

# IMPACT ON WHĀNAU WELLBEING OF TRANSFER TO SECONDARY OR TERTIARY HOSPITALS AFTER A DISRUPTION TO THE BIRTHING JOURNEY

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#### Abstract

This article explores the impact on whānau wellbeing following wāhine being transferred to either secondary or tertiary care hospitals to receive health care for themselves or their baby during the birthing journey. It was found that throughout this process, the wāhine and whānau faced a series of challenges that compromised their wellbeing. Feeling isolated from their home, support networks and baby, and not fulfilling their motherhood expectations were major challenges. Three solutions are suggested that may encourage the delivery of culturally responsive care in this context: building environments that provide a sense of whanaungatanga with the people and space, allowing greater whānau participation in the cares of their baby and respecting the voices of whānau by engaging in meaningful conversations with them. Ensuring these changes are made may lessen the challenges encountered by wāhine and whānau, and support flourishing wellbeing.

#### **Keywords**

wellbeing, Kaupapa Māori, whānau, hospital transfers, maternal-infant continuum, health care systems

# Introduction

In Aotearoa New Zealand Māori women and their babies experience poor health outcomes during or following their birthing journey. The Perinatal Mortality and Morbidity Review Committee (PMMRC, 2016) reports that compared to non-Māori babies, Māori babies are twice as likely to have a potentially preventable perinatal death. Associated with perinatal death and harm is premature (preterm) birth. Preterm birth is an adverse disruption along the mother-baby continuum and is associated with death, brain

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haemorrhage, infection, chronic lung disease and long-term growth impairment and harm, such as cerebral palsy, and cognitive, visual and learning impairments (Chang et al., 2013). More Māori babies are born preterm (before 37 weeks' gestation) than non-Māori babies, and there is clear evidence that preterm infants do not do as well as their term peers (Craig et al., 2004; Craig et al., 2012; PMMRC, 2016). This article focuses on the babies who passed due to a medical event or were harmed by being born preterm, resulting in their need to receive intensive medical care at a Neonatal Intensive Care Unit (NICU) or a Special Care Baby Unit (SCBU).

Aotearoa has a unique maternity system: it is largely midwifery led, and most maternity services are free to all eligible women (Makowharemahihi et al., 2014). A lead maternity carer, most commonly an independent community-based midwife, provides primary maternity care throughout a woman's pregnancy, and then up until baby is around six weeks old. Secondary and tertiary maternity care is required if there is a disruption to the hapūtanga and the health of the pregnant woman or her baby is at risk. Secondary care is usually delivered by hospitals that have access to obstetricians and an SCBU. Tertiary care is the most specialised care, delivered by specialists with particular expertise. NICUs deliver tertiary care for babies. NICUs are based in the large urban centres of Aotearoa and are a part of the mainstream health care system that has been informed by and adheres to biomedical views. Such views are individualistic, monocultural (Eurocentric), and often maintained by inflexible policies (Wilson & Barton, 2012).

Given that the evidence suggests Māori wāhine encounter more disruptions and experience poorer health outcomes, wahine who live regionally and whose hapūtanga is disrupted are often put at a greater disadvantage, as some regional areas have limited outlying maternity care. These women are often required to be transferred out of their rural, primary health care providers to a secondary or tertiary level hospital. While receiving higher-level medical care is necessary, it comes at the cost of removing the woman or baby from their base of wellbeing: their home and network of whanau support (Elder, 2017; Masters-Awatere et al., 2017). Whānau who want to be there to support their ill loved ones are then faced with the challenge of travelling and staying in the area where the hospital is located. Even if whanau in these situations are able to receive transport and accommodation funding from support services, they may

not have access to a roadworthy, legal vehicle, or they may not be able to afford time off work (Rameka, 2006). This article explores the impact on whānau wellbeing of women being transferred to either secondary or tertiary hospitals to receive health care for themselves or their baby.

