

“More than bloods and obs”

Whānau Māori discuss health and hospital care



By Rebekah Graham and Bridgette Masters-Awatere

Cover image by: Sharron Masters-Dreaver

Suggested citation: Graham, R., & Masters-Awatere, B. (2019). "More than bloods and obs": Whānau Māori discuss health and hospital care. Māori and Psychology Research Unit, University of Waikato: Hamilton, New Zealand.

ISBN: 978-0-473-49822-1 [PDF version]

ISBN: 978-0-473-49821-4 [Softcover book]

Version: 31 March 2020

Acknowledgments

First and foremost, we would like to thank the research participants, who opened up their homes and gave us time to discuss their experiences, aspirations and challenges to living well as a whānau.

Secondly, we would like to thank Dr Nina Scott and Associate Professor Polly Atatoa Carr, who invited us to join the Harti Hauora Tamariki tool trial project and allowed us the space to explore and engage in the qualitative component in ways that reflected and supported our community psychology values and principles. We would also like to thank Dr Amy Jones, Pera Paekau, Tina Baty and the wider Harti Hauora Tamariki team, who have endured our passion and enthusiasm to influence positive change for whānau. To Sharron Masters-Dreaver who has gifted us this image, and given permission to use it for this report. Lastly, we would like to thank Dr Joeliee Seed-Pihama (Te Kotahi Research Institute, University of Waikato) and Dr Jade Le Grice (School of Psychology, University of Auckland) who peer-reviewed the report for us.

Lastly, we acknowledge the support we received from the Māori and Psychology Research Unit, Division of Arts, Law, Psychology and Social Sciences, University of Waikato, Hamilton as well as Te Puna Oranga, Waikato District Health Board, Hamilton. This research would not have been completed without the funding support of The Health Research Council of New Zealand.

Ngā mihi

Rebekah and Bridgette



THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato



Table of Contents

Table of Figures.....	iv
Table of Contents.....	iii
Executive summary.....	v
Background context.....	1
The Harti Hauora Tamariki tool trial.....	3
Qualitative Research Approach	4
Introducing the Case Studies	6
Introducing the ‘Usual Care’ cases.....	8
Manaia (Greater Waikato).....	9
Mason (Hamilton City).....	14
Celia (Hamilton city)	15
Clare (Hamilton City)	20
Ngaio (Hamilton City)	23
Whetu (Greater Waikato).....	25
Taryn (Greater Waikato).....	29
London (Hamilton City).....	31
Introducing the ‘Harti Whānau’ cases	34
Jodie (Hamilton City)	35
Mere (Hamilton City)	40
Aroha (Hamilton City).....	43
Maegan* (Greater Waikato/Auckland)	48
Penny (Hamilton City).....	49
Astra (Greater Waikato)	52
Anahera (Hamilton City)	56
Kiri (Greater Waikato).....	63
Discussion	65
1: Barriers to health care	65
2: Facilitators to access.....	68
3. Everyday health	70
Recommendations.....	72
References	75
Research publications and dissemination	81

Table of Figures

Figure 1: Children playing outdoors.....	12
Figure 2: Appointment letters	16
Figure 3: Wall heater	17
Figure 4: medications kept in the fridge.....	22
Figure 5: Windows and condensation	26
Figure 6: Walking on a sunny day	27
Figure 7: Kawakawa leaves in the bath.....	28
Figure 8: Fan heater used for heating house.....	37
Figure 9: Living areas with blankets, windows open for airing house; bathroom with window that does not close; mould on new bunting in bedroom.....	38
Figure 10: Fruit and healthy routines	39
Figure 11: New bedding.....	42
Figure 12: Children engaged in physical activity.....	45
Figure 13: Purchasing and eating healthy snacks	46
Figure 14: Twins playing on the lawn.	59
Figure 15: Family outing to Hamilton Gardens.....	60
Figure 16: Babies in capsules at the Hamilton Lake.....	61
Figure 17: Cousins 10 year birthday party.....	62

Executive summary

The impact of colonisation on Māori, the Indigenous people of Aotearoa New Zealand, combined with negative interactions with health workers, has contributed to insufficient resources and reduced access to primary health care. The purpose of this report is to share narratives of whānau Māori who have experienced a child's hospital admission in order to highlight the common aspects (good and bad) of their stay at Waikato Hospital.

The overarching aim of the Harti Hauora Tamariki (HHT) tool trial, within which this report is located, is to demonstrate the measurable impact of a developed screening tool (referred to throughout as the Harti tool). The Harti tool is a comprehensive approach to assessing and addressing holistic health needs for hospitalised children and their whānau. Our recruitment strategy gave priority to those whose kōrero would capture the realities of those living in situations of few resources. This report presents findings from conversational interviews with whānau of tamariki Māori admitted to the paediatrics ward of Waikato Hospital. We have purposefully presented the interview findings as narratives to allow the reader to engage in their own interpretation of commonalities of experiences. Each case study follows the same format: an overview, their hospital experience, and their description of everyday health.

Across all the cases, similarities of experience emerge; financial stressors and strain; hunger and isolation; concern for their child(ren); and families that are actively engaged in caring for their children's health and well-being. The Harti tool, when administered by a culturally competent Harti Research Assistant (Harti RA), appears to work to counteract previous alienating experiences. Being treated with dignity, respect and value had a positive impact. Participants spoke at length regarding how wonderful it was to be able to engage with the Harti RA's as Māori and in a culturally appropriate way.

Recommendations:

1. A **dedicated Harti RA/health professional** who engages with all families of admitted children to the Paediatrics Wards at Waikato Hospital.
2. A **designated Harti administration person/team**. Having allocated administrative hours will help ensure that regular updates of available services for the Harti tool will occur, that these will be tailored to the Waikato DHB, and keep the Harti tool up-to-date.
3. All health professional staff at Waikato Hospital to consistently **provide high-quality experiences for Māori patients and whānau** in order to overcome past histories of prejudicial and inequitable conduct.
4. **Provide 3 meals a day for at least 1 caregiver** staying with a child who has been admitted to the Paediatrics Ward at Waikato Hospital

Background context

The impact of colonisation on Māori, the Indigenous people of Aotearoa New Zealand, and subsequent colonial-driven approaches to health has been significant and is well documented (Reinfeld & Pihama, 2007). Health inequities are exacerbated by the unjust distribution of social determinants of health (Chin et al., 2018) and by experiences of racism (Harris et al., 2012). This legacy of colonisation in public health policy (Cram, Smith, & Johnstone, 2003), combined with past negative interactions with health workers (Pitama, Ahuriri-Driscoll, Huria, Lacey, & Robertson, 2011), results in whānau receiving sub-optimal care at a primary health level. Inequitable Māori health outcomes are consistent with broader Indigenous experiences of colonization that include theft of land, degradation of language, racist policies, discrimination, and social exclusion (Reid & Robson, 2007). Practices associated with colonisation reduce access to social determinants of health (Blakely, Ajwani, Robson, & et al., 2004), resulting in higher rates of adverse events in hospitals (Davis, Lay-Yee, Dayall, & et al., 2006), and increased likelihood of inappropriate care and follow-up (Jansen & Smith, 2006). Additionally, insufficient access to adequate resources (Hodgetts & Stolte, 2017), deepens reduced access to primary health care. Subsequently, Māori patients and whānau find themselves having to engage with tertiary health services in order to receive healthcare in a timely manner.

Health service design and delivery in Aotearoa privilege individualistic, clinical discourses and acute need (Gifford, Cvitanovic, Boulton, & Batten, 2017). This form of health service provision disadvantages Māori. Subsequently, Māori have been, and continue to be, dispossessed in their own lands (Waitangi Tribunal, 2001). Māori patients typically receive inequitable access to interventions and quality of care (Westbrooke, Baxter, & Hogan, 2001) and consistently report negative hospital experiences (McKinny, 2006). Correspondingly, Māori families accessing hospital care for a child have encountered systemic barriers (Bolitho & Huntington, 2006). Māori patients and their whānau consistently experience barriers between themselves and the health treatment they require (and are legally entitled to).

Collectively, experiences of coldness, micro-aggressions, discriminatory behaviour, and shaming communicate a sense of 'not-belonging', and are a continuation of ongoing exclusion (Blakely et al., 2004). These experiences result in Māori patients and whānau disengaging and/or actively avoiding health-related interactions as much as possible. This disengagement is a sensible tactic that works to sustain and maintain one's sense of self when under attack (Stolte & Hodgetts, 2015). Dominant group members draw on negative stereotypes of Māori and misinterpret these survival tactics as failure to take responsibility for individual health (Penney, Barnes, & McCreanor, 2011). This form of structural violence (Hodgetts, Chamberlain, Groot, & Tankel, 2014) is a tactic of hegemony and is perpetuated by dominant groups (Gramsci, 1971). Blaming marginalised groups for their responses to oppression simultaneously works to blame those who are the target of negative behaviours while absolving those in power of their own responsibility for change (Sue, 2014). Together, these tactics form a powerful act of silencing within which disengagement becomes an act of resistance to dominant health hegemonies.

Healthcare encompasses much more than doctor's visits, medications, and treatment plans. Nevertheless, the personal and culturally relevant ways in which Māori patients and whānau manage their health (e.g. rongoā, listening to their body, being with whānau) are routinely disregarded or misinterpreted by healthcare professionals. Negative experiences result in participants feeling unable to

talk freely with health workers, particularly concerning tikanga Māori based approaches to well-being. These do not exist in a vacuum, but are highly congruent with historical and collective memories of past events of racialized and patronising treatment (Halbwachs, 1950/1980). Contributing to this overlapping of present and past events is the bodily memory embodied in responses to smells and sounds (Seremetakis, 1994). The visceral response to the physical environment of the hospital setting, for example, evokes memories of past hospital visits and folds time across generations. In this manner, the public healthcare system in Aotearoa New Zealand unwittingly continues to perpetuate historical trauma against Māori (Pihama et al., 2014).

The Ministry of Health provides multiple health promotion resources and programmes for Aotearoa New Zealanders¹. A recent evaluation of the Healthy Families NZ initiative documented the challenges of collaborative approaches in a competitive funding model, an over-emphasis on measurable outputs, legislation that prioritises food and alcohol industry positions, insufficient mental health support, and socio-economic inequality as key barriers to improving community health (Matheson et al., 2018). This evaluation represents a shift from the dominant paradigm of individual behavioural change embedded into many health promotion campaigns (e.g. GRx, Project Energize, PHO enrolment), and the deficit-oriented clinical model of healthcare care (e.g. BMI-focussed Healthy Eating and Exercise pamphlets). This approach has resulted in a proliferation of physical and health 'education campaigns'. However, while knowledge has been disseminated, researchers note that this does not necessarily result in improved health and well-being; rather there is an acceptance of food as a guilty pleasure, on over-monitoring of the body, and the removal of the enjoyment associated with physical activity (Burrows, Wright, & Jungersen-Smith, 2002). Additionally, the deficit model has resulted in negative attitudes and incorrect assumptions regarding understandings of health by Māori and the various ways in which Māori patients engage in health-related activities (Kerr, Penney, Moewaka Barnes, & McCreanor, 2010; Penney et al., 2011). These assumptions by clinicians and health-promotion workers become a barrier to high quality interactions with Māori patients and their whānau.

For many Māori the existing public health system is experienced as hostile and alienating (Masters-Awatere & Graham, 2019). While some individual health practitioners do their best to interact in supportive ways, such instances are experienced as conspicuously noticeable, rather than the norm. The responses of Māori patients and their whānau in a modern-day context must be considered within the wider context of the collective memory of multiple decades of second-rate treatment, active discrimination, and patronising interactions. Greater efforts need to be taken to ensure that tikanga Māori practices are supported within mainstream healthcare systems. Furthermore, healthcare environments and staff must recognise the many ways in which Māori care for their health, and understand the influence of historical and inter-generational trauma in the here and now. Finding ways to reduce alienating experiences, eliminate barriers to healthcare, and support whānau is an important way forward in reducing health inequities in the public health system. One such way is grounding services and staff within Kaupapa Māori practice. Doing so has the potential to directly impact patient and whānau experiences of health care.

¹ See the Ministry of Health website for more: <https://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/surveys/new-zealand-health-survey/improving-health-new-zealanders>

The Harti Hauora Tamariki tool trial within which this report is located is one such example with the potential to address health inequities using current services. Given the negative experiences that have been well documented, we have engaged this report with the express purpose of prioritising whānau Māori voices about their experiences. This report can be read both independently of the quantitative research conducted within the randomised control trial (RCT), and in conjunction with that study. This report provides a voice for the lived experiences of whānau Māori who experienced an admission to Waikato Hospital paediatrics in 2018.

The Harti Hauora Tamariki tool trial

This section briefly describes the wider Health Research Council of New Zealand funded project within which this report is located: *“Does a Whānau Ora approach improve outcomes for hospitalised tamariki?”* (HRC# 17-054), Primary Investigator Dr Nina Scott, Associate Investigators Associate Professor Polly Atatoa Carr and Dr Bridgette Masters-Awatere. Ethical approval for the research was granted by Aotearoa New Zealand’s Central Health and Disability Ethics Committee, reference number 18/CEN/88.

The Harti Hauora Tamariki (HHT) tool trial is a mixed-methods randomised control trial (RCT)². Both quantitative and qualitative evidence is being gathered regarding the effectiveness of a developed screening tool (hereafter referred to as the “Harti tool”). The Harti tool is a whānau ora assessment instrument within inpatient care and takes a comprehensive approach to assessing and addressing holistic health needs for hospitalised children and their whānau. Using the Harti tool within the hospital setting is intended to improve access to health and social services for children admitted to hospital (and their families). The quantitative component of the trial involves recruiting 1100 tamariki Māori aged 0-4years who have been admitted to Waikato Hospital under a paediatric medical team. The intervention will be randomly assigned to half of these children and their families. The control group receive usual care only, and are referred to in this report as ‘Usual Care’. Usual Care is the de facto clinical care provided as a matter of course within the paediatrics ward at Waikato Hospital. It describes the full spectrum of patient care practices in which hospital clinicians have the opportunity (which is not necessarily seized) to individualize care. The other half of the 1100 tamariki Māori who are involved in the trial will experience the Harti tool as administered by the Research Assistant (Harti RA). We use the term ‘Harti Whānau’ to refer to whānau who experienced the Harti tool screening assessment and follow up support as administered by the Harti RA.

The overarching aim of the HHT tool trial is to demonstrate a measurable impact of the developed screening tool (Harti tool). The immediate aims are:

- provide quantitative and qualitative evidence of the effectiveness the Harti tool within inpatient care
- determine the level of unmet need (as identified by the Harti tool)
- assess the impact of the Harti tool on meeting needs and achieving improved health outcomes for tamariki Māori and their whānau.

² The wider study is included in the Australian New Zealand Clinical Trials Registry, trial registration number: ACTRN12618001079235

Additionally, through use of the Harti tool the research team aims to change the way those who deliver health services see their role, and that, by actualising their power as change agents to address health inequities, providers and staff will take an active responsibility for improving Māori health.

