ensuring we maintain our Māori-focused research intentions.

Discussion

In the next section of the paper we outline the learning we undertook to come to terms with these two concepts before taking the next step to then conceptualise our treatment of "Māori whānau data" in the discussion. The examples provided above highlight the complex nature of defining whānau and how we define, treat and then use "Māori data". In failing to take account that our Māori patients could potentially have non-Māori spouse/partners we had not thought through the issues of collecting non-Māori data as part of a Māori whānau dataset. Our original ethical approval did not include the collection of individual data from non-Māori, thus if we had continued to collect non-Māori data, we would have been working outside the scope of our ethical protocol.

The initial oversight, in failing to consider non-Māori spouses of Māori patients on our information and consent forms, although easily rectified, did cause us to stop and think about the wider implications for the project. Although we had taken an inclusive approach to whānau at the conceptual level, in line with the diversity of understandings of the term "whānau" among Māori (Lawson-Te Aho, 2010; Statistics New Zealand, 2012), we needed to operationalise the notion at the level of the consent process. We needed to allow for the diversity amongst all our participants if we were to remain true to our intention of implementing a Kaupapa Māori approach to the project.

Thus, as a team, we began to ask ourselves a number of important questions; "what is the make-up of a Māori whānau in 2017? Can a Māori whānau comprise non-Māori partners, spouses and significant others? Does it even matter that a participant's partner is non-Māori if the whānau, as a collective, identify as Māori? At what point, if any do we stop collecting "Māori" data and collect the data of a "Māori whānau"? At a conceptual level we were asking "what is the implication of this for identity politics?" At a pragmatic level, we asked "what are the implications for our analysis and for our presentation of our data in the future?"

Knowledge of where whānau go and why in hospital care is important to understanding the flows of support and decisionmaking between whānau members and the significance of engagements with hospital staff, structures and systems. We think the complexity does matter and we are seeking, if not to "solve" the issue in this study, then certainly to unpack the complexities that we have identified. However, it is an issue we need to grapple with and be explicit about how we treat non-Māori data in a "Māori whānau dataset". We are still working through the implications of what this means in terms of our data analysis and study findings. This is likely to be important in facilitating optimum wellbeing outcomes for both the patient and their wider whānau, and needs to be facilitated within the complex configuration of current public hospital services.

The whānau unit has been encouraged since Pākehā arrival to become progressively smaller to fit within the dominant worldview of what constitutes a "family". Cram and Smith (2003) condemn urbanisation and land confiscations for their devastating effects on the intergenerational transfer of cultural knowledge amongst Māori whānau to express their needs to healthcare professionals. While the current trend is towards whānau-centred care approaches that have long been integral to Māori conceptualisations of health and wellbeing, we need to keep sight of our focus on whānau ora. In describing whānau ora, He Korowai Oranga notes that: "To achieve whānau ora, the health system will work in a way that acknowledges these aspirations and the central role that whanau play for many Māori, as a principal source of strength, support, security and identity" (Ministry of Health, 2016). Westernised health systems are increasingly recognising family-centred practice as an important component in healthcare. Family-centred practice is characterised by a "partnership between parents and service providers, a focus on the family's role in decisionmaking, and recognition that parents as the experts on their child" (Law, Hanna, King, Hurley, King & Kertoy, 2003, p. 357). While the concepts of family-centred practice are firmly embedded throughout Aotearoa New Zealand's education, health and social welfare sectors (Chenery, 2004), a disconnect between what is best practice and what actually occurs has also been identified (Alliston, 2007).

Consistent across health policy (Alliston, 2007; Cheney, 2004), health research (Slater, Matheson, Davies, Goodyear, Holdaway & Ellison-Lochmann, 2016), and public discussion is the desire for family-centred care that improves patient wellbeing. Our study seeks to make explicit the challenges whānau and clinicians navigate to provide care and support to whanau in hospital. These challenges are significant and demonstrate a substantial commitment to healing and wellness. The anticipated outcomes of our study are; more frequent and deeper engagements between whanau and hospital staff, more successful hospital stays, greater compliance with patient rehabilitation plans, and less re-admissions, which will realise a reduction in the burden of negative health experienced by Māori. As a team of researchers, we want to understand both sides of the healing equation (Khodyakov, Stockdale, Jones, Mango, & Lizaola, 2011) and ways in which whanau can remain active in the care of their family members (Wallerstein, & Duran, 2010). To do so, we need to carry out critical partnering activities with a range of stakeholders (Barkin, Schlundt, & Smith, 2013; Cram, 2014; Glasgow, Green, & Klesges, 2006; Simmons, & Voyle, 2003) that will spawn a range of exciting context-dependent research trajectories (Greenlund & Giles, 2012; Khodyakov, Stockdale, Jones, 2011; Michener, Cook, Ahmed, Yonas, Coyne-Beasley, & Aguilar-Gaxiola, 2012).