#### Method

### Framing the research

This article shares findings from the Kaupapa Māori-being by Māori, with Māori, for Māoridoctoral research of the first author. Kaupapa Māori research puts whānau at the centre and asks after their lived reality, privileging their knowledge, experiences and interpretations of their world. At the same time, researchers seek to understand the structural barriers to Māori living good lives "as Māori" (Ormond et al., 2006). Jones (2001, as cited in P. Reid & Robson, 2007), for example, describes three pathways to unequal health status that impact on Māori: differences in access to the resources of society (e.g., education), differences in access to health care and differences in the quality of health care received. The trauma of settler colonisation and land alienation is a fourth pathway for understanding "long lasting structural changes and psychosocial challenges" (J. Reid et al., 2017, p. 9) that contribute to contemporary Māori health and wellness.

Kaupapa Māori health research is about facilitating the sharing of Māori experiences to inform the elimination of structural barriers and thereby the culturally responsive transformation of the health system. Whakawhanaungatanga was utilised to build and strengthen respectful and trusting relationships with the wahine and their whānau throughout the research. The first author achieved this with the whanau participants by finding the connections in our whakapapa and by sharing the same goal of wanting to improve experiences for other women. These relationships were essential for the sharing of stories to be possible between whanau members and the first author as they established a relationship context between the would-be knower (the researcher) and what could be known (the knowledge held by the whānau) (Bishop, 1999; Macfarlane, 2013; Porsanger, 2004; Stevenson, 2018).

Ethical approval for this research was obtained from the Northern B Health and Disability Ethics Committee (16/NTB/29). Locality authorisations were also obtained from the District Health Boards that participated in the research.

#### Participants

Ten whānau who had experienced the harm or loss of their baby shared their stories through kōrero. Data collection spanned 14 months, and numerous whānau members were involved in each kōrero.

Eight of the 10 wāhine were transferred to secondary or tertiary care (see Table 1), ending up at a hospital between one and five hours' drive from their whānau home and staying there between two and six weeks. The babies of three wāhine were preterm, and two other wāhine had babies that were small for their gestational age. One baby had low oxygen levels at birth, and one baby died seven days after birth. This article shares the experiences of these eight wāhine and their whānau. Pseudonyms have been used to protect their anonymity.

### Interviews

Wāhine and their whānau were asked to tell their stories regarding their hapūtanga journey that resulted in the harm or loss of their baby. A rich description of the event was built up, with wāhine and their whānau identifying important points on their journey. These points were then explored in depth through follow-up questions and inquiry to understand their significance and the attributions whānau made about the direction (e.g., positive, negative) their journey took. Each whānau was interviewed once and followed up informally two times post-interview. Interviews ranged from one to three hours and were audio recorded following consent. The follow-up interviews were over the phone to check the wellbeing of that whānau following the interview. During these interviews, whānau were also sent their interview transcripts so they could have the opportunity to review what had been recorded.

#### Data analysis

Interpretative phenomenology analysis (IPA) was used to analyse whanau experiences. Although IPA is not grounded in Kaupapa Māori, it aligns well with two Kaupapa Māori principles: tino rangatiratanga and whānau. Other Indigenous researchers have used IPA (Jones et al., 2010), and it is based on the assumption that humans are not passive objects, but rather active agents in interpreting and understanding their world by making sense of their experiences (Smith et al., 2009). IPA allows researchers to find meaning in the experiences as shared by the participants (Brocki & Wearden, 2006). IPA encourages participants' involvement by the researcher sharing the themes and findings with them to confirm that the meanings derived are appropriate and accurate (Bond et al., 2016), a process known as memberchecking. This was carried out in the follow-up

Participant	Admitted to care	Distance away from community (hours by road)	Length of time away from community	Neonatal outcome
Kristen	NICU	4	5 weeks	Congenital anomalies
				Neonatal death
Becky	SCBU	2.5	2 weeks	Intrauterine hypoxia
				Low Apgar <sup>*</sup> scores at birth
Nadia	NICU	1	4 weeks	$SGA^{\dagger}$
Tahlia	SCBU	2	4 weeks	Post-birth seizures
Teina	SCBU $\times 2$	3	3 weeks	SGA twins
				Respiratory distress
Waiata	SCBU	2	3 weeks	Preterm
Ngahuia	NICU $\times 2$	5, 2	6 weeks	Preterm
	SCBU			
Ashton	SCBU	2	3 weeks	Preterm

• The Apgar score is a test given to newborns soon after birth to see if additional medical care or emergency care is needed. The test is usually carried out two times: once at 1 minute after birth and again at 5 minutes after birth.