The New Zealand Public Health and Disability Act 2000 specifically notes in Section 3 the obligation of the New Zealand government to;

achieve for New Zealanders the improvement, promotion, and protection of their health...the best care or support for those in need of services...to reduce health disparities by improving the health outcomes of Maori and other population groups... [and] to facilitate access to, and the dissemination of information to deliver, appropriate, effective, and timely health services, public health services and programmes. ("New Zealand health and disability act," 2000)

The illnesses that resulted in hospital admissions for this study were preventable. While poverty contributed to illness, the health system has a responsibility to mitigate illness through medication and medical care. For this study, the right treatment is intended to reduce the likelihood of a readmission.

Qualitative Research Approach

For the qualitative component of the HHT tool trial (which this report describes), we aimed to document the experiences of whānau of tamariki Māori admitted to Waikato Hospital. Our particular focus here was on engagement between whānau and hospital staff. Through this action we intended to examine how whānau health needs, both direct and indirect, were assessed and/or addressed. Through the formation of a research relationship with whānau, we hoped to explore what health-related practices whānau were undertaking in their everyday living. The importance of placing people within their historical, social and geographic context is an essential element of our work as community psychologists (Teo, 2016). With a strong preference for collectivist interdependency over individualism (Robertson & Masters-Awatere, 2007), this work is a collaboration of Māori and Pākehā researchers who draw attention to issues of social and cultural justice. As noted earlier, this report can be read both independently and in conjunction with the quantitative research conducted alongside as part of the HHT tool trial.

The overarching approach taken in this technical report is that of Pūrākau (Lee, 2009). Pūrākau as a research method shapes the way in which we share the everyday health and engagement of whānau and their experiences of Waikato Hospital. In this context, Pūrākau was sought as a decolonising tool to give primacy to Māori stories told as an act of resistance, and for the sharing of those stories to be acts of resurgence (Seed-Pihama, 2017; Simmonds & Gabel., 2016). Pūrākau enables connection to Māori cosmologies as important cultural concepts, particularly in regards to the colonial impact upon Maori health (Ware, Forster, & Breheny, 2018). Biomedical and reductionist models that focus on presenting symptoms dominate health research approaches. Subsequently, many medical studies subsume the experiences of marginalised groups into dominant individualistic, colonial narratives.

The second interview with whānau gave opportunity for whānau to utilise visual research techniques in the form of a photo-elicitation interview (Reavey, 2011). This assisted in revealing how broader health narratives and relationships are interconnected and embedded within the everyday life of whānau (Hodgetts, Hayward, & Stolte, 2015). Utilising visual methods also works to create a more enjoyable and equitable research paradigm, locates the researcher more fully into the life-worlds of participants, and situates participants as co-creators of knowledge (Richard & Lahman, 2014). Interview aids such as photographs are useful in triggering participant thoughts, memories, reactions, and explanations (Hodgetts et al., 2011). Spending time with participants as they discuss these aids uncovers the more personal and meaningful aspects of both food-related (Graham, Hodgetts, Stolte, & Chamberlain, 2018a) and health practices (Nikora, Hodgetts, Carlson, & Rua, 2011). These interview processes have produced a unique, novel and rich data set regarding whānau health practices and aspirations.

Pūrākau and associated images from whānau are presented in this report as cases. Each of these cases can teach us about the strengths and resilience of whānau as well as allow us to learn about the problems that need to be addressed. As cases, the descriptions allow for generalised observations (Small, 2009) to people in similar situations and circumstances (Radley & Chamberlain, 2012; Ruddin, 2006). Case studies allow for understanding of experience in contemporary phenomenon within the real life context (Flyvbjerg, 2006). That is exactly what we hope to achieve through presenting the everyday realities of these 15 whānau who had to adjust their lives when their young child was admitted (or re-admitted) to Waikato Hospital in 2018. Interviews were undertaken with whānau (n=15) of tamariki Māori admitted to the Waikato Hospital Paediatrics Ward (WaiKids) during July – November, 2018.

We deliberately selected inclusion criteria that prioritised the perspectives of Māori who are both high end-users of hospital paediatric services, and whose perspectives are commonly overlooked, subsumed, or otherwise ignored. Our inclusion criteria were:

- 1) The child is Māori and aged 0-4years at time of admission
- 2) The child was admitted with a disease of poverty, and/or
- 3) The parent answered yes to one or more NZiDep questions, and/or
- 4) Whānau of the child lived in a highly-deprived neighbourhood (Quintile 4 or 5).

We purposefully selected whānau located within Hamilton City and whānau located within the Greater Waikato area, in order to capture both rural and urban experiences. Participants were recruited into the wider HHT tool trial by the Harti RA on the Paediatrics Ward at Waikato Hospital. From here, participants who consented were randomised into either the Usual Care or the Harti Whānau group. For interviews, the Harti RA identified potential participants from the admitted tamariki and their whānau who met our inclusion criteria, and who had consented to further contact. From here, the first author (Rebekah) made telephone contact with the listed caregiver and arranged a mutually agreeable time and place to meet.

Participants predominantly chose to meet with the first author in the domestic space of their home. At this initial face-to-face meeting, Rebekah explained again the qualitative component, and, if consent was given, proceeded with the first interview. At the close of the first interview, arrangements were made for the second (photo-elicitation) interview. At each interview, Rebekah brought a koha of food and provided a NZ\$100 supermarket voucher in recognition of both the participant's time and their knowledge as subject matter experts. Interview questions were embedded into conversation so that the interview progressed in a way that felt comfortable, non-intrusive, and enjoyable.

After every interview extensive field notes, including reflexive notes, descriptions of interactions, observations and remembered conversations, were taken. This information was utilised along with quotes generated during the research process. Each participant gave insights into healthcare, access, poverty and marginalisation that is of significance beyond their individual lifeworlds. Analytically, we drew on Pūrakau interpretative practices (Lee, 2009). This involved considering the wider cultural context within which participant experiences occurred, as well as ‘looking at and behind’ words used in the construction of health narratives (Hodgetts et al. 2014). It also involved being aware of our positionality as researchers and the way in which this influences narratives told during research interviews (Radley and Billig 1996).

We have utilised pseudonyms for all participants throughout. We deliberately did not collect detailed age or ethnicity data (such as iwi affiliations) for participating whānau as a way of protecting their anonymity as much as possible. The age and demographic data presented regarding the admitted child and their whānau is sufficiently detailed, and we wished to avoid further potentially identifying participating whānau. The quantitative component of the HHT tool trial will incorporate a more thorough demographic analysis, as the number involved makes identifying individual whānau less likely.

Introducing the Case Studies

The enclosed whānau stories summarise the nature of whānau experiences as they recall staff interactions during the hospitalisation of their tamaiti (child) 1-2 months prior to being interviewed. We have chosen to present our interviews here as cases in order to provide a wider context of the complexities of people’s lives. We are aware that there is often a disconnect between groups; middle income New Zealanders can struggle to comprehend the challenges faced by impoverished groups, who face conflicting demands and additional pressures (Hodgetts & Stolte, 2017). We are also aware of dominant health narratives regarding low-income Māori. Subsequently we have intentionally presented our conversations in a way that highlights the experiences and perspectives of whānau, with minimal interpretation. Where appropriate, we have summarised our interactions and offer explanations of provided quotes. Overall, our intention is to highlight the realities as experienced and perceived by our participants.

The cases are presented in two groups. First, the experiences of whānau who received usual care, and then whānau who experienced the delivery of the Harti screening tool (Harti Whānau). While the two are inter-related, we have chosen to present the cases in this manner to provide for comparison between the groups, particularly with regards to Harti Whānau. Each case study begins with an overview of the whānau and their current living situation in order to provide the reader with a sense of their wider context. We then present interview conversations regarding hospital experience that highlight key issues of the hospital admission for families with limited resources. Within the cases we can observe the creative ways whānau stretched limited budgets to keep their children well through descriptions of their everyday health.

Throughout the cases, participants refer to the following health services:

Whare Ora. The Whare Ora Programme is a free Waikato District Health Board initiative that supports whānau to create healthier homes that are warmer, drier, and safe. Eligible whānau can be referred by contacting the Whare Ora team. Once referred, whānau are contacted for a Healthy Homes assessment. The assessment is sent to the Whare Ora hub who review it and create an action plan to be confirmed. The Whare Ora hub coordinates products and services that the whānau are eligible for. See <https://www.waikatodhb.health.nz/your-health/wellbeing-in-the-waikato/whare-ora/>

Tamariki Ora. All tamariki living in Aotearoa New Zealand are eligible for Tamariki Ora. This service is specifically designed for Māori, and includes a universal health and development assessment, whānau care and support, and health education. These services are offered to all Aotearoa New Zealand tamariki and their whānau from the date of accepted enrolment to four years of age. See <https://www.tpo.org.nz/well-child-tamariki-ora>

Quit Smoking. This is a support programme designed to assist whānau to quit smoking in a supportive environment by offering practical and social support. See <http://www.onceandforall.co.nz/>

Participants also refer to **CYFS** and **WINZ**. These are each named departments of Aotearoa New Zealand's Ministry of Social Development, and are responsible for the provision of welfare benefits and for child welfare. **CYFS** refers to Child, Youth, and Family Services. It has been re-branded as Oranga Tamariki, but is still referred to as CYFS colloquially. They are the department responsible for uplifting children from their families, and have a long history of targeting low-income Māori whānau³. **WINZ** refers to Work and Income New Zealand. It has since been re-branded as Work and Income, and, again, is still referred to as WINZ during everyday conversations. This is the department responsible for administering welfare benefits and providing additional support to low-income New Zealand households. They also have a history of punitive action against low-income whānau; academics such as Hodgetts et al., (2014) refer to this practice as structural violence

³ See, for example, this recent news report: <https://www.newsroom.co.nz/2019/06/14/635071/the-tip-of-the-iceberg>

Introducing the ‘Usual Care’ cases

Each Usual Care case is briefly summarised here with key identifiers to guide the reader prior to reading the cases in full.

Manaia is a young mother of four children under the age of 7. From an impoverished background, Manaia is currently on home detention, and is struggling with both being unable to leave her sister’s house (where she lives) and in providing her children with the parenting she herself never received. Manaia viewed the hospital system as something to be endured in order to access the healthcare her sick child needed.

Mason is a solo father of a 9 month old child. He is recently clean and sober, shares a home with his cousin and her children, and enjoys being able to provide care for his daughter. He felt well taken care of during his daughter’s hospital stay.

Celia spoke of her previous daughter, who had died in hospital some 4 years prior. Celia felt that more could have been done at the time to keep her daughter alive. This time round, Celia is thankful that hospital staff and specialists were taking her concerns for her son seriously and including her in his care plans.

Clare and her two young children recently moved to Hamilton to be closer to family supports. Clare is currently studying and hopes to find permanent work to support herself and her children. Her youngest has ongoing health challenges, and Clare does her best to ensure the family is as healthy as possible.

Ngaio runs a large and busy household. Her and her family recently moved to Hamilton to be closer to the hospital services. She is currently in the process of whāngai for a soon-to-be-born baby of a family member who is unwell.

Whetu is mother to one highly active toddler, and is well involved with her local kōhanga. Situated at her local marae in the Waikato township where she lives, the kōhanga is a source of practical and emotional support for Whetu. While in hospital with her child, Whetu struggled with being so far away from her family and friends.

Taryn is a new mother to a 4 month old baby. Her and her partner have plenty of family support, and are looking forward to being able to live in their own place on family land. Taryn spoke highly of the clinical care her daughter received, but had concerns regarding the discriminatory treatment of her own health-related decisions.

London has 3 young children under the age of 6. Her eldest child was a whāngai to family in another town, and London retains close links with this family. London lives close to the hospital, and does her best to ensure all her children are well fed with plenty of fresh air.

Manaia (Greater Waikato)

Overview

Manaia is a young Māori mother in her early twenties with four children, aged 8 years to 18 months. She lives near a local marae on the outskirts of township in the Greater Waikato region. The house she lives in belongs to her brother and sister-in-law, and, together with sibling(s), this whānau of 8-10 people make do in a small two-bedroom house with additional sleep-out. Manaia is currently on home detention, and cannot easily leave the property where she lives. She had permission to stay at Waikato Hospital with her youngest, but was not able to leave the Hospital grounds in any way, not even to access the café or dairy across the road.

Two months feels like forever when you've got four kids and you can't go nowhere, you can't take them to the park.

Manaia's finances are very tight. She would dearly love to live in her own place, but she simply cannot afford the living costs. This places additional pressure on her familial relationships, which at times spills over into angry words and frustrated interactions. Complicating these interactions is that, from the age of 9, she was bounced around from foster parent to foster parent, eroding her own capacity and resilience in relationships. Subsequently, she has had to work hard to prevent the State⁴ from uplifting her own children, and has since completed the required parenting, relationship, and drug and alcohol courses.

Hospital experience

Coming from out of town, and with little disposable income, Manaia spent much of her hospital stay hungry, tired, and distressed. She had come to the hospital straight from the GP at her home town, and had no change of clothes for either herself or her young child, no personal toiletries, and no money or means to purchase additional items. She had left her other children with family members, and was confident that they were being well taken care of. However, family were unable to come visit or bring additional items due to the cost of travel and that absence of provisions at the hospital for additional family members.

This time around I went to the hospital straight from the doctors. I didn't get called in from home, I just went to the doctors and they checked her over there and from there it was like, nah you need to go to the hospital. So I went straight to the hospital, had nothing there and didn't really know what the hell was going on, but just sat there and just let the nurses do what they had to do because I was by myself.

Manaia's menstrual cycle began during her time on the ward, and she had no money to purchase menstrual products she needed, and no family/friends nearby who could bring these items to her. Fortunately, the Harti RA noticed and providing support, despite her being in the Usual Care group. The Harti RA also ensured that she received her travel and food support, located spared toiletries, and looked after her baby while Manaia had a shower and looked after her personal care needs. This alone made a

⁴ In New Zealand, the state department responsible for uplifting children is Oranga Tamariki, previously Child Youth and Family Services (CYFS). CYFS remains the commonly used term; where participants refer to CYFS they are referring to New Zealand state child welfare services

significant difference to Manaia, who deeply appreciated someone taking the time and making the effort to look after her:

when Nan [Harti RA] turned up and she was like, “have you had a shower”? I was like, “nope”. She was like, “I’ll go and get you some shampoo and conditioner”. So she went down to the office and got some little shampoos and body washes and stuff and bring them up. She was like, “this is all I can find.” “Oh primo, thank you!”

Receiving such care is especially poignant when you consider Manaia’s history and the absence of a parent figure to do such mundane, caring practice on a regular basis. Manaia was also well aware of the perceptions of others, and sensitive to her status as a young Māori mother with few financial resources:

We do need to be looked after, us Mamas and us parents that are here, we all need to be looked after. You know what the white system is like, they see the Māoris and they’re like aggh ... And they’re Māori, jeez hurry up, get them on their way. Hurry up, pump them up with whatever we can and get them on their way.