Conclusion

Māori have consistently been active agents in their own care seeking and healing, and have a history of travelling in search of tohunga healing and resources (Te Awekotuku, 1981). In Māori society, care of the sick was the concern of family and community, with religious or spiritual persons often referred to for guidance, intercession or practice that would bring the sick person and their whānau into wellness. This sometimes meant travelling in search of experts, including Tohunga, and healing resources such as waiariki, cool springs or natural remedies, in communities beyond their own. Given the ethic of care amongst whānau, the unwell person rarely travelled alone.

With colonisation and the subsequent rise of western medical science and health institutions in the 20th century, care of the unwell in Aotearoa New Zealand has predominantly become the business of general practitioners, medical specialists and hospitals (Robson & Harris, 2007). While current philosophical and academic debate highlight a desire for an integrated care process that gives equal emphasis to Western and traditional Māori healing (Boulton & Gifford, 2014; Slater, Matheson, Davies, Goodyer, Holdaway & Ellison-Loshmann, 2016), the ability of Māori to determine their own health pathways has been shaped by government policies and the increasing centralisation of intensive specialist healthcare. Such processes have made hospital transfers a growing reality, especially for Māori whānau who live outside the main centres (Durie, 1998). The geographical configuration of health services often necessitates referral and transfer to settings beyond where Māori usually live, including for example, for cardiovascular and cancer-related treatment, two leading causes of death for Māori (Ministry of Health, 2015a; 2015b). Inter-facility transfers can be related to both acute situations and elective admissions, for example where post-operative complications mean additional levels of care are required (Ministry of Health, 2016).

Engaging Māori and their whānau is critical as these whanau are likely to have differential exposure to healthdamaging environments, different experiences of healthcare, and a higher risk of inter-generational transfer of social inequities. Health service improvement, leading to better health and wellbeing, requires researchers who are involved and trusted in communities and are able to work in transdisciplinary environments. Our team has found that, by employing a reflexive approach we have already raised important questions requiring further exploration as we progress the study; questions regarding the changing nature of Māori self-identity, the constituent parts of a Māori whānau in a contemporary context, the meaning of "home" for Māori and consequently where and how Māori whānau prefer to receive care. We have approached the study with a willingness to question so-called "known truths" and with the key goal of improving the experience of hospital transfers for whānau in the future. To achieve such a significant outcome, our engagement in meaningful, mutually beneficial and transformative research with multiple stakeholders is essential. With those concluding thoughts in mind, we remain ever cognisant of the whakatauki (a proverbial saying used as daily guide):

He aha te mea nui o te ao? He tangata, he tangata, he tangata!

What is the most important thing in the world? It is people, people, people!

Glossary	
Aotearoa	New Zealand
hapū	subtribe
iwi	tribal group
kaupapa	purpose, philosophy, orientation
Kaupapa Māori	Māori philosophy
Kaupapa whānau	collective who come together for a common aim/purpose
mana	respect or authority
mana whenua	the authority of those from the land
marae	communal buildings and adjacent grounds
Māori	indigenous people of New Zealand
Pākehā	white people, people of predominantly European ancestry
Rangatiratanga	chieftainship, right to exercise authority, chiefly autonomy, chiefly authority, ownership, leadership of a social group
tāngata whenua	people of the land
te reo	the Māori language
Treaty of Waitangi	document signed recognising relationship between Māori and the British Crown in 1840
Tohunga	person with skills and/or specialist knowledge
waiariki	hot spring, thermal pool (suitable for bathing)
Waikato	collective name of the tribes living in the Waikato Basin. Also the name of the river from which they take their name.
whakatauki	proverb, significant saying, formulaic saying, cryptic saying, aphorism.
whānau	family and loved ones, including extended family

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