<sup>†</sup> SGA = small for gestational age.

interviews when the whānau were given the opportunity to review and edit their transcripts. No whānau edited what they had shared in the initial interview.

Analysis began with the reading and re-reading of transcribed interviews. Connections and differences between the journeys were then sought. This process allowed for repetitive themes to emerge. Using the qualitative software NVivo as an aid, the first author coded and compared themes that emerged from these observations across participants' transcripts/accounts and sorted them into super- and subordinate themes. Analysis was deemed complete when no more themes emerged from the data and when all themes were checked for validity through member-checking.

# Results

Four themes emerged: E noho ana ki te tauwhenua, Ka mokemoke i te wāhine, Māmātanga and Hokinga ki te ūkaipō. Their presentation follows the experiences of the wāhine chronologically, covering from when they were transferred to the NICU or SCBU, then moving on to the challenges they faced in the hospital context before discussing their discharge. Subthemes are presented within the different stages of the transfer journey.

#### E noho ana ki te tauwhenua

This theme translates to "being in a foreign land". Wāhine and whānau felt that they were in a foreign place within NICU and SCBU environments because it was somewhere that they had very little connection to place in. This lack of connection extended beyond the walls of the hospital to also encompass the geographical area and tribal territory of the hospital. As a result, the wāhine and whānau often felt isolated and alienated.

#### **BEING TRANSFERRED**

Health practitioners made the decision to transfer the post-birth wāhine to a higher-level hospital. Even when wāhine were given a choice, it was difficult to make, and eventually the health of their unwell baby took precedence. This was explained by Becky:

I was so determined to have baby in [the local hospital] . . . but it didn't work out that way. My midwife said it wasn't good, baby wasn't in position and he was the wrong way so . . . she wanted to send me to [a secondary hospital] straight away but I was asking if there would be any chance not to go there because I had it in my head that it was going to be fine and he would turn at the last minute and everything will work out . . . I was just so determined to have baby at [the local hospital].

Transfer often represented the first step in shattering the birth plan of a wahine, as it clearly signalled complications with her hapūtanga. Becky had a plan to deliver her baby in her hometown and she was adamant about making that plan a reality. This strongly influenced her decision not to transfer. The decision to transfer was eventually made by Becky's midwife as an emergency developed, with her baby becoming increasingly distressed. While whānau may have been angry about being transferred, they were also aware that the lives of the wahine and her baby may have been at stake. This was particularly evident when transfers were urgent.

Teina felt frustrated because the decision to transfer her to a second hospital was made at the last minute. She blamed this late decision on poor planning and communication between maternity and neonatal teams:

Theme	Subtheme
E noho ana ki tauwhenua	Being transferred
	Concern and anxiety
	Health practitioner communication
Ka mokemoke i te wahine	Separation from whānau
	Separation from baby
Māmātanga	Dictated motherhood
	Rangatiratanga
Hokinga mai ki te ūkaipō	Postnatal support

TABLE 2 Overview of themes and subthemes

We were booked to deliver at [the local] hospital ... but then we had to go to [a second hospital] because the SCBU unit was full without being told ... What pissed us off that they didn't make the decision to transfer us to [the second hospital until] two hours before we were supposed to have had surgery.

Undoubtedly, health practitioners' decisions to transfer the wāhine were made with the best intentions, yet there could have been improvements in how the decisions were made and communicated to Teina and her whānau to reduce their concerns and anxiety.

### CONCERN AND ANXIETY

Common concerns and anxieties were expressed by the wāhine and whānau as a result of being removed from their base of wellness to be within a very foreign, clinical environment with their ill baby or babies. Nadia commented, "It was quite horrific but it just wasn't what I was expecting or preparing for . . . It's just so foreign up there, everything is so clinical."

Wāhine felt they were not kept fully informed about what was happening, even though it was about them, which deepened their distress. Although the health practitioners may have chosen to not inform the wāhine to help reduce their anxiety, their actions actually created more anxiety: "We were blissfully unaware ... but then I knew it wasn't good when they moved us in to our own room ... it was so scary" (Kristen).