The hunger and absence of food – and inability to get more –was particularly difficult:

Oh my god, and all you get is toast. What the fuck is toast going to do for you? Like straight up – two pieces of fucken toast is all you get to eat during the whole day when you are watching a baby. No fruit, nothing!

You don’t get nothing, you just get a dinner and that is pretty much all the left overs of what the patients have, and you get the left overs. It is fucken rat shit ... We are kind of like patients too because we’ve got to sit there and look after the fucking kids

Again, Manaia deeply appreciated someone taking the time to ensure she had something to eat, and being able to engage with her in a culturally appropriate manner:

How she asked me about the kai – she [Harti RA] was like, have you got kai? I was like, yeah I’ve got some kai! Where, I don’t see your kai? Where is your kai? I was like you bitch! It’s alright Whaea, I’ll get some kai soon. She was like no, I’ll go and get you some bread and soups and stuff. I was like, nah it’s all good Nan. Sure enough she went down. She was like, when I go down and get my mokos I’ll drop you off home and I’ll stop in here before I go home. I was like in my head thinking, whatever Nan, you are just going to go home and probably forget about it on the way home man, Jesus. Yeah nah, she turns back up with bread and stuff. Wow – it is all good.

Manaia deeply missed her children and found being separated difficult. However, as she had been in the hospital 5 years ago with her eldest, she was aware that the hospital didn’t cater for additional whānau members or children. Her main concern was keeping her other children healthy, and she was reluctant to expose them to the “germs and bugs” of the hospital environment. Manaia was also aware of the cost of travelling back and forth and that they could not afford the petrol nor purchase additional meals. Subsequently, her family stayed in their hometown for the duration of the child’s hospital stay.

With regards to clinical care, sometimes Manaia wasn’t sure what medical staff were saying. However, by asking questions she was able to learn how to manage her child’s condition:

knowing and asking them questions this round it kind of gave me what I need to know, like why do I need to give them 6 pumps and they can breathe in 6 pumps. Why do they need this and why do they need that? How can I stop this from happening again? They were pretty helpful with that ... they were really helpful and the staff explaining it and information and stuff, if you ask them. If you ask them for it and ask them the questions then they will give it to you ... Sometimes they are in a rush that they totally forget and they just move past that patient and that is when you are standing there like – but what did that mean? What is happening with my baby again? Shit! There were a couple of times when I'd done that and I pulled in my nurse and I was like, so what is happening with her? And then she would explain and I was like – thank you, that is all I needed to know. Didn't understand those flash words. There were some pretty big words they said, which I did not know. Damn, I don't even know half of my big words!

The next interview revealed that Manaia was well aware of her children's medical needs, their medications, and how to utilise both prescribed and home-based remedies to care for their eczema and asthma.

Everyday health

Manaia does her best to ensure that her children get plenty of outdoor play and fresh foods.

They were inside and it was an ugly as day, so I just waited for the sun to come out and once it came out I was like, go and play outside. So they went outside so I thought I would get a photo to take. They are outside having some oxygen in their lives instead of sitting inside dwelling on mugginess ... that is our play set out the back. We have got tramp, swings and a slide and a pool. So the kids are pretty sussed.

However, she is currently constrained by her home detention and unable to take her children to the park or on other adventures, which she finds frustrating and difficult. She is looking forward to having her ankle monitor removed and being able to spend time at the beach:

I've been stuck inside for fucking two months, just about three. So when I get off my bracelet I'll be able to be free because the first place I'm going to is the beach! I need to go and release some stress and go and get me some pauas and just put my wairua into the bloody tāngangao... there is nothing like going to water, especially when you have not seen it run over your face, go for a dive for like ages. I am missing my diving. I feel like Pākehā being on a fucking bracelet – shit. I've got to go to the Countdown to get my oysters, what is up with that?

As well as the detrimental impact on her spiritual health, Manaia was concerned about her physical well-being. She shared with me her concerns about a health issue of hers, her reluctance to seek medical advice, and her fear that there was “something wrong”. In response to these feelings, Manaia endured the pain and inconvenience associated with her issue, rather than endure the shame and potential for humiliation associated with seeking medical advice.



Figure 1: Children playing outdoors

As well as physical access, the other barrier Manaia faced to purchasing food is the financial cost. On the day I visited for our second interview, she had just been to the welfare office⁵ for a food grant:

I've had a bit of a hard week, I've been struggling this week with putea. So I got me a food grant from WINZ

Despite her constrained circumstances, Manaia does her best to ensure her children have vegetables that they like to eat. She described in detail their various food preferences and the way she encourages healthy eating:

My big boy likes his mashed potatoes with silver beet, so that is how he has his bit of veggies. Giovanni, he just likes his roasted, and I'm like no – you can just eat whatever is on your plate. Deveraux, he will eat anything, he is pretty good. He eats anything and so does Payton ... Those mangoes you brung last time, they are lollies. Everything that is fruit that are dried we call them lollies ... My kids eat more veggies and stuff

⁵ In New Zealand, the state welfare office is named Work and Income. A previous iteration was Work and Income New Zealand, or WINZ. Participants commonly refer to this office as WINZ.

than what I do. I just choose and pick when I feel like it, even though I should be eating them continuously.

Manaia found it especially stressful when, after spending her meagre funds on food, the children didn't like to eat it:

It is so fucking dear to get the healthy food. That is why I just choose to go for food that is simple – it is like, yip, that is cheap as. You go and look at a salad, you are paying \$6 for a bag – it is like I could get three bread for that and a milk, my goodness. What the hell? Where is the seeds, I'll just grow it in my garden! That is my big thing around healthy, like healthy food is the price. It is so dear trying to get healthy and when you've got four kids ... You go and buy those things, you go and give it to them and they don't eat it. I get angry because I am like, there are kids out there that have nothing – just eat your food, you are going to get strong, I don't want you losing out on this or that, just eat it!

Nevertheless, Manaia does her best to provide for her children and to manage the best she can with what she has.

Mason (Hamilton City)

Overview

Mason is a Māori male in his forties with a young daughter under 1 year of age. He lives with his cousin and her two young children (both under 5 years of age). Their arrangement seems to work well with regards to reducing living costs and providing suitable housing for everyone. Mason's ex-partner has 4 other children to a previous partner, and Mason's daughter often spends weekends with the mother. However, the past two "family weekends" has resulted in Mason needing to take his daughter to hospital with viral chest infections (bronchiectasis). Subsequently, he is re-considering overnight stays for now.

Mason is currently working on quitting smoking, and has reducing down from 10 to 3 smokes a day. He finds the patches helpful, and is hoping to quit smoking altogether soon. He has previously had inpatient treatment for alcohol addiction, and appears to be doing well with his fresh start. Having a baby to care for helps provide him with a meaningful role in society and gives a focus to his day. He seemed to enjoy his role as a parent, and spoke at length about his daughter, her health needs, and the changes he was making to ensure a healthy, happy home for her.

Hospital Experiences

Mason's whānau support made his hospital stay a more pleasant one. Family and friends brought him meals and clothing, and he was able to move freely back and forth to home. He commented that "you'd think they'd never seen a solo father before", and found the attention showered on him by hospital staff a little overwhelming, but he also appreciated the care they showed:

The nurse would ask if I needed anything or wanted anything, but I had family and friends come up anyway. They would watch baby while I took a break or something.

This was his second time on the ward, and he was well familiar with the processes and services available to him, and the need to ask for help:

When I did ask for something or ask for help on something, yeah they always did it.

Overall, Mason was happy with the care his daughter received, the follow-up visits with the GP, and the support from his friends and family in caring for his child.

Everyday health

Despite making further contact, Mason did not show at the times we arranged, which was taken as Mason declining consent for a follow up interview.

Celia (Hamilton city)

Overview & background

Celia lives with her partner, and together they have a boy 1 year of age. He was admitted to the Paediatrics Ward of Waikato Hospital after having a seizure. Their ethnicity is recorded as Māori. They had another daughter, who died in 2014 at 7 months of age. Celia felt at the time like the hospital staff did not do all they could to resuscitate her daughter, and she was quite distraught at her loss. This was the very first topic that Celia discussed. Her demeanour was calm throughout, and she was matter-of-fact in her re-telling, yet it was clear that this incident had a significant and ongoing impact on Celia and her family. I listened and nodded as she talked; I had little else to offer other than my time and attention. Once Celia had finished recounting the story of her daughter, along with associated emotions and concerns, she was then open to my questions regarding her most recent hospital experience. Even so, references to her daughter's death are scattered throughout the subsequent conversations, and it becomes clear that the memory of that incident remains with Celia as she seeks clinical care for her son.

Hospital experience

Living locally with a partner to provide support made the hospital environment a little easier to bear. However, the whole situation was stressful. Both Celia and her partner dote on their son, and it was hard for the Dad to be away from his boy when he was in hospital;

Only one of us could stay there, even though we live in Hamilton I had to be the one that stayed there...Dad [was] going to sleep in his van but I told him to go home.

Dad is the primary caregiver, as his disability makes it hard for him to find work, so it is doubly difficult for him to spend time away from his son. As it turned out, he had the better sleep and Celia was quite tired from the noisy hospital and uncomfortable bed.

Celia felt like the medical staff included them in the care plan and gave clear advice and support. She appreciated this, as the first time her son had a seizure it was complete chaos:

They gave us really good advice on what to do if it does happen and that stuff ... which was really good because that is what we needed. The first [seizure] we were in the dark about – what the hell are we supposed to do? Like yelling at each other and the poor child is still having a seizure ... And we didn't have our phones then so running around like headless chickens, going to the neighbours.

The medical staff are still unsure what is causing the seizures, and Celia is currently awaiting the results of tests and for appointments with specialists. Celia showed me the many, many letters she has from the hospital – she has multiple appointments, but never on the same day. Indeed, she has appointments with two different specialists on consecutive days, requiring the family to pay for petrol, parking, and associated costs two days in a row.



Figure 2: Appointment letters

Despite her frustration at not knowing what was wrong with her son, and the time-consuming nature of hospital appointments and requirements, Celia was thankful that her son was alive, grateful that they now knew what to do if her son had a seizure, and pleased that their concerns were being taken seriously.

Celia would have appreciated more support in terms of providing physical care for her child. This was particularly challenging as the medical staff were not sure if he had a contagious illness (such as meningitis), so he needed to be in isolation. This made it hard for Celia as she didn't like to leave her boy alone and in distress:

With making his bottles and I know it is my job, but he is screaming down the hospital, you can hear him in the kitchen. Even if they provided like a microwave or something in your room so you don't have to juggle something and you don't have to go all the way down there and you are still in the room. I know it is not a motel or hotel, but having those little things in your room help so you don't have to walk out of the room and he is screaming his head off because they are not allowed in the kitchen or corridor.

Keeping a 1yo cooped up in a room, not being able to play or explore was frustrating for all involved. Being unable to make a cup of tea or go outside for a break made the enforced isolation difficult and left Celia dreaming of escape:

You are contained in the room with the child every day. You kind of get a bit, you know, what am I doing? Just looking out the window going – I wish I could just jump out that window ... I was getting really bored, even though there is a TV in there, what I want to watch is not kid friendly, they do have kid channels for kids and you are sitting there watching kids TV

Her partner visited during visiting hours, which provided a nice change in routine and a chance for a break, but in-between visiting hours the time dragged. Adding to this was the absence of toys/play equipment for her son, who was also struggling with the enforced isolation.

Everyday health

Celia and her partner live in a HNZ home. When I visited at their home, he was busy in the garden, digging over the soil and planting seedlings. He has club feet, so physical activity can be extra challenging, and it takes him a while to wake his feet each morning – they require massaging and stretching before he is able to move and walk. However, given time and with rest breaks, he is able to manage most tasks. The cold affects him more severely, but they have limited choice over where they live.

Celia mentioned the house multiple times, and how she felt it contributed to her son's ill health. The house rarely seems warm, unless it is a very hot, sunny day, and heating the house is prohibitively expensive. Celia also had concerns about the safety of the provided heating:

It is not safe too. My son, he can pull onto it and it has come off so it is just sitting there at the moment.



Figure 3: Wall heater

Subsequently, the family all gets “in our blankets and just cuddles up in the blankets”. Celia shared her concerns about the impact of the house on her son's health; the drafts coming in from windows that don't shut properly; and mould that forms on the window “We wash it off and it still forms”. The family had previously been living in a tiny HNZ flat in a different part of town. They requested to move for their son's health, but it seems this new home isn't much better:

Then in the back of our minds we were like if we end up staying here we are going to lose him like we lost our daughter. Everything in the back of our mind was we really need to get out of here otherwise he is going to get sick. Eventually we moved and

now he is getting sick. He has his seizures now and again. But he hasn't had one since he has come out of hospital, so hopefully we are doing it right this time. Doing his health and eating a bit right this time. You don't know, because when you are taking your kid to day-care you have sick kids and sick everything.

The above quote demonstrates the ongoing worry that Celia has for the health of her child. As well as taking extra effort with her son's eating and providing a healthy diet, Celia has to pay extra for her son's prescriptions. This puts extra pressure on the family's finances, but they find the money:

His medication is not government subsidised, so it is like \$17.... It is like the little tubey thing. That for \$17! ... I ask the doctor is that actually subsidised and he goes yeah, it is free I think. Get to down here and they say it is \$17. What? \$17!! They were going to give me the 5ml and it was a straight out \$21 and I was like, no let's go back to the one the actual doctor prescribed me and then we will go from there and then she goes, that will be \$17. If it was subsidised it would make heaps of things easier.

Nevertheless, Celia is thankful that doctors' visits are free, and that they are able to see a specialist and get hospital treatment as needed.

Celia and her partner do the best they can to eat healthy foods and exercise regularly. Complicating their efforts are Celia's working hours and her partner's disability. Celia explains:

His health isn't that bad, apart from his foot. His foot does give him a lot of grief because it will swell up and he won't be able to walk on it. He's getting gout...it is real annoying. Winter is the worst for him, he gets really cold and yeah...he can't walk that far. He can walk probably just around the block or to the dairy, but then any further than that we are struggling because his feet starts playing up and it starts going like this with his feet like that. We don't do much exercise and we don't do much running. We would like to go to the gym though...He has wanted to get back into swimming because he is a big person, like he will lose weight, put it back on and then lose it and put it back on.

As mentioned at the start of the section, Celia's partner has dug over the ground and planted vegetable seedlings in preparation for the growing season, and to provide an ongoing supply of fresh produce. Celia and her partner do their best to eat healthy, despite the higher cost of fresh produce (hence the garden). Making it more challenging for Celia is that she is surrounded by cakes and biscuits at work, and gets very tired from managing work and home. The last thing she feels like doing after a long day on her feet at work is more exercise:

I do more exercise at work than I do at home, and when I am at home I don't want to do anything, I just want to relax – but you can't relax, not with a kid around. I might as well say a 48 hours 7 day a week bloody job with work – managing work, managing your home.