#### HEALTH PRACTITIONER COMMUNICATION

Poor health practitioner communication was noted by whānau as being when practitioners spoke in, and expected comprehension of, medical jargon; being told what to do ("Every eight hours you have a different nurse telling you what they think you should be doing" [Nadia]); providing inconsistent messages; and withholding information. Poor communication caused frustration, which was further compounded when wāhine felt like they had to speak in a certain way to get information. As Teina stated, "I was lucky I had [my cousin] there cos she knows how to talk to [the health practitioners] properly whereas I'm like F this and F that, but she did it the proper way."

Receiving inconsistent information from different health practitioners added to the confusion wāhine felt about what the "right" thing to do was:

They'll say one thing and then just walk away. That just leaves me [*pauses and looks confused*]... because she wasn't giving me enough information of why baby ended up back in NICU when she was already on the path to go to the next hospital. Because we had her at one hospital, then she got transferred to the next and then transferred to the next. (Ngahuia)

Poor communication from health practitioners contributed towards making the NICU and SCBU environments feel foreign and enhanced the concerns of wāhine and their whānau. While this was unsettling for the wāhine, they also learnt how to adapt by learning medical jargon and ensuring whānau who were effective at communicating with the practitioners were present.

### Ka mokemoke i te wāhine

This theme speaks of the sadness and challenges the wāhine experienced during this time by being separated from their whānau and separated from their ill baby.

# SEPARATION FROM WHĀNAU

Separation from whānau was enforced through hospital geography and policy, with both having a significant negative impact on wellbeing. The policies and guidelines of NICUs and SCBUs were found to be gatekeepers of whānau support because they were applied as a means for health practitioners to maintain control. One particular hospital policy that was commonly cited was the restriction on partners staying overnight. This made some of the wāhine feel isolated:

Following her birth . . . [her husband] had to go home cos hubbies aren't allowed to stay—that was so hard, I was balling my eyes out saying don't leave me cos I just had this new little baby . . . So we're in this room, this little jail cell in the hospital, like you're not allowed to leave the room with your baby apart from going to the communal area during visiting hours, if you have visitors. (Nadia)

Nadia likened the NICU environment to being in a "jail cell". She felt that the environment was restrictive and controlling and found it difficult to cope.

Individual health practitioners were noted as being another level of gatekeepers of whānau support because they controlled who and when whānau could offer their support:

I think it's silly how . . . you're only allowed two visitors even in that common room, and when you're family is from up here and has travelled all the way down, it's dumb.... It was like they'd have turns coming in for 15 minutes and it was like, not get hōhā, but it was weird cos we couldn't all sit down together. (Tahlia)

At a vulnerable time, support from their whānau was all the wāhine wanted. These policies, and the health practitioners enforcing the policies, often left wāhine feeling frustrated with the NICU or SCBU system and environment because they were separated from their whānau support, the foundation of their wellbeing. While these policies are in place to protect the babies being cared for in the NICU or SCBU, perhaps this needed to be better explained to whānau.

The geographical location of the NICUs and SCBUs became a gatekeeper for whānau support: "That was one of the things that I struggled the most when I was down there-being so isolated from whānau" (Tahlia). The distance away from their home areas caused challenges for whanau to travel to be at the hospitals with their loved ones. Sadly, only a few wahine who were eligible for formal support services, such as petrol vouchers and accommodation, reported receiving this support. The support also often arrived late: "Yeah so the thing is, we didn't even get offered the motel support until the very end. It just seemed to happen that the social worker would come when I was out, which wasn't very often . . .!" (Teina's cousin). This poor delivery of support services needs addressing to better remedy the separation between whānau and wahine in these environments.

#### SEPARATION FROM BABY

Being separated from an ill baby heightened the anxiety of wāhine. Health care issues that cause wāhine's disconnection from whānau and their baby tend to stem from the biomedical approach of caring for the baby as an individual patient, rather than viewing the baby as part of a whānau unit, enforcing the need to treat the baby as a separate being. For Nadia, her distress was evident when she faced the unimagined situation of leaving her baby behind and having to go home:

We were under so much pressure, I mean driving home from the hospital every night with an empty car seat in the car and crying my eyes out, and then having to set my alarm to get up in the middle of the night to express whereas you should be getting up to a crying baby.

Nadia felt like a failure as a mother because travelling to and from the hospital without her

baby was beyond how she envisioned motherhood being.

Other wāhine remained in hospital with their baby because they required medical care as well. With this came the challenge of being separated from their other children at home:

It's kind of hard when you've got other kids and your whānau so far away. . . . With all the kids there, it meant that we couldn't stay in with baby for long and it was hard because these kids weren't allowed in there because they have a strict rule that kids under five ain't allowed in the NICU. We ended up dropping them off in the next few days back to my mum and them. (Ngahuia)

Ngahuia had to juggle the demands of her ill baby in NICU with the needs of her other young children. This added to the pressure she was under because the NICU location and environment isolated her from her whānau support.

The demands of baby receiving medicalised feeding, such as nasogastric (NG) feeding instead of breastfeeding, was another form of separation between mother and baby. This had occurred in Nadia's journey and she was frustrated at this. The frustration stemmed from there being little explanation of why her baby was put on NG feeding. Nadia felt that her sovereignty as a mother was challenged because her ability to feed, play and bond with her baby was interfered with by the sedation of NG feeding:

It makes sense from their [health practitioners'] point of view because they're trying to get them [babies] better and feeding them helps them do that, but at the same time . . . they don't explain very well. . . . It's like they're [the babies] sedated with food the whole time and if they cry [the practitioners] just chuck some more food down there. . . . It's very frustrating. (Nadia)

Another aspect of medical care that enforces separation between mother and baby is the immediate need to incubate the baby following birth. While this may be a necessary medical intervention for the baby, it interferes with the immediate mother-andbaby bonding opportunity through skin-to-skin. Kristen experienced this and struggled with this aspect of her journey:

They took him and they put him in the incubator ... and then they rolled the incubator over to me and I had to put my hand through to try to touch him, and it was so surreal. I felt like I was in an

alternative place because this is not how I do things ... I didn't get to have that initial bonding with my boy when he was born.

This experience was so far removed from how she knew being a mother was that everything felt "surreal" to Kristen. This experience saddened her and challenged her view of māmātanga.

### Māmātanga

This theme explores how expected notions of motherhood were challenged during the admission of the babies to the NICU or SCBU.

#### DICTATED MOTHERHOOD

Relinquishing their parental care to the health practitioners and clinical practices of the NICU and SCBU contrasted to the way the wāhine expected motherhood to be. Instead of fulfilling their expected motherhood role, they were tasked with adapting to "dictated motherhood" within the foreign NICU or SCBU environment. Dictated motherhood is a term used in this paper to capture how the wāhine described what being a mother meant in this clinical context. The wāhine said that when their baby was first admitted, the health practitioners told them what to do and when to do it, making them feel as if they had minimal control over the care of their baby.

So we got the night shift telling us what to do, then the day shift nurse and then the afternoon shift nurse, and we were just like "Oh my god, this is our baby!" And they were like, "You need to go home and have time out", and we were like, "If we had a newborn at home we would not get time out, we've got nowhere else we'd rather be than sitting here on this ward with our baby". It was so bizarre. (Nadia)

Some pāpā also had to relinquish their role as supporters and fathers to the health practitioners, and one acknowledged the difficulty of this: "I wasn't allowed staying [*sic*] on the night of the birth, I felt real bad cos I had to leave" (Nadia's husband).

It was commonly voiced by these wāhine that they wanted to have sovereignty over the care of their baby. They wanted to learn how to carry out some of the care that they observed the health practitioners carry out on their baby regularly. In some cases, the health practitioners helped teach the wāhine how to carry out particular cares, and this was positively reported on. In other cases, they were taught by fellow mothers who were also in the unit: It was so good having her because . . . we'll be up in the middle of the night breastfeeding and it's just having that support person because [her partner] wasn't allowed staying [*sic*] there, so she was cool and we'll just look out for each other . . . and learn from each other. (Ashton)

Being able to carry out some of their baby's or babies' care enabled the wāhine and whānau to feel that they had retained some rangatiratanga of their māmātanga, their baby's wellbeing, and thus their own wellbeing.