Despite the challenges with work and feeling tired, Celia and her partner do their best to ensure that their son eats healthily:

...we try and give him vegetables as daily stuff. I don't know if we are giving him the right stuff for him to eat – meats and vegetable. I know for one he doesn't like

pumpkin. We tried giving him pumpkin the other day...I had to kind of make him eat it. He doesn't like pumpkin...but if it is mashed up with potato he will eat it and doesn't know the difference ... Breakfast is just Weetbix and nothing else. He likes to eat little snacks everywhere.

The food referenced in this quote is common everyday food for young children in Aotearoa New Zealand, and is congruent with public health messaging. The provision of such foods by Celia indicate that she is aware of broader public health messages and is following the recommended guidelines for healthy food.

Other than his seizures, Celia's son seems in good health and full of energy. Nevertheless, Celia worries a great deal about what is causing his seizures and what they can do to make it better:

We do everything possible to make it more healthier for him, it just doesn't seem to work. I am just hoping, because the next month is coming up, that he doesn't have another seizure. The first was around about September, June and then November is coming up, so I'm hoping he doesn't have another one. We took every precaution. A couple of weeks ago we went to our god son's birthday back in my home town and we took everything from treasures to his medication and made sure that he had some loose clothes so he wouldn't get hot. Then there was heaps of kids so he was running around. When we got home he just got hot and bothered and just wanted to go to sleep. Oh my god, please don't have another sick breakdown because I don't feel like going to the hospital, not today.

Underpinning her concern is that there is uncertainty with her son's diagnosis, with no-one currently sure what is causing the seizures, or why he is fitting. Subsequently, Celia and her partner are trying to be as healthy as possible to reduce any possible "lifestyle" contributors.

One such contributor is cigarette smoking. Both Celia and her partner smoke, and they would both like to quit. Celia expressed concern that their smoking was also affecting their son's health, and they have tried at various times to quite but found it next-to-impossible:

We'd both love to quit smoking but smoking so long it is just hard. We have tried to go cold turkey and it doesn't work. To be honest, it doesn't work. Especially when we are both trying to give up and we both are at each other and then...it is not a good look. We are still smoking. Maybe one of us will have to do it first and then the next one.

As far as could be ascertained from their narrative, neither Celia nor her partner were offered Quit Smoking packs during their hospital visits. Comments from participating Harti Whānau, presented later in the report, indicate the key difference is in the way the Quit Smoking packs are offered that effects their uptake. Celia and her partner expressed a desire to quit smoking. Because they were in the Usual Care group, they were not offered quit support. Access to an Harti RA and the Harti screening tool could potentially help them begin their Quit Smoking journey.

Clare (Hamilton City)

Overview

Clare identifies as New Zealand European and Māori. In her early twenties, she has two young children aged 3 years and 18mo. She is studying at the local polytechnic, and currently lives with her father in a low-decile suburb in Hamilton. Her youngest was born 6 weeks premature, and has been in and out of hospital since. This year she has only been in hospital 4 times, the most recent visit due to a lower respiratory infection and a high fever. Clare notes that the period of time in-between hospital visits are growing longer. There was some concern initially that her prem baby might be developmentally delayed, but she seems to have 'caught up' and, according to Clare, is highly active and full of chatter.

Clare herself is highly talkative, and talked about many things unrelated to the interview topic. In presentation she seemed scattered and irresponsible. Yet, on conversation she showed an in-depth knowledge of her children's likes and dislikes, food preferences, routines, and healthcare needs. Overall, Clare appears to enjoy being a mother and is currently studying towards future employment. She far prefers the quiet, stable environment of her father's place to the busy, chaotic, and noisy household she left in Auckland. Not only was the Auckland home a long way from the hospital, but there were 8 people living in a tiny 3-bedroom house, with Clare and her two children occupying just one room. In contrast, here in Hamilton her girls share a room, and Clare has a room to herself. Additionally, she is close enough to the hospital to be able to come home for meals and to shower and see her older daughter.

Hospital experience

Clare is highly familiar with the hospital environment, having been in and out of hospital with her youngest. Medical staff often underestimate her medical knowledge, in part I suspect because of her youthful appearance (she doesn't look a day over 18). She has learnt to ask for what she needs, and to be resourceful when promised items fail to appear:

We kind of got annoyed with the ED though, because like how she keeps on bringing up her food and then I was like let's get some Pedialyte⁶ so I can get some nutrients and rehydrate her, because she wasn't drinking water or anything, and then they were like – yip, we will be back, and then they never came back. I was like, never mind. So I asked my friend to bring me some Pedialyte. She was like, you are in the hospital, and I was like – I know!

Clare understood that hospital staff get busy, and forget, or are unable to respond in time. She noticed a difference between the Emergency Department (ED) and ward staff, with ward staff more focussed and more able to respond when help was required. She also appreciated the provision of a bed so she could stay with her child, and that car-parking was free:

Parking, I was like – oh my god, I have no money! And then they gave me the ticket and I was like...I've got nothing. I just get there and then all the parking was for free. I was like, oh my god I panicked for no reason!

⁶ Pedialyte[®] is a therapeutic oral hydration solution that replenishes vital minerals and nutrients lost during diarrhoea and vomiting and to help prevent mild to moderate dehydration in infants, children and adults

Clare's finances are very tight: during the interview she discussed having to walk to her tertiary campus as she wouldn't have money for petrol for a few days. It was less a complaint, and more a reality of life – too many bills and not enough money for the week.

Living near the hospital means that Clare could come home for a shower and to change her clothes. It also meant she was able to eat. She contrasts this with her previous experiences in Auckland:

But then in Auckland where I was staying to the hospital it was like too far, I will just go to the dairy and get me a pie and a drink. But then I ended up buying little meat packs and cooking it up, but then at [name], because I was staying there, we got breakfast and lunch and everything so it was good and I ended up getting fed. I was like oh thank god! I'm dying with this one pie and drink for a day – oh! Give me like some buttered bread!

The pie and drink Clare refers to are the \$2 specials corner stores often have, where you can buy a hot meat pie and a cold can of fizzy drink for \$2. It is a cheap and cheerful meal, popular with high school kids and affords a cheap, filling, and tasty meal. It also comes in for much derision due to the high fat, salt, and sugar content, and absence of much nutrition. Nevertheless, it is affordable for people such as Clare who are in constrained circumstances and in need of a cheerful meal.

When transferring down to Hamilton, there was insufficient space in the ambulance for Clare to accompany her daughter. Consequently, she had to drive herself. Complicating this is that Clare had never driven on the highway by herself. Clare describes the experience below:

I was in [name] for two months. I go, I want to be transferred down and then they were like, yeah we can do that. And then they transferred all the records down before they took her down. Then they were like, there is only room for her in the ambulance and I'm like, oh well that is wonderful, how am I going to get down to Hamilton? ... I am going to be stuck in Auckland without my child ... Oh my god the scariest fright of my life. I am driving out of Auckland to somewhere I don't even know where I'm going, so I'm like Google mapping. I'd get to a town and pull over and then I'm like, OK I just keep going straight. And then I was like just follow the signs – common sense! Then I followed the signs and I was like, yeah I got this now. Then I was like now how do I go around Hamilton to find where everything is. Google Maps to this address and then I'd just go and pick up my daughter. She was so happy. We are going to go and see your sister, she is nearly at the hospital. OK. So I just put her in my car and I just drove there and was like, go and see your sister and she was like all happy.

Transferring to Hamilton has meant that Clare is able to care for her older daughter, who had previously been staying with other family. She is also closer to the hospital than in Auckland, making hospital stays less arduous, and, as mentioned previously, is in a less crowded household. She is also closer to the polytechnic, making further study possible, and has access to good quality ECE.

Everyday health

During the second interview, Clare discussed her daughter's medications and their application, showing a detailed knowledge of what her daughter should take and when. As well as keeping the medications out of the reach of her children, Clare is very particular about keeping the house clean to reduce dust mites and minimise allergic reactions. Clare outlines her routine below:



Figure 4: medications kept in the fridge

Generally, the house is cleaned and vacuumed usually every morning and every night, apart from this morning because I was too busy dealing with everything else, but I was getting there. Yeah, vacuumed every day and every night because the dust and because I have real bad allergies. Dishes are done straight after use. Her bed sheets are changed every two days.

Both times I have visited, the house has indeed been very clean and tidy, lending credibility to Clare's routine. Clare also discussed in detail her daughters' bedtime routines, the standard dinner-bath-bed type evening rhythms, and how this assists them in going to sleep and resting at the end of the day. She also has a detailed knowledge of what foods they like to eat, and described in detail the healthy lunches she prepares for each day:

Generally, they will have a yoghurt, in a container not the little individual containers, the big bulk containers and then put into little containers. And we have like chips and crackers, a couple of plain biscuits and a couple of chocolate biscuits depending. Tania doesn't like the look of plain biscuits because it is not chocolate! And like cut up fruit...and a sandwich, depending on what spreads we have or what meats and salads. Generally my lunch is just a sandwich, my two sandwiches.

Like many of the parents interviewed, Clare does her best to provide inexpensive yet healthy meals for her children. The lunch Clare describes is fairly typical of many children, easy to eat with little fingers, and provides for their food needs during the day.

Overall, Clare is highly health literate, well versed with the hospital system and able to navigate it with ease, and shows an in-depth knowledge of her children's health needs.

Ngaio (Hamilton City)

Overview

Ngaio and her partner have 4 children, ranging in age from 10 years to 7 months. When I visited, several other family members were present, as is common for Māori whānau. Ngaio and her partner are in the process of whāngai for a relative, who is currently in Henry Bennett and severely unwell. So unwell, that, at 37 weeks, she has been recommended for an induction. Ngaio didn't feel that they could let state welfare services (Oranga Tamariki, previously CYFS) take the baby and give it to strangers, so they will be caring for the baby once it's born and are likely to whāngai the baby on a permanent basis. Ngaio's 7mo is the child who was hospitalised with bronchiectasis. He was born prematurely at 27weeks, and has been in and out of hospital since. This most recent visit he was initially in Neonatal Intensive Care Unit (NICU) and then transferred to the ward, and was in hospital for a week in total. When first born, the family were living in a remote Waikato township. However, they found it too far to travel to get the specialist care the baby needed, and subsequently moved to Hamilton, where they live in the low-decile suburb.

Ngaio's father still lives in the remote township they left, and he is unwell with diabetes, high blood pressure, and gangrene in his toes. As Ngaio says "He's got the whole jambalaya in there. He wants to be greedy and take all the diseases!" While baby was in hospital, Ngaio's father was also admitted to hospital, which placed additional pressure on the whānau to care for sick family members. Ngaio found it all very stressful, as she had to leave her sick baby alone in hospital while she went to care for her father and bring him to Waikato. Her partner was busy looking after their other 3 children, who were also sick with coughs and colds.

Hospital experience

Overall, Ngaio was happy with the clinical care her child received. She was pleased that he was getting better, and delighted that he was able to come off the oxygen and come home. She didn't like to complain about anything, preferring to stay positive, and was happy that her baby was able to get the medical care he needed. Ngaio particularly noted the excellent collaborative/inclusive approach of the doctors, who intentionally and deliberately included her in their discussion about her son's care. Ngaio noted that this felt strange, in that she was used to "just being told", but she far preferred this inclusive approach, the value placed on her knowledge as the child's caregiver, and that her contributions were seen as important.

She found that some nurses were chatty and happy to help and answer questions, others she found rude and dismissive. Ngaio didn't like to complain though, as she knew the nurses were busy and doing their best. However, she would have appreciated a little more personable interaction. What Ngaio did appreciate was the way in which the ward staff kept her informed of her son's progress. Even though she wasn't able to be there with her son 24/7, the staff would ring her regularly and update her.

It was good service too, it was really nice to be there with them. Nurses were constantly coming in and checking up on him. One day we had to be out because we had so much to do with our other children and there was always a nurse in there when we would go. They would be there giving him cuddles, they would ring us, which was a nice thing to know that they were doing.

She also felt able to ring the ward and enquire as to his condition, which meant Ngaio still felt included despite her absence. Ngaio noted the difference between NICU where you had a dedicated nurse with you all the time, and the ward, where you had one nurse running multiple patients. She felt much safer in the NICU and worried that the nurse with such a high workload would miss potential changes in her son. She also noted the time delay in requested help and help arriving, but did not want to complain or make a fuss. Ngaio did not want to experience any more distress, and worried that if she complained, that things might go wrong or her child might experience worse outcomes. She feels that it is best to accept the service provided in order to focus on improving her child's health, and that her own experiences of inadequate service are inconsequential. Ngaio highlighted several times going hungry and how this made the hospital stay more stressful and difficult. Her partner was busy with their 3 older children, and unable to bring her food. She found the cafe food too expensive and instead spent the day drinking endless cups of coffee to stave off hunger pains, eating her son's unwanted pureed meals as a change from toast:

Some of the parents, like when I was there, we were complaining about not getting fed. We only get fed a dinner and then we have to go out and find our own means of breakfast and lunch ... it is just food more or less, I just dislike the whole thing of having to go hungry during the lunch period. But then all day ... My needs, just more along the lines of just hungry but grateful for my husband and that we stay in Hamilton now and that we didn't have to wait until pay day and then get some food in us ... pureed stuff is what he was getting so I was eating that.

Parking costs and difficulty with parking were briefly mentioned. While there was some provision (albeit meagre) for Ngaio as the primary caregiver, there was little available provision for other whānau members to provide care for Ngaio, or even to come and relieve Ngaio for a bit, as the provided supports were denied to whānau. That is, transport vouchers were not seen to be available for whānau, only the immediate parent; same for meal vouchers. This meant that unless whānau had pūtea (money) they were unable to provide support.

I went through a lot when he was in hospital. Missing my babies and just talking to them over the phone and seeing them wasn't enough, I wanted to touch them and kiss them and give them a goodnight kiss because they were away from me for so long.

While Ngaio felt that, overall, the hospital met her baby's needs, and met his clinical/physical healthcare needs, she felt that there was little regard given to her wellbeing. While individual health workers were kind and thoughtful, and she felt included in clinical care conversations, the overall set-up in terms of care for the caregivers left her feeling alone, hungry, stressed, and isolated from her whānau. Implementing Recommendation 3 and 4 (presented later in this report) would go some way to changing this experience for mothers such as Ngaio.

Everyday health

The living areas are warm and dry, but the bedrooms are cold. Subsequently the family congregates in the living rooms. There is a heat pump, but Colleen said it is rarely used due to the living areas being warm - and the sheer number of bodies in the room. Ngaio was in the process of adopting a newborn (whāngai), so we postponed our second interview. Despite several texts and phone calls, I have yet to make contact with Ngaio to arrange a second interview.