# RANGATIRATANGA

Co-construction of care was considered by wāhine as a way to overcome dictated motherhood and reclaim their rangatiratanga as mothers. Coconstruction of care involved wāhine and their whānau being provided with the opportunity to participate in the care of their baby. These whānau received more education and opportunities to be with their baby, which in turn built greater confidence. This usually occurred later in the hospital stay: "I felt good and confident that I could do most of his care, like I did most of his feeds and temperature checking and all that sort of thing" (Ashton).

The pāpā were also pleased to have the opportunities to bond and participate in the wellbeing of their baby when the health practitioners involved them in the co-construction of care. Teina shared how her partner was able to bond with their twins when the SCBU practitioners showed him how to provide the required care for his babies: "[My partner] got real close with them [the twins] because the nurses let him draw up all the babies' medications and their food and change and bath them and everything . . . which was cool." Reclaiming rangatiratanga within the clinical context was seen to be a facilitator to wāhine and whānau wellbeing.

#### Hokinga mai ki te ūkaipō

This theme means to return home. Returning home to their ūkaipō and whānau with their baby was the ultimate goal of the wāhine and their whānau. Some whānau said they were willing to change their ideas of parenthood to align with the medical model placed upon them if that meant they would be able to return home sooner:

But you don't want to call the nurse because if you do it looks like you're not doing your job so you won't be able to go home, ... It's like a bloody health lesson where you have to prove yourself as parents! ... I dunno it was like everyone gives in to bottle feeding just to get out in the end, and like for a hospital to be pushing bottles like that I was pretty mortified. (Nadia)

When their baby had recovered enough to be discharged from hospital, it was, for most whānau, a time of excitement and relief. Nadia and her husband did not feel like they were actually parents until they got discharged and returned home with their baby:

Yeah so that [being in NICU] was pretty stressful but once we got home it was sweet. (Nadia)

We just got into, aye, got into parenthood. (Nadia's husband)

Yeah and you actually get to finally become parents. (Nadia)

However, for some wāhine, the excitement of returning home to their ūkaipō was short-lived because they were subjected to unnecessary, avoidable stress and emotional trauma by being inappropriately discharged. These women were discharged without a discharge letter given and with no explanation for their transfer journey. Consequently, these wāhine were still uncertain about what had happened to them and their baby and were left feeling frustrated and stressed:

I don't know what it was that caused what went wrong, no one pinned it down in the end. (Becky)

No one understands what happened. (Teina)

I still don't know what happened to my baby . . . I'm still waiting for answers. (Tahlia)

Regardless, these parents were relieved their baby was discharged and were excited to start their home-based journey as parents.

#### POSTNATAL SUPPORT AT HOME

Whānau being there at home to offer postnatal support helped the wāhine with their transition to motherhood:

It's good having family, especially my partner, he's mean [i.e., great] support, and then my parents are good with the kids too. If something comes up they'll come here and my kids can go to them. ... It's the whānau support that basically gets you through whatever you're going through. (Ngahuia) Wāhine who had good access to health care support, such as postnatal midwives or doctors, were also better able to transition into motherhood in their home environment:

Yeah when we were allowed to go home, it was fine because we were really well supported and we had a midwife and a nurse come and visit us, so we had heaps of support. It was actually fine being home, once I got over it and confident. (Ashton)

Postnatal follow-up services that were responsive to whānau who lived regionally and away from the NICU unit were positively reported on:

Yep but they [NICU practitioners] come to me which is even better. . . . It's all changed now because we used to have to travel to either them in [the secondary hospital one hour away] or [the tertiary hospital three hours away]. And that was a mission just for a check-up appointment. But now [tertiary hospital practitioners] come to you . . . they're awesome. It's good that they're working around families and knowing that if we can't make it to them, they'll come down to us. (Ngahuia)

Meeting Ngahuia in her home to check up on her baby rather than requesting her to present at the NICU based five hours' drive away was a way these practitioners enabled a responsive health care service for Ngahuia. When she compared her previous experiences of going to check-up appointments and how much of a "mission" that had been for her, she was pleased with the changes with her current baby.

#### Discussion

Findings from the research described in this article demonstrate that when wahine were transferred to a secondary or tertiary hospital, their wellbeing was at times compromised. Throughout the entire journey from being transferred to being a mother within that clinical environment and to returning home, the wahine and their whanau faced a series of imbalances: of whanaungatanga (through being separated from their baby and whānau), in their rangatiratanga (through relinquishing their parenting sovereignty to health practitioners and policies) and in their mana (their power was not recognised in comparison to the health practitioners', who were acknowledged as the decision-makers and power-holders). The discussion will focus on broaching possible solutions, derived from the findings, that can rebalance these three points and, in turn, become facilitators for whānau wellbeing. The three solutions offered include creating supportive whānau environments, allowing greater whānau participation and respecting whānau mana by listening to them.

# Rebalancing whanaungatanga: Building supportive environments for whanau

Whanaungatanga is the flourishing of energies and comes about when we are comfortable with each other and within a space together. Whakawhanaungatanga nourishes and nurtures mauri (Stevenson, 2018). When whakawhanaungatanga is avoided, we tend to feel unconnected to the place and people within that place. This can create feelings of isolation and unfamiliarity. Engaging in whakawhanaungatanga includes "the doctor taking time to listen, communicating in understandable language, taking an interest in whanau health history, and engaging with the patient to deliver a collaborative style of healthcare" (Cram et al., 2003, p. 6). Often this did not occur because communication from health practitioners was rushed and impersonal.

Whakawhanaungatanga is just as important with space and place as it is people because places have a healing role. When whanau were transferred to intensive care units, they were required to relinguish their connectedness to their whenua and walk within foreign environments. When people are alienated from their environment, poor health outcomes may eventuate because their wairua becomes fractured within the foreign environment and knowledge systems (Durie, 2004). Wilson and Barton (2012) demonstrated that Maori perceived hospitals as the antithesis of a healing environment, with this exacerbating their desires to be discharged and return home even if they were still ill. The experiences expressed in this article align closely with this and suggest that the NICU/SCBU health care system has some way to go in terms of creating a welcoming space for whānau.

Strict visiting hours and regulations limited the amount of whānau being present in the NICU/ SCBU space, and the geographical distance of the hospitals from home whenua increased isolation felt by the wāhine and whānau. These factors hindered the ability to create meaningful relationships with people and the NICU/SCBU place. The wāhine and whānau expressed their desire to be with their whānau during this time, yet this could not happen due to visiting policies and restrictions. Although there are medical implications behind these policies, perhaps consideration could be made for relaxing visiting restrictions when circumstances allow. In research that examined the experiences of women following a severe maternal morbidity event, non-Māori partners were found to be allowed to stay overnight (Cram et al., 2019). This not only highlights the inequality that exists within the maternal-infant health care system, but also that policies can be relaxed when the gatekeepers allow. Other changes that may be recommended include improving access to support services and making spaces more accommodating for whānau to ensure a welcoming space that allows access to whānau and thus wellbeing.

# Rebalancing rangatiratanga: Allowing greater whānau participation

Given that healthy whānau are the functional unit of wellbeing (Elder, 2017), health care must be shaped and delivered in a way that allows whānau to provide healing and wellness to those admitted to a health service. Instead, biomedical systems and procedures continue to dominate health care service delivery (and design). These systems prefer an individualism and universal approach to health care (Wilson & Barton, 2012) that is often hardpressed to include whānau. The findings of this research show that this approach limited whānau participation, which wāhine experienced with regard to the care of their baby and which at times limited the ability of whānau to even be present.

In a systematic review of Māori experiences of health care, it was recommended that to improve experiences of health care for Māori, whānau-based care and involvement in the health care system should be included (Palmer et al., 2019). This supports what this article stresses, in that greater whānau presence and participation throughout the transfer journey is a facilitator of wellbeing.