Whetu (Greater Waikato)

Overview

Whetu lives with her partner and their child (under 12 months in age) in a town in the Greater Waikato Region. Her ethnicity is recorded as Māori, and her child's as New Zealand European and Māori. This was her first visit to Waikato Hospital with her young child, who was admitted due to severe facial eczema. In her stress and worry Whetu discovered she had not packed clothing for herself or her baby, had brought no food, and had no phone charger. The absence of sufficient funds meant she was caught short at the hospital, with no money to purchase additional much-needed items such as a change of underwear or food to eat. She has good whānau support at home, but the hospital was too far away for family to visit, and she felt isolated and alone.

At Whetu's request, our interviews took place at her local Kōhanga, while her child played nearby. The Kōhanga is small in size (only 3 families), and permission was sought and given for us to talk in their space. Only conversations with Whetu are included in this report. The kōhanga is a source of support for Whetu; their van was used to transport her child the hours' drive to hospital, and Whetu planned to use the provided koha for interviews for materials for the kōhanga.

Hospital experience

Whetu was very hungry while in hospital. She had no money to afford food from the café. Additionally, Whetu didn't want to leave her baby alone. Instead she survived on what was provided, which was toast in the morning and a dinner meal at night, plus any leftovers of her child's meal. An uncle visited and bought KFC which was much appreciated. Nevertheless, her overwhelming memory is of being very hungry all day.

I had family that came to visit but because my phone was broken...I don't like to ask, even whānau, I don't like to ask them to bring things up. Although my Uncle did bring up some kai. I was starving. So that was cool, but apart from that I didn't have any means of getting stuff. I was told there is shops you can go down and use the laundromat and things like that, but I couldn't take her out and walk all the way down there in between her doses of medication.

Being so far away from home, and from her support networks, Whetu felt very isolated at the hospital. She was able to pack a few items before leaving, but was so stressed and worried about her baby it was less than ideal. It was only after she got to the hospital and was settled into the ward that she realised how inadequate her quick grab of items was.

Once in the ward, Whetu was reluctant to leave her baby alone. Subsequently she found it difficult to bathe or do any personal cares until the baby was fast asleep. This was really draining for Whetu, and she was very tired.

[it] was kind of a bit awkward to leave [baby] in the room to go down to make the toast. The nurses were busy, so I didn't want to ask them 'can you look after baby?' There was one nurse who was awesome who would come in and say 'do you want a cup of tea?' and took my toast down and made it for me, so that made it a bit better. I was told not to take [baby] out of the room and to call somebody in. I had actually

rung my bell at one point and nobody came for ages. I've got a wrap thing that I put over here and I just went down and made my own. I took her with me.

Additionally, the provided bed was uncomfortable. So much so, that the last night Whetu crammed herself onto baby's cot for a more comfortable (co)sleep. Despite these challenges, Whetu remained thankful that her child was getting the treatment she needed to get better:

"I felt good knowing that she was in the place that was going to help her ... So the fact that we were in hospital where she was going to get the right treatment was good, but the fact that I didn't have enough stuff ... I had no money. I had actually used the kōhanga van to get over there and the van was supposed to go in for service the next day and I'm like, oh my gosh how do I get the van back?"

Whetu commented that some sort of checklist, available from the GP, would be very helpful in guiding first-timers at the hospital. Her mind was elsewhere, she said, and a checklist would have helped her focus, and ensured she packed appropriate and needed items, such as snacks and changes of clothing.

Everyday health

Whetu discussed her house in great detail, specifically, the difficulties she faces in keeping it warm and dry; the high cost of heating her home; sleeping in the lounge to try and stay warm; the high moisture and mould content in the house; and lack of healthy home options. She shared an image of the condensation on the windows and her attempts at placing an additional layer of plastic to help insulate the windows and reduce moisture, with limited success (see Figure 5).



Figure 5: Windows and condensation

Whetu does everything “right” - that is, she airs the house regularly, opens the windows to let air in, puts up plastic on the windows to keep heat in, rewashes the curtains to prevent mould, and regularly cleans off mould. This is a huge amount of unpaid labour by Whetu, and still the house is damp and cold and expensive to heat. Whetu worries that living in a cold and damp house will continue to make her child sick, yet her options as a tenant are limited by what is available and affordable in her town.

Whetu is aware of healthy eating and exercise messages and is doing their best to implement them. Figure 6 is Whetu's image of the family going for a walk on a sunny day. She discussed attending the local gym and challenges thereof while at home with a baby.



Figure 6: Walking on a sunny day

Whetu was very aware of what she needed to do for her child's health, and for her own, and spends a fair amount of energy doing her best to meet these needs. While visiting, I observed her young one eating corn, yoghurt, and fruit. Whetu does her best to ensure her child has a range of healthy foods to eat.

As well as healthy foods and exercise, Whetu was very interested in Rongoā. We had an in-depth discussion of the types of rongoā suitable for use with her child's condition. Whetu would have liked to have discussed this with someone more medically knowledgeable at the hospital, but despite her request, the kaitiaki did not visit while she was in the ward. She expressed concern that medical staff would not support the use of rongoā:

I didn't know where to get that information from. I don't think the hospital would support that too much ... What else is there, like Rongoā is out there.



Figure 7: Kawakawa leaves in the bath

Overall, Whetu is doing the best she can with what she has to meet her child's and her own health needs. She is aware of healthy eating messages, knows what medications to give her child, and is actively seeking out health knowledge that will benefit herself and her child.

Taryn (Greater Waikato)

Overview

Taryn and her partner are a young couple with a new (3mo) baby. The child's ethnicity is listed as New Zealand European, Māori, and Samoan, and he was admitted due to right eye cellulitis. The family lives in a smartly furnished one-bedroom flat on the main road in small rural town on a State Highway. Traffic rumbles loudly past throughout our interviews, and at one point, a train thunders by, leaving the wall reverberating with vibrations. Taryn said her baby doesn't seem to mind the noise, other than the loud motorbikes which roar past from time to time. Her and her partner are looking for somewhere more suitable for raising a family, and hope to one day purchase a small block of family land where they can build a tiny house and enjoy rural living.

Taryn's partner works nights to support the family, and Taryn is enjoying this time at home with their baby. They both have supportive families. When I first visited, Taryn's partner's two cousins had arrived to meet the baby. This trio of strapping young Samoan men took the baby out for a walk in his pram while Taryn and I conducted the research interview. Overall, the impression is one of a wider family delighted with this new addition and one that provides social and practical support.

Hospital experience

Overall, Taryn was satisfied with the clinical care her and her son received while in the hospital. She appreciated the efforts staff made to make them comfortable:

It was all good. They [staff] were really good. Yeah. Nice and clean. They always made sure I had fresh blankets and pillows and stuff like that, which is nice. They had places for me to shower and everything like that, which was good.

Taryn had her mother and her partner with her at various times during her child's stay to provide support. She was thankful to staff for being flexible with visiting hours so she could see her partner, and that her family were able to provide additional snacks and food for her:

They [staff] understood because he [partner] works night times, so he was allowed to come and leave at 10 when visiting hours I think it was 8. So they were open for that.

They [staff] ended up getting me a sandwich and showing me the hot drinks and everything like that. There were snacks sometimes. When we were in the room all I got was just bread. My partner always brought food – I always had food anyway.

The bread that Taryn is referring to is the provided bread and spreads on the ward. Initially Taryn took her baby to the Emergency Department (ED), and from there they were admitted to the ward in the early hours of the morning.

Neither Taryn nor her partner are immunised, and they have chosen not to immunise their baby. Clinical staff raised the issue of immunisation with them several times during the course of their stay. Taryn found this challenging:

...because we were all not immunised we didn't want our son to be immunised. And just how they reacted to me, kind of looking down on me since I said that. Then we weren't allowed to be around the main area which we can entertain ourselves with TV

and everything, we had to go around the corner at the back. I kind of felt discriminated by that. There are a lot of kids that aren't immunised, we had to share with other people as well. I felt there should be an area – even though it is a hospital you are going to pick something up. But it was alright, everyone there helped out which was amazing because it just happened so fast. It was comfortable staying there.

As well as the multiple conversations regarding immunisation, and feeling like staff were “pestering” her in this regard, Taryn and her mother had what they felt was a hostile encounter with the ED doctor. Taryn explains:

He was even saying how much do you earn? He was even talking about how much do you speak a week on cigarettes. I didn't even get to tell him that we're not heavy smokers, and then he was like – I bet you it is like \$70 a week. \$70 a week you could have been saving that for your family. Do you want to go on holidays, do you want to eat? ... I was like, we've just finished a date night. My Mum was fuming. I thought maybe this is what it is at the hospital, this is normal. My Mum was like, this is not right!

I was just really angry about it because he was too worried about us that we were smokers, he didn't even look at our son – he didn't look at him! He went away and then he came back and then he looked at him.

I feel like us being Maori and we're smokers, I feel it was kind of an aggressive thing 'I have to have this conversation with everyone, so I'm just going to be an asshole'.

This example showcases how the delivery of an intervention can alienate the very people it is designed to benefit. The “aggressive” manner of the health professional resulted in Taryn and her mother being actively disinterested in further support. Such encounters, over time, make it even more difficult for mothers such as Taryn to engage with health services and create a barrier to accessing support. The assumptions of poverty, ignorance, and hunger as evidenced in Taryn's re-telling of her interactions signpost the ease with which health professionals can internalise negative, deficit-oriented stereotypes regarding their Māori patients.

During our interview, Taryn was well-presented, articulate, and capable. Her partner and his friends were laughing and joking together, and thoughtfully vacated the tiny lounge so we could chat in peace. Their home was well organised, had no trace of cigarette smoke, and it was apparent that this was a much-loved baby born to hard working parents doing their best to provide a warm, stable home. Taryn talked of going to live on whānau land as their child grew up and the potential for more babies once this occurred. Yet all this capability was negated during an interview with a health professional who viewed them as nothing more than ‘poor Māoris who couldn't afford food’.

While a second interview was initially scheduled, Taryn was unable to meet before the end of the year.

London (Hamilton City)

Overview

London lives with 3 of her 4 children (ages 5 years, 3 years and 7 months) in her parents' 2-bedroom state house. Her eldest lives with another family member in a rural Waikato home (whāngai). Her youngest was born prematurely, and spent the first 4 weeks of his life in hospital. His ethnicity is listed as Māori, and he was admitted due to difficulty in breathing.

Our interview took place in London's bedroom, as this is the only 'private' space of the house. We perched on the edge of her bed to talk, with her 7mo baby sleeping in his car seat on the floor and her unwell 5 year old snuggled up in the bed watching YouTube videos on a smartphone. The Kōhanga van had arrived shortly before our interview to transport her middle child to Kōhanga.

Hospital experience

London talked with me both about her son's first 4 weeks in hospital, and about this most recent visit. This most recent visit seemed to go well - London wanted to talk more about his previous visits and interactions then. For her, it felt like all these experiences blurred into each other, and were not easily separated out into disparate visits.

When we were at the hospital when he was premature, we were in there for four weeks. I had to go to Tauranga because they had no room at the hospital ... I had to go by myself, my Mum stayed here for my other kids to get them ready for school and stuff. I had to go by myself. I was a bit sad because I didn't want to leave close to home, I didn't really know anyone in Tauranga until my cousins were like – we live in Tauranga. I was like, thank god! So they came up every day and helped me with baby and let me go out for some fresh air now and again. We stayed up there for two weeks and I was dying to come home and see my babies. I didn't like the video calls because that wasn't cuddling them or anything... When I got back we went up there [Waikato Hospital] and stayed there for another couple of weeks. It was alright, at least they had internet and I got to see my babies so that was the main thing. I just wanted to hurry up and come home and be in my own space. He was fine. Did alright. Everyone kept asking me if he was my first baby, and I said no he is my fourth! They were like, oh.

London's home is located nearby to Waikato Hospital, and she greatly appreciates the easy access to home; living so close to the hospital and with her parents made it much easier for London to both see her other, older children, and also to come home and have a shower and change of clothes. Her mother brings her up hot meals, which London appreciates a great deal.

I would ring her and she would be like, What do you feel like? Can you make me some boil up and bring it up? OK, I'll be there at 6, make sure you open up the door. Alright. So yeah, anyone would bring me food – my Mum especially.

Overall, London was happy with the clinical care her son has received and that his physical health needs are taken seriously.

While staying with her new-born child, the opportunity arose to spend some time with her other children. London was very much looking forward to spending a day with them and had missed them terribly. She arranged with the staff nurse to leave for the day. However, the duty nurse was unaware of this arrangement and expressed her disapproval when London went to leave:

The nurses in the red shirts who are in charge ... I asked her when she came in to check on baby and I said, can I go and see my kids tomorrow, they've got a day off school. I'll pump some breast milk and just leave it here and go down because I live down the road, so I can go and see my other kids and spend the day with them or a couple of hours. She was like, yeah sure – I don't see a problem with that. Then the next morning I got ready, pumped milk and stuff and got ready to go. And then I said, do I sign out or something and then I'll be back in. The nurse was like – you can't go. And I'm like, but the lady in the red shirt said I could go so I can go and see my other kids. She said, oh I didn't realise you had other kids! I'm like...wow. The only place I'd leave is to get some fresh air but I want to see my other kids. She was like, I don't think you can do that. But the lady came in and said she has pumped enough breast milk so she can go down for a couple of hours and spend some time with her kids. The lady just looked bummed...she got told off. I was like, bye! I was just happy to come and see them. I looked so tired but it was worth it, we had a good day out.

We had my other cousins over too. It was just like I went to the park and the lake and had a feed. We went to the \$2 shop and kicked a ball around at the park. I went back up because they crashed out early so I thought I'd better go now, because if I leave while they're awake they will start screaming.

London looks much younger than her actual age, and, as such, is subject to assumptions regarding young mothers, as well as assumptions about Māori mothers. This results in her being treated like a negligent mother or ignorant child, rather than a loving parent juggling multiple demands on her time. London had worked hard to organise a fun day out with her children as one way to minimize the impact that her absence was having on her older children (due to the premature arrival of her son). Despite her own exhaustion, she prioritised her children's emotional well-being. In conversations it is evident that ensuring her children's well-being is important to her, and she works hard to ensure they are well cared for.

Everyday health

Like any busy mother, London spoke of taking the kids to the park, bathing them every day, and of trying to get them to eat their vegetables:

We do play outside a lot. I try to get them outside as much as I can to get fresh air and stuff. I used to like playing outside when I was a kid. We play outside and kick the ball and stuff like that if it is a nice day. If it is raining we cuddle and watch movies and sit back. Overall they're healthy and happy. They brush their teeth. I don't like the smell of morning breath...you're having breakfast and your breath smells like Weetbix and morning breath together, you are brushing your teeth! They are good babies, sometimes. They have their moments!

I am trying to cook healthy stuff now because after having him all my weight has gone to these hips and they have gone bigger and hips run through our family. I am trying to get them to eat healthy but they don't like vegetables, so I'm trying to hide it but they notice it. I try my best but it just doesn't work sometimes ... The only healthy thing they eat is burger with lettuce and tomatoes, that is about it ... Sometimes she likes that broccoli and cheese sauce. She doesn't like carrots cooked, she just likes them raw. She likes her fruit though. She likes especially. Every week – grapes mum. What kind of fruit do you want for school? Grapes and oranges! OK. Sometimes I mix it up and go grapes and bananas or something different for my other kids too.

Overall, London is well aware of healthy eating messages and does her best to ensure that her children have healthy food for school lunches, healthy breakfasts, and dinners that her children enjoy eating and include vegetables.

Additionally, London described reading to her children each night and navigating the endless paperwork of health and education systems:

We have this form thing that you are supposed to fill out when you read books. I keep forgetting to fill them out. We have read heaps of books, I just forget to record it down and write it on the book because I've got two other kids. We all read a book and then one starts crying and then I totally forget about it. So her book looks like I have done nothing!... [I tell them to] go to bed because if you go to bed late you're going to be grumpy in the morning, especially her. She goes to bed at 9 o'clock and she is so grumpy in the morning. She just sits there for ages like this, for like a good half an hour! Lucky I got you up at 7!

London is aware of the constructions of her as a “failed mother” due to being both poor and Māori. Yet, as the above quote indicates, London is heavily invested in her children's education. Her middle child is enrolled with a local kōhanga reo, which he attends daily. Her eldest has started school and London works hard to ensure they are well rested and up early in order to be ready:

On the day we spoke, London was in the process of preparing for a trip to see whānau members in another town:

It was my Uncle's birthday on Tuesday so we're going up for a road trip to go and see him at the cemetery at our home town...I whāngai'd my other daughter out, so she lives [there] with my aunty. That is where we're going today, so I drop off her present and go and say hello before I have to come down and get my son. He gets picked up and dropped off, so my Mum will get him if I'm a bit late.

Maintaining whānau connections is an important component of Māori well-being and wider health. In this instance, London is combining connections with both past and future family members. She is remembering her uncle and spending time with her oldest child, who is being raised by wider family members. The fluidity of whānau and the wider importance of whānau connections for health and well-being is easily overlooked in dominant constructions of both family and well-being.

Introducing the ‘Harti Whānau’ cases

This section presents the cases from each of the whānau interviewed who were the recipients of the Harti screening tool, as administered by the Harti RA. Each case study is briefly summarised here with key identifiers to guide the reader prior to reading the cases in full.

Jodie has 3 young children, and lives with her precariously employed partner. Her father has recently moved in to assist with living costs. Her youngest was admitted to the acute ward at the same time as her eldest was undertaking scheduled surgery, placing a great deal of strain on the family to provide an adequate level of care for each child. The Harti helped ease some of this stress and strain, and make a significant difference to Jodie’s sense of being able to cope.

Mere is a mother and a grandmother. Her and husband have their mokopuna (grandchild) through whāngai, who has a chronic illness. They live with extended family members, who provide support and care for the children while Mere and her husband spend time in hospital caring for their ill moko. Her interactions with the Harti RA was the first time Mere had felt able to relax and enjoy her interactions with a health worker.

Aroha has 3 young children under the age of 5, and a partner who has recently been committed to a Corrections Facility. She is more used to “being given a hard time” than she is to positive, welcoming interactions with health professionals.

Maegan was homeless. She had been staying with family, but it was unsuitable for the baby. Maegan was under a great deal of stress attempting to locate a suitable and affordable home to live with her 6 month old baby. Although randomized into the Harti group, Maegan was ultimately discharged to another DHB.

Penny is an older, experienced mother. She was in hospital with the youngest of her 7 children, and found this hospital stay far more culturally supportive than previous ones with her older children.

Astra lives with her partner and young baby in her Mother-in-Law’s house, in a nearby Waikato township. Her baby stopped breathing one night. Fortunately, Astra was able to resuscitate her due to recently undertaking a First Aid course. Her hospital stay was primarily positive, although as a breast-feeding mother she was not provided with sufficient food.

Anahera has only recently been housed with Housing New Zealand. Prior to the birth of her twins, her and her partner and her child were living in a motel. Anahera works very hard to care for her twin babies, yet often feels like a “bad mum” due to their chronic facial eczema.

Kiri has Type 2 diabetes, a pre-schooler with brittle asthma, and a household full of children; her widowed partner has 3 school-aged children from his previous relationship, and they also have 2 young children. Kiri lives in the Greater Waikato area and her health interactions are textured with discrimination and State interference.

Jodie (Hamilton City)

Overview

Jodie lives with her partner, their 3 children aged 6, 4, and 1, and her father in a private rental in a Hamilton suburb. Her partner has been in and out of work, and the financial cost of having a child in hospital has pressured their already tight budget. Jodie has recently enrolled her youngest in Kōhanga Reo, in the hopes that she will then be able to find work to alleviate the financial strain the family is under. From the data recorded, this is a dual-heritage family; Jodie and her father are Pākehā, her partner Māori. The child's ethnicity is recorded as NZ European/Māori, and he was admitted due to acute bronchiolitis.

Jodie was near tears when given the \$100 countdown voucher as koha for her participation in the research, exclaiming “Holy shit! What the hell! Oh my god! We have got no food! So, yes!” Jodie later went on to explain that things were particularly tight, as, not only had there been extra costs associated with the hospital stay, but her partner had been out of work for two weeks. The family had literally eaten everything in their pantry, leaving Jodie highly stressed regarding providing food and lunches for the children:

These couple of weeks have been our most poorest weeks and my kids come home [saying], “we’re hungry, we’re hungry”. They don’t understand the concept of we have to rationalise what food we have and there is not enough money to buy anything else. They don’t understand.

The research vouchers alleviated this initial stress, and by the time I visited for the second interview, her partner had started a new job and things were less strained.

Harti tool & hospital experience

Jodie was one of the first Harti tool recipients, and spoke very highly of her experience. She received a car-seat, engaged with Whare Ora, and very much appreciated being given information on accessing affordable food and cheap internet. She also accessed Quit Smoking support for her partner.

Jodie thoroughly enjoyed the entire experience of undergoing the Harti screening tool, particularly her engagements with the Harti RA, commenting time and again on how good it was:

[The Harti RA] made sure I was fed and all of that. She was making sure I was alright, if I’d had time to go for a shower and to the toilet and all that. I hadn’t because I couldn’t leave him because I had no one else up there.

She was someone really that I could just talk to.

[The Harti RA] even brought me lunch the next day. I felt like I really just had a friend to talk to. I was up there by myself and going crazy in that little room.

I think it was real good. Yeah. Like they actually cared. When you have kids in there you don’t get fed at the hospital, so it was good having someone come in – especially if you don’t have anybody up there and you are just stuck. I thought it was quite good.

As well as her interactions with the Harti RA, Jodie appreciated the practical support and the connection to other services. The provision of a car seat in particular was highlighted as significant positive. Jodie had been using an old (and unsafe) car-seat she had found in her in-law's garage.

I have told everyone – holy shit, when I went to hospital I got this and I got that. I got hooked up with all this! I have messaged my Mum and my cousin. Holy shit cuz, you know I got a free car seat when I was at hospital!

Having a new, safe car-seat for her child eased her worries about safety and was a tangible reminder of care for her family's well-being.

Jodie only recently moved to Hamilton from another New Zealand town, and was unaware of many of the services on offer and available to her. Her experience of the Harti tool was that it gave her a number of additional options and she found this hugely supportive:

Nobody knows about all of that stuff. I had no idea. And the house insulation, like I feel like a lot of people will want their house insulated so the kids don't get sick. You know what I mean? I found it real good. It just gives you an idea of what services are out there to help. It was very good. I don't see why anyone would not want to know all of this.

Overall, Jodie could not speak highly enough of her experience with the Harti RA and the associated tool processes. At the close of the interviews, Jodie had only engaged with Whare Ora as an external service; her partner was reluctant to quit smoking, they didn't qualify for the cheap internet, and she had yet to visit the community house for cheap fresh produce. Nevertheless, the general feeling that Jodie was left with was one of hope and empowerment; knowing that there were services she could access, and how to access them, along with the provision of a car-seat and help with her home, left Jodie feeling cared for, and reduced her sense of being isolated and alone.

Aside from the Harti screening tool, Jodie's experience of hospital was highly stressful. This was due in part to one child going for scheduled surgery, while another ended up in the ED due to trouble with his breathing. This left Jodie stretched between 2 sick children in different wards, a sick partner, and a third child at home:

We had nobody else to come up. We were just like – what do we do? I can't leave my daughter there by herself, so they made [my partner] put a mask on and stuff. He had to stay up the night there with her because I couldn't stay. They weren't even going to let him stay because [he was sick]. Oh my poor child – she didn't want to be there, she wanted to go home. She just did not want to be at the hospital.

Fortunately, Jodie's father was able to assist with child care, her partner got well, and both children eventually returned home. However, in the meantime, Jodie was left isolated and alone on the ward, worrying about both her children and feeling unable to leave her baby to visit her other child. She notes that even going to the toilet was difficult:

Every time I was ringing the buzzer for a nurse so I could go to the toilet, no one was coming. Even when he pulled out his feeding tube, nobody came and seen us until about an hour later.

The provision of a Harti in a caring manner provided a significant contrast, and left Jodie feeling less stressed and not so alone.

Everyday health

Jodie was particularly concerned with the state of the house. While the living areas are warm and dry, the bedrooms are cold and damp. Jodie worried that the damp, cold bedrooms were making her and her son sick.

This house is real damp. I don't think [insulation] is installed down that end, and since we have been out of hospital my son has been sick a couple of more times. I've just found mould everywhere too ... My Dad stayed in one of my daughter's rooms a few times and he ended up in hospital with his breathing the one night, and he was like – no, no one can sleep in there. It is just wet.

Jodie took great care to air the house every day, to open the windows and wipe down the condensation that occurred overnight (see Figure 9), but even so, the house remained damp and cold. The family could not afford heating; the only heat provision for the house was a small fan heater that was used in the living area only:



Figure 8: Fan heater used for heating house

Jodie noted that no matter how much you heated the bedroom end of the house, it was still cold, and they simply couldn't afford to run heaters in every room. The living areas also received passive solar

heating, contributing to their warmth. Jodie thought that the living areas were insulated already, which would also help explain why they remained warm and dry. Sometimes the family slept all together in the lounge where it was warmer.

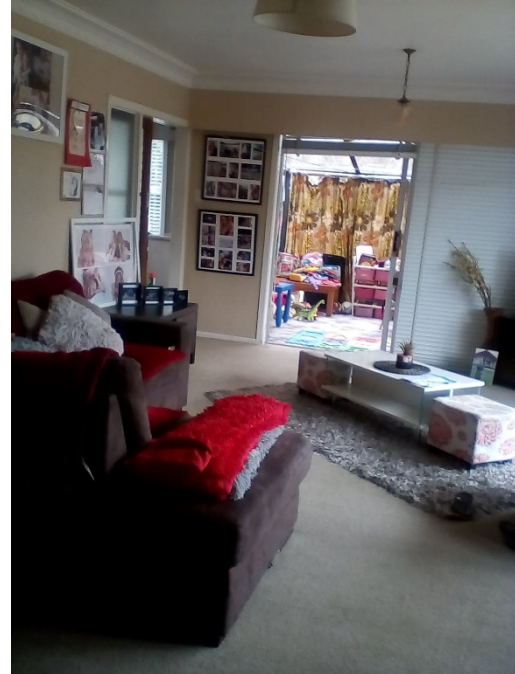


Figure 9: Windows open for airing house; Living areas with blankets; Bathroom with window that does not close.

Jodie commented on the level of mould in the bedrooms and the rotting windows in the bathroom. When they moved in, Jodie contacted the landlord regarding the absence of taps in the shower; she was having to use a pot to heat water for the children's baths. The entire bathroom is flaking paint, it appears that the landlord has simply painted over things instead of fixing the issue. Jodie worries about the impact of the mould and damp on her children's health, but also feels powerless to do much more than she has already. She is hopeful the Whare Ora visit will result in a warmer, drier home.

Jodie does her best to ensure her children have fruit to eat every day, eat healthy snacks, drink only water, and regularly wash their hands and brush their teeth. She took photos of each of these parts of their daily routine. She had noticed a slight cavity in the teeth of one of her children, so was being particularly careful with regards to eating sugary foods and brushing of teeth.



Figure 10: Fruit and healthy routines

Overall, Jodie did her best to provide a clean, healthy home for her family on a constrained income. She has her children enrolled in school and Kōhanga Reo, airs out the family home daily, purchases fruit and healthy snacks for the children, has an excellent dental health regime, and is able to navigate the health system to get her children the clinical care they require. She felt that the Harti tool as administered by the Harti RA supported her health aspirations and empowered access additional supports previously unbeknown to her.

Mere (Hamilton City)

Overview

This is a large, complex household. Mere and her husband, Koro, are an older, Māori couple in their sixties and with grandchildren of their own. The child at the centre of the preceding hospital admission has been whāngai'd by Mere and her husband, along with her two siblings, into their family. She has a chronic illness, and is the youngest of the household; she celebrated her first year of age on the day of our first interview. Her most recent admission was for bronchiolitis. Altogether there are 7 children in the house, ranging in age from 1 year to 22 years. Mere and her husband spend a great deal of time in the hospital with the baby. They were finding it untenable to take all their children with them every time the baby was in Starship (Auckland Children's Hospital), and it was affecting their schooling. Subsequently, Mere's brother has come to stay with the family to care for the younger children. During interviews, family members flow in and out of the home. The hospital records note that there are 8 people who live in this 3-bedroom private rental, however the number is likely more. Mere confessed conspiratorially to me that, in order to rent this place, she had to lie about how many were in the family. She didn't like having to do so, but the alternative was to go homeless. While the house was a little small, it was affordable and better than living in a car or motel.

Harti tool & hospital experience

Mere spoke very highly of her engagements with the Harti RA, and overall Harti tool experience. Subsequently, the whānau engaged with Whare Ora and Tamariki Ora, and has been referred to Quit Smoking.

A lot of people, whānau most of them, told us about Whare Ora and referred us to Whare Ora, but they hadn't. I didn't know there was a Tamariki Ora until I met [Harti RA]. I am really looking forward to that one, because she hasn't been immunised. She was never allowed.

Mere and Koro are very familiar with the hospital environment, yet, despite their familiarity with the public health system, this was the first time somebody had taken the time to sit with them, explain the various services, what they provide, and the benefit to whānau of engaging. Mere particularly appreciated the time that the Harti RA took to explain everything thoroughly:

She went through a lot of things with us, it was really good too. Like the house is one of them she went through. She made sure that we were up to date with everything that had to do with her, like assistance from everybody. Yeah ... So we are really interested in that Tamariki Ora, and the Whare Ora. Yeah, she referred us to Quit Smoking ... She was awesome. Really. I mean what took maybe was supposed to have been half an hour took us maybe two hours. It was awesome. Yeah, it was just cool. Made sure that we knew about this, we knew about that or if we were hooked onto this – right down to Work & Income, if we were getting that and if we knew that it was there. It was awesome. She was good.

Koro's first language is te reo Māori, and Mere enjoyed being able to converse and engage with the Harti RA, instead of having to translate:

I found it really relaxing. Questions I could relate to ... It was so refreshing to talk to somebody that knew where you were coming from ... It was really awesome that [the Harti RA] took that time to explain. My partner, he is more understanding in Māori than he is in English, so for her to take that length of time was good for him.

Mere also commented that sometimes services were culturally inappropriate for their family. She gives an example of offered respite care below:

Hospice has offered respite ... They will take baby for the night or for the weekend. Oh my gosh, we can't even put her in her cot and the cot is right beside the bed. That is beautiful, but no thank you!

Mere and Koro appreciated the offer for additional care, but simply couldn't bear to be away from their young grandchild, or to leave her alone with no whānau members nearby to care for her. Their family is used to being surrounded with people, and even more so during times of difficulty:

When we go to Starship – our first journey to Starship we took all the kids and our older children that live in Auckland they had the kids. My baby will have the kids one night or a couple of nights, and then they go to the North Shore to another older sibling. That is how they rallied around. We have [baby] and her two older sisters and we have three college children, so everybody rallied around for those ones. But our eldest girl took the rest of the year off to help us with her when she went into the coma.

Having a positive connection with whānau is a source of strength for this family, and the emotional and physical support helps them navigate the challenges of the hospital environment, and of providing additional level of care for the child. Being able to share the care load works to support Mere and Koro and alleviates the stressors associated with chronic illness. It also means that there is family to stay with the baby when she is in hospital, so other whānau members can take a rest, come home and have something to eat, and so on and so forth.

The private rental house that the family is living in is inadequate for their needs, and appears to be having a negative impact on the rest of the family's health:

In winter, like now, the walls get mildew and we are forever wiping them ... Our eldest girl had to stay overnight in A&E just recently, a couple of days ago and now this one here, she got a really sore chest and coughing. We figured it is that room.

Despite the house being equipped with a heat pump, Mere commented that it was expensive and ineffective to run "And we have had that heat pump going but it doesn't do much. It takes two days to heat the house, so we don't turn it on anymore." Additionally, family members were sleeping on mattresses on the floor and in the lounge: "Because [daughter] is sleeping on the floor now. Her bed broke." As a result of their referral to, and subsequent engagement with, Whare Ora, they have new beds and new bedding:

Additionally, the Whare Ora connector has made plans to work through a HNZ application with Mere, advising her what letters of support she needed and who to request them from/through, and how to

engage with the process in order for HNZ to understand the need of the household for a suitable home. Mere and Koro explain:

Koro: [Whare Ora connector] is great though. Not very many Māori people can get into those houses [HNZ] because they ring up a phone call and they tell you, you can't, you don't qualify for it and then finish there.

Mere: We were told that so that is why we stopped. Three times we applied and three times we were told, "No". And I did say, "Would supporting letters from social workers and doctors help?" This lady said, "No". I told [Whare Ora connector] that and he said, "She had no right to say that, she had no right to say that". Like you get the people from overseas and they get a house straight away. He [Whare Ora connector] said, "Because they are persistent. They have supporting letters. That is what you need to do, get the letters and always get on their back". He [Whare Ora connector] is going to ring up for us ... We don't know how to talk around those kind of things.

Mere: So [Whare Ora connector] is going to be our advocate for Housing New Zealand. So we have got letters coming from the development specialist, Child Cancer. I rang Starship and they are going to get some letters. Who else? Rainbow.



Figure 11: New bedding

The Harti process, along with subsequent referrals, has worked to assist the family in accessing available social supports in a culturally supportive manner, leaving them feeling supported and valued.

Everyday health

Mere and Koro declined to take photographs, preferring instead to talk with me about their experiences of Whare Ora, of how well their children are doing, and their delight in seeing their baby get well: “we are getting her immunised in October”.

Aroha (Hamilton City)

Overview

Aroha is a Māori woman in her mid-thirties and lives in a worn-out rental home in a low-decile suburb with her 3 children, the eldest of whom is almost 5. Her youngest has been admitted to hospital 3 times this winter with respiratory distress. Her partner has been sent to jail for several months, leaving her particularly reliant on family members to help care for her children when she is in hospital with her youngest. The household's ethnicity is recorded as Māori, and her youngest was admitted due to bronchiectasis.

Harti tool & hospital experience

At the time of experiencing the Harti tool, as administered by the Harti RA, it was Aroha's third time on the ward this winter. One Dr had previously mentioned Whare Ora, but it wasn't until the Harti screening tool was administered, and the subsequent referral by the Harti RA, that someone from referred services made contact. Aroha had not engaged with and/or been offered access to services during her prior visits (it is unclear whether she was offered and declined, or simply had not been offered support: from Aroha's perspective, it was subsequent to experiencing the Harti tool that external services engaged with her). At the time of the interviews, Aroha had received a car-seat, had a Whare Ora assessment, engaged with the Quit Smoking programme, and had plans to meet with Tamariki Ora.

Having 3 young children at home, and with unreliable transportation, having services who were able to come to her eased the pressure she felt, and made such services far more accessible. Additionally, prompt engagement alongside being treated with dignity and respect, resulted in higher engagement by Aroha. Comments by Aroha allude to a history of being disrespected and shamed by others, particularly government services. We see hints of this in Aroha's comment about receiving a car-seat from the Harti RA:

And I really can't afford to get a brand new [car-seat] and I've been asking on PIF [Pay It Forward, a Facebook site set up for helping people] and I was telling her [Harti RA] about it, and the next minute she [Harti RA] walks in with a car seat for me. I was gob smacked man. Not very many good things like that happen to us. It was awesome.

The positive engagement with the Harti RA was particularly influential in leaving Aroha feeling competent and able to navigate services. She felt as though she could be honest with the Harti RA; initially she was wary of the deprivation questions and scared to answer honestly, in case her answers were used to punish her:

There was a few questions that I was a bit wary of answering, like just the ones where I thought it might be me in trouble – have you ever reached out to a service for food, or something like that ... I have with WINZ, will that get me in trouble? Does that mean I can't feed my kids? ... Oh my gosh, I have been for food grants and stuff ... I just said straight up to [Harti RA], like really if I answer this am I going to get in trouble? I want to be honest here, but I'm not going to be honest if it means I'm going to get in trouble.

Aroha's comments allude to a far grimmer reality than is perhaps initially obvious. To Aroha, "getting in trouble" refers to experiences with State Agencies and their punitive interference. These experiences include examples such as such as having WINZ⁷ accuse her of fraud and/or incurring a debt which must be repaid; it means dealing with state welfare services (Oranga Tamariki, previously CYFS) along with the threat of having her children being uplifted; it means the start of what could potentially be an ongoing stressful interaction that leaves her even more isolated with even less financial support. Aroha's previous experiences with State Agencies have taught her that one's personal circumstances are best kept secret. These historical experiences sit at the back of the conversation, influencing her perspective and resulting in a reluctance to engage openly and honestly. In her quote above, Aroha invokes a history of state interference in the lives of low-income Māori whānau that actively prevents people from achieving their aspirations. In contrast, the approach taken by the Harti RA prioritises self-determination, autonomy and actively works to support whānau to achieve their aspirations, giving choice regarding engagement level.

As a result of her engagement with services, Aroha had significantly reduced her smoking, going from 10 cigarettes a day down to 4, thanks to the smoking cessation programme. She had been considering stopping smoking, and the hospitalisation of her son, along with the referrals from the Harti RA gave her the means and the motivation:

I have been thinking about it for a while but I've always been putting it off – man, I'm going to start going crazy and I've got the kids to look after by myself. No! But it has actually been really good, and I'm glad that she gave me the push to do it ... [they] referred me to the quit smoking coach, so she comes around every week to talk to me as well, so that is cool for support.

Aroha commented that, because she would smoke outside and in her dressing gown, she didn't think it was affecting the kids, but actually, after talking with the smoking cessation person, she realized that it was still affecting her child and that it was time to quit. Aroha wondered aloud how life might be different if she'd had the Harti when her son was first admitted, "I mean, if you were around at the first...I might be smoke free already".

Aroha also enjoyed her interactions with the Whare Ora connector. She was able to tell me all about dust mites and how to reduce/limit their activity, how to remove mould effectively, and ways to reduce damp and mould in the home. Whare Ora were also providing fresh blankets, bedding and curtains, which Aroha was very much looking forward to receiving.

They rang me up and they have ordered the beds and the linen and curtains and stuff and it should arrive next week. Very exciting! I can't wait, I couldn't believe my luck. I was like – really? I thought we were putting the beds on there just like a maybe.

With spring around the corner, Aroha was feeling a lot more positive about her children's health and hopeful that there would be no more hospital visits.

Everyday health

During our second interview, Aroha was in the process of putting together a bicycle (from scratch – it came in a box with instructions and looked very complicated!) for her eldest daughter. She showed me

⁷ New Zealand state welfare department

images (see *Figure 12*) from the past week of her children actively engaging in exercise; bouncing on the trampoline, riding their bikes, and going for a walk/scooter.



Figure 12: Children engaged in physical activity

Aroha commented on her children's endless energy, as well as arranging for school enrolments, and doing her best to ensure her children were happily and actively engaged with their education. Her preferred primary school of choice has a good reputation: "I want a school that is going to challenge her, not a school where she is just going to drag on by." Unfortunately, where Aroha lives is just out of zone. Undeterred, she is exploring other options for enrolment "I think I might just ask my Aunty if I can use her address."

Aroha does her best to ensure that her children eat healthily. Fruit and yoghurt are particular favourites with her children (see *Figure 13*). Below Aroha comments on making her children's lunches:

I just give them fruit, yoghurt and sandwiches, maybe a biscuit. And they have morning tea and afternoon tea at kindy as well. They provide morning tea and afternoon tea. So I've been told that I provide them with too much, but when I was younger I always went to school with not very much lunch and I was always hungry, so I really don't want that for my kids. I like sacrifice what I want so that they can have enough in their lunchbox.

Here Aroha alludes to her own experiences of childhood hunger, and her determination to protect her children from living through the same. While the focus of the interview was on Aroha's everyday life, interview snippets (such as the quote above) from both interviews hint at a childhood with limited means. Aroha's desire to provide her children with different childhood experiences means she prioritises food and items for her children, at the expense of her own needs. Nevertheless, the cost of fresh fruit and healthy snacks places additional strain on her budget. In the following quote Aroha notes the added financial cost of providing the required pre-approved food items for kindy:

It was really hard this year for about two months they had some children that were allergic to peanuts. It was really hard. They weren't allowed anything made in the area of peanuts or anything, so basically they were just having fruit and jelly really and a yoghurt – but not a chocolate yoghurt, it had to be a fruit yoghurt. It was more expensive, because the less healthy food is the cheapest. So, we tripled up on fruits. It was like, Mum we only need two pieces of fruit, how come I've got four? Because you are no longer allowed chips, biscuits or muesli bars anymore.



Figure 13: Purchasing and eating healthy snacks

Later on in the conversation, Aroha refers again to the impact her childhood experiences have on her own parenting:

I try not to let mine know if we can't afford something...because I used to worry all the time. Going through the supermarket and I'm like oh no do we have to put anything back. I can laugh about it now – me and my siblings we all laugh about it now! ... We would get to the counter and Dad would be like "do you really need these?", making it look like we didn't really need it while he was putting it back. "No, Dad – it is alright, we don't need those!" Ohhh. Yeah, I'm not going to have my kids do that.

Aroha's memories of her father's behaviour reflect current research into the practices of low-income, food-insecure parents. The stress of insufficient income to feed the family leads to stress and tension over eating food. Aroha remembers regularly being sent to her room for not eating a meal, which at the time she found terribly unfair. Later, as an adult, she learnt the source of her father's anger in this regard: "He just says to me you always used to waste everything, we didn't have the money for you to be wasting it all". Now a parent herself, Aroha better understands her father's underlying distress. Still, Aroha aims to prevent her own children from experiencing the same.

One particular challenge that Aroha faces right now is managing all 3 children on her own. With her partner in jail, she is solely responsible for everything. This is especially difficult when just needing to 'pop out' for a bit. Aroha explains:

You really notice it when you just need bread or milk and it is raining or something and you have to put all the kids in the car just to go around the corner to the shop to get milk or bread. But oh well, such is life.

She appreciates that the 'kindy van' will come and collect her child, which makes managing on her own a little easier: "That is why we picked that kindy actually because they do pick-ups and drop-offs." Aroha is conscious of the stereotyping of others with regards to her parenting, and subsequently takes particular care to ensure that her children are never left on their own, always have sufficient food to eat, and are actively engaged in learning and education.

Maegan* (Greater Waikato/Auckland)

Maegan is a young Māori mother of a 6 month-old baby. She consented to the study, and randomised into the Harti group. Rebekah met with Maegan on the ward and she was more than happy to talk further after discharge. However, Maegan was currently homeless, and unsure where she was going to live. Megan had been living with family in a rural Waikato township. The house was cold, damp, and overcrowded, which likely contributed to the baby's illness. Subsequently her Aunt had said, don't bring baby back, it's no good for him. Maegan was clearly worried and distressed about this, and she shared her concerns about where she was going to live once baby was better. The Harti RA assisted Maegan to find somewhere to live, and she was discharged to live with family Auckland, moving her out of the Waikato region (and the criteria for inclusion).

Despite dealing with some very trying circumstances, when Rebekah met Maegan she was continuing to do her best to care for and look after her baby. She was still breastfeeding at 6 months, and her son seemed settled despite the unfamiliar circumstances, indicating that his mother was ably providing him with relief and sustenance.

Penny (Hamilton City)

Overview

Penny and her husband have 7 children, 5 ranging in age from 22 to 15 years of age, a 3 year old, and a 3 month old. Penny has worked part-time for the Women's Refuge for the past 7 years and is familiar with many of the social services on offer. Subsequently she didn't access any additional services via the Harti tool. Nevertheless she still provided worthwhile feedback regarding the tool and its implementation, as well as her experiences on the ward. The household's ethnicity is recorded as Māori, and her child was admitted due to high fever and rash.

Harti tool & hospital experience

Penny spoke very highly of the ability of the Harti RA to engage with her as Māori. She noted that some of the questions were invasive, but the way in which they were asked meant that Penny felt she could answer them honestly and without feeling whakamā:

I think the questions are a bit too personal, but it was [Harti RA] that made me feel comfortable answering them. I suppose it depends on who is delivering it ... The questions that she [Harti RA] was asking me, I didn't have a problem with because I didn't have issues with those things, but a lot of our people do and might feel a bit whakamā. So it has to be somebody that can connect on that level – open them up to be able to speak.

Penny commented from her observations with her workplace that sometimes whānau can feel very whakamā about answering certain questions. Subsequently it is important to ask these things in a way that leaves whānau feeling supported and cared for, not shamed and alone. Penny felt that the usefulness of the Harti tool was dependent on who was administering it (i.e. the Harti RA) and their cultural competency, particularly their ability to manaaki whānau and engage positively with Māori.

Penny mentioned manaakitanga multiple times, particularly the (in)capacity of the hospital paediatrics wards to manaaki parents, who are doing the caring work for the sick child. Penny explains further:

[Care] is much more than that. I mean, yes they [medical staff] are there to monitor and look after the sick person, but the parents are the ones that are looking after the other stuff – their emotional needs, making sure they are getting enough – just the practical things. That was my experience in there. All they were doing while I was in there was administering meds and observing his obs, so making sure he is not going up and down or whatever. Everything else was on me. And that could be a stressful hard thing when it is just you in there, you and your baby.

Penny felt that if the hospital could manaaki parents better, that would make a huge difference for both the sick patient and for the wider family. She commented on how stressful she found it, having to leave her sick baby alone in the ward to get herself something to eat:

It would be really good if the hospital could feed the parents as well, because I would have to wait until baby was asleep and then run down the road or run to the café or whatever and try and get back before he woke up. That is just another added pressure. It would be good if the hospital could take that pressure off ... the café is too

expensive so I have to go to the shop across the road from the hospital, and I worried about that when I went over there quite a lot, if he wakes up are they going to know that he is up, are they going to hear him crying because they are so busy.

As with many other families, her partner has his hands full, juggling paid work and care for their other children at home. This left Penny hesitant to ask him to take on additional tasks:

It puts a lot of pressure on home life as well. For me I have got my husband here, but we have got six other children, so the last thing I wanted him to do was run around and get me a pie and chips and KFC when he is busy looking after the kids and going to work.

While Penny felt fortunate that their family was able to make it work, she was aware of how stressful it was for her, and for other families as well. She also noted that, while the staff did their best, they also had their hands full doing their work, leaving Penny loath to ask for help:

That ward that I was on, they are mega as busy. I would push the button and sometimes be waiting or 20-30 minutes for somebody to come. They are like super doper busy. The only time they would come pretty much straight away is if I pushed the emergency button, which I ended up doing once, just to see... Just to see if the emergency button actually works.

The busyness of staff acts as a barrier to asking for help, as parents are reluctant to interrupt unless it is absolutely necessary.

Penny had previously had negative experiences with hospital staff and health professionals, but on this stay she noted a difference in approach:

The good thing about it was there were doctors and nurses that came in and greeted you with Kia Ora. And they are quite, what is the word – you know they are not Māori, but they're making the effort. They are making the effort to make me feel welcome and I appreciate that. There was one doctor who actually came in and was having full on conversations in Māori, who was not Māori at all. She is obviously learning more than the normal greeting – hi, bye. It was how are you, how has your day been – all in Māori. So that was really refreshing. That was really cool.

Overall, Penny felt that the staff respected her as Māori and were able to engage with her respectfully. This has not always been the case. Penny remarks:

I've got a Pākehā daughter in law and if she is not there then it is different, but then if she turns up it is different again. I am like wow – you need to come with me! Anytime I feel like I need her to be there I will ring her!

During this hospital stay, Penny felt so supported she didn't need to ring her daughter-in-law in order to receive adequate care. She shared an example of her previous experience on the ward, which contrasts with the refreshing attitude she encountered this visit:

One of the nurses come in and said, how do you say his name? I said, [FULL NAME]. She says, oh I'll just call him [FIRST SYLLABLE] aye? I said, no. Like, not even I call him that. It was just "I'll just call him [THIS]".

This time Penny observed that all personnel made an effort to speak te reo Māori. Regardless of whatever learning level they were at, their behaviour represented a significant change in attitude for Penny. She felt that a truly bicultural and bilingual health system would be transformative for Māori, particularly if such a system could incorporate values such as manaakitanga for the whole whānau.

Due to difficulties in finding a suitable time, there was no second interview.

Astra (Greater Waikato)

Overview

Astra, her partner, and their three children (aged 6 years, 2 years, and 6 weeks) live in her mother-in-law's house in a small Waikato township. Previous half-finished renovations are evident throughout the house, and it is clearly in need of additional renovation work. Due to being owned by family, it provides an affordable and stable home for the family, with a large yard and room for everyone. The household's ethnicity is recorded as Māori, and the reason for admission was an apnoeic episode.

Harti tool & hospital experience

Astra was admitted to the Paediatrics Ward from the Emergency Department in the early hours of the morning. Her 6 week old had stopped breathing, and, while Astra had managed to get him breathing again, there was some concern about why this had happened. It was felt it was best to admit the baby in case it happened again and to try and gain answers. Despite being eligible for meals, Astra received only toast in the morning, and hot drinks during the day. Astra comments on needing to rely on family members for food and support:

I couldn't really go anywhere and get anything. I was just lucky that I had people who were coming. If I didn't I don't know what I would have done ... I was breast feeding her too, so at the night-time I didn't actually know [you didn't get meals] and my partner went home and he wasn't coming back up till the next afternoon so I rang my brother – come up, I'm starving. He was like, what did you have to eat? I was like, only toast ... I just got toast in the morning ... My mother would bring up some food and my brother would bring some up, whoever was coming up would bring some.

Astra was unaware that she was entitled to meals, and, being her first time on the paediatric ward, she simply assumed that was the way things were.

As with many parents, Astra was reluctant to leave her baby alone, preferring instead to wait for family to arrive so she could take a break. She was thankful for family who could come and sit with her baby so she could take a break:

I won't even want my kids to be alone, even to think that they were alone...with baby when she was asleep, I would go out for a little bit and make myself a cuppa, get a drink.

You don't always want to leave your kid there with someone knowing that they are working and they could have other things to do and stuff like that ... you can't always depend on some stranger to be there for you just to do things ... my brother stayed with my baby the second night. They stayed with her for an hour so I could go for a ride and get some fresh air and stuff like that.

Astra spoke highly of the nursing staff, and their efforts to care for her, and for other patients and parents on the ward. She appreciated the efforts made to communicate with her and keep her informed:

They were really nice though. They always made sure that I knew that they were changing over and stuff like that.

Astra also deeply appreciated that her concerns for her young baby were taken seriously, and that clinical staff made every effort to check for any underlying health issues that could have caused him to stop breathing.

Astra spoke positively of her engagements with the Harti RA and her experience of the Harti tool. She was delighted to receive a Pepi pod and associated items for her baby, and had been referred to Whare ora. She elected to stay with Plunket, as she had just been referred to them from her midwife. Astra didn't feel like the questions were too intrusive:

She [Harti RA] did tell me that they might have been, that some people think they are intrusive questions before she asked them and stuff. She made me feel comfortable.

Astra felt that face to face was best, as that gave opportunity to ask questions and to clarify what was being asked.

Everyday health

Astra elected not to take photographs for the second (photo-elicitation) interview, but was more than happy to talk further about the ways in which the family took care of their health needs, of which food was a key component. Astra and her partner share cooking duties, with the children having the option to choose the dinner meal on a Thursday evening. Astra notes that this gives the children some choice over their diet, while preventing ongoing requests and nagging for particular meals.

So, it all depends on what we have. We will just have roast chicken and veggies or like boil up or what else? Nachos. The kids love nachos now. It is good ... We try and let them choose what they want on Thursdays, so that we can try something if they've seen something new ... If they could they would live off mince and chicken.

Previously, Astra has taken a healthy cooking class at the local health centre, and found this enjoyable and informative:

It was teaching you how to cook healthy food and trying to teach you that just because it has vegetables in it doesn't mean it is healthy ... Because Chinese [takeout] has vegetables in it doesn't mean it is healthy. There were also instructions on cooking with reduced oil or fat while doing a roast meal, and plenty of ideas for cooking mince and including vegetables for meals the children will eat.

Astra has found that the household works well if her and/or her partner is in the kitchen preparing dinner while the children do their homework. Astra quite enjoys preparing meals for the family:

It gives the kids time to lax and do what they want to do while I cook dinner, or while my partner cooks dinner and then he will be with them...Do their homework or whatever.

As well as being able to choose the dinner meal on a Thursday night, Astra and her partner include their children in preparing the meals:

My youngest son [2 years] likes to help, so if you don't let him help he just cries the whole time. Here is your potato, figure out how you are going to peel it ... we just give him a potato or something. Or we let him wash the potatoes. Jump up there and

wash them, it will take you long enough and by the end of it you will be soaked and need a bath.

While they enjoy cooking meals for the family, the cost of purchasing food remains a constant stressor. The local community house has a garden and you can purchase a fruit and veggie box for around \$12, which Astra finds more cost effective than growing her own, once the time and effort involved in growing vegetable is factored in:

Interviewer: So what things you find make it hard in terms of health and staying healthy?

Astra: The cost of it, I guess, that would be the main thing. The cost for healthy eating. So called healthy food... That would be it. I have been to cooking classes that teach you how to cook healthy food and how to make your own gardens and stuff, but time is probably a good one too actually.

While Astra and her partner enjoyed their crop of plentiful tomatoes from the year they attended a gardening course, the time and effort it took to maintain and grow them, along with the time and effort required in running a busy household, made it impractical to continue.

As well as cost, Astra finds that the healthy messaging around food is confusing, and gives conflicting messages. The below exchange documents Astra's confusion at Weetbix, a low-fat, low-sugar, wholegrain breakfast cereal, being declared no longer suitable for children's breakfasts:

Interviewer: What would be the things that you would find hard in terms of staying healthy or eating healthy?

Astra: Just the cost of it I reckon. Just the cost of it. And actually, not having all the knowledge about what actually is healthy. What would come under healthy cooking and a healthy lifestyle.

Interviewer: There is a lot of conflicting information.

Astra: Yeah, so you can get something that says it is healthy and then you cook it and all of a sudden it is not healthy anymore!

Interviewer: Yeah. Stuff like with eggs, they were healthy and then they weren't and now they are again. It is very confusing.

Astra: Yes, that too. Even Weetbix, they say that Weetbix isn't healthy for kids to have every day ... It was on the news. It even made it to the news. I was like, oh my gosh. My kids stopped having Weetbix ... They are constantly changing. Always changing – you can go in there one day and it is fine and then the next day they're telling you that it is not.

The constant onslaught of both food-related advertising, research findings, and health promotion messaging leaves Astra unsure who to trust and how to categorise the foods they eat. Nevertheless, she is able to recognise that some breakfast cereals are less healthy than others:

My sister's son has Fruit Loops for breakfast. That is just a whole heap of sugar and she is like – no, look it says it is healthy. No, it is not. That is why he bounces off the walls for an hour and then he is hungry again

Astra also appreciates the simplicity of health promotion efforts:

The five plus a day thing is good to see, just doing the kids. The kids were like that is cool, yeah we should eat that. Yeah, you should!

Although, as Astra comments later in the interview, having too much fruit a day can be unhelpful with regards to portion sizes and weight control.

The other health challenge Astra faces is access to primary health care. Astra notes that it can be a challenge to make an appointment with a General Practitioner (GP) in the small town where she lives:

At our [GP practice] you have to wait for a while. It is usually like three days will be the least amount of time you will be waiting. By the time you go to it you are not sick anymore! ... It is like a miracle if you get one the next day.

Subsequently she accesses alternatives to ensure her children are getting the healthcare they need or if she is concerned about their wellbeing:

I will take him to the A&E [Anglesea Clinic]. I ring the HealthLine actually too to see what they recommend and tell them that the doctors is a couple of days away and it seems like it is getting worse. They are pretty good. I trust HealthLine a lot.

Astra particularly appreciates that the staff at Anglesea Clinic “don’t ever make you feel like it is nothing, which is good.” She would rather get her children checked quickly when they are unwell than wait around worrying about their well-being. Being treated with kindness and respect by healthcare professionals means that she has few qualms about taking her child to the doctor promptly.

Anahera (Hamilton City)

Overview & background

Anahera, a young Māori mother (age 22), lives in a Housing New Zealand home with her partner and their 3 children (5 years and twin boys, 12 months). One of the twins suffers from severe eczema, and he was admitted to the Paediatrics Ward due to infected facial eczema and bronchiectasis. While Anahera was pregnant with twins, her and her partner were homeless; Work and Income housed the family in a local motel for 4 months. While this was better than sleeping in car, Anahera found the transient and non-family centred nature of their accommodation difficult and highly stressful. She spoke of becoming increasingly depressed and unable to function. After the birth of her twins Work and Income found a suitable Housing New Zealand (rent-controlled) home, and Anahera has deeply appreciated having a stable home to live in, and that her oldest child can attend school.

Hints of gang affiliations in the form of red clothing, bandanna's and posters can be seen in the home, and Anahera's manner of speech and habitus signify someone who spent their childhood surviving, rather than having the freedom to focus on learning and school. During our conversations, Anahera shared her experience of being uplifted by the State as a child and the subsequent instability and anger:

We were CYFS8 kids, so we were like from house to house. This family for this week, that family for next week. And then I think that is why I turned out the way I did. I was always mean and then I was like all of 9 years old and every single word that was coming out of my mouth was a swear word, so nobody could handle me.

I used to go to school with black eyes and bumps and stuff all over me, but I'd blame my brother. I blamed my brother one day and they rung my aunty to tell me that I had gone to school with a black eye and then she admitted to doing it. So then I got taken off her and that is when I went back to being a little shit again. Then I got kicked out of Intermediate and never got accepted into a school again in Auckland, because I threw the chair at the principal and then flipped his desk ... my Nan had just died the week before. I got called to the principal's office and he was like "Why are you being like this?" I was like, I just couldn't be bothered. He said "It's not our fault your nan died". That is when I just went stupid "fuck, I hate you!" I started beating everything. "You had no right to do that, like bring my Nan into this. This had nothing to do with my Nan."

While her aunt offered some stability, the discovery that she was engaging in violence against Anahera resulted in another round of unstable foster care. At age 12, when Anahera's grandmother died, the unempathetic response from her school principal and Anahera's subsequent angry outbursts signalled the end of her engagement with formal schooling: her first child was born when she was 16.

Harti tool & hospital experience

Anahera felt able to leave the hospital and come home to shower, change, and eat, which alleviated many of the pressures and stressors other parents faced. Her partner was caring for their other children

⁸ Child Youth and Family Services. This is the State department responsible for child welfare in New Zealand.

at home, so she also wanted to come home to see her family. This hospital stay was the first time her twin boys had been separated, and she was concerned for both of their wellbeing:

He is a twin, so yeah. So their dad came to get the other two. They said I could have his twin brother there because they have never been separation, but he wasn't sick and I didn't want him to get sick so I said no and asked for his dad to come and take him.

Anahera spoke highly of the care she received from the nurses and medical staff. "I haven't had a bad experience there ... I like my stays that I've had so far." Overall, she felt like the staff had her child's best interests at heart, and were doing their best to ensure that he got well.

Being at the hospital on her own and feeling worried for her children, Anahera particularly appreciated the positive interactions she had with the Harti RA:

It was pretty cool. I liked it because it was someone to help me get it off my chest sort of thing, but wasn't going to judge me for what I was saying, so it was cool. I liked it. It wasn't a nurse that would write down notes and then the next nurse reads it and then asks you. So that is what made it easier for me.

Anahera also spoke positively of her experience with undergoing the Harti screening tool. She said yes to smoking