An example of how this was achieved was through the co-construction of the care of the babies. Co-construction of care represents a familyintegrated approach to health care and allows for greater participation and confidence for parents within the NICU/SCBU environment. A large multicentre, cluster-randomised controlled trial across NICUs in Canada, Australia and New Zealand that tested the effectiveness of family-integrated care on infant and parent outcomes found positive outcomes for both parents and babies (O'Brien et al., 2018). Infants were seen to have improved weight gain, and parents were found to feel less stressed and anxious, and have greater rates of exclusive breastfeeding upon discharge from the NICU. These evidence-based positive outcomes should encourage the uptake of whanau-based or co-constructed care within NICUs because "how

care is provided to the family, not just the infant, has a positive effect on the wellbeing of both infant and family" (O'Brien et al., 2018, p. 252).

# Rebalancing mana: Hearing and respecting the voices of whanau

The mana of whanau must be recognised within the maternal-infant health care system (Palmer et al., 2019). It is a common notion that health care professionals are holders of knowledge and patients are incapable of providing credible knowledge and information (Kidd & Carel, 2017). This epistemological credibility imbalance is driven by, firstly, beliefs held by health practitioners that patients are emotionally compromised in their situations; therefore, their credibility is lessened because "they cannot think straight" (Kidd & Carel, 2017, p. 177). Secondly, health practitioners may believe that those they are caring for lack the same medical training and knowledge they have acquired and so they are unable to make meaningful contributions. Holding these beliefs engenders communication difficulties because the health practitioner enters the conversation holding a perceived position of higher power. Acting on that perception means that they do the talking and restrict those whom they are caring for from any viable participation in the conversation. While these two beliefs are not applicable to all health practitioners, they were supported at times by some of the experiences shared by the participants in this study. Wāhine often shared how their voice was disregarded and the health practitioners did things that went against their wishes. Health practitioners who spoke *with* the wahine instead of *at* the wahine had positive feedback from the wahine. This was because they felt valued and that they had a role in the decision-making of their baby's care; therefore their mana was being respected. Health practitioners who communicated well were better perceived to care about the wellbeing of their baby and entire whānau (Wright, 2019).

# Conclusion

This article has illustrated how being transferred from rural communities or hospitals to intensive care units such as NICUs and SCBUs impacted on the wellbeing of eight wāhine and whānau. It was found that the NICU and SCBU environments can be uninviting for wāhine and their whānau who have been transferred because there was a lack of whakawhanaungatanga with the space and with the people within that space. Palmer et al. (2019) showed there was a lack of alignment with tikanga, such as whakawhanaungatanga, and involvement of whanau in clinical services. They suggest that to improve Māori experiences with the health care system, there needs to be greater involvement of whānau and tikanga Māori. To improve whānau experiences in the health care system and their wellbeing, therefore, change is required. This article suggests three solutions that have been generated from the experiences of wahine and whanau and that align with tikanga to help the maternalinfant health care system better deliver culturally responsive care. These are building environments that provide a sense of whanaungatanga with the people and space, allowing greater whanau participation in the cares of their baby, and respecting the voices of whanau by speaking with rather than to them. These solutions may be a way of improving whanau wellbeing following transfer to secondary or tertiary hospitals.

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### Glossary

Aotearoa	New Zealand; lit. "land of the long white cloud"
e noho ana ki te tauwhenua	being in a foreign land
hapūtanga	pregnancy
hōhā	annoyed
hokinga ki te ūkaipō	returning home
ka mokemoke i te wāhine	sadness and challenges faced by the women
Kaupapa Māori	research by Māori, with Māori, for Māori; a term used to describe traditional Māori ways of doing, being and thinking, encapsulated in a Māori worldview
kōrero	talk, speech, story
māmātanga	motherhood
mana	authority, prestige, power
Māori	Indigenous people of Aotearoa
mauri	life essence

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pāpā	father(s)
rangatiratanga	sovereignty
tikanga	customs and practices
tino rangatiratanga	self-determination, leadership; the self- determination principle of Kaupapa Māori theory and methodology
ūkaipō	place of nurturing; to breast feed
wahine/wāhine	woman/women
wairua	spirit, spiritual wellbeing
whakapapa	genealogy, ancestry, familial relationships
whakawhanaungatanga	building relationships
whānau	family, birth, kinship; the extended family structure principle of Kaupapa Māori theory and methodology
whanaungatanga	the state of established relationships
whenua	land (living and non- living), placenta (afterbirth)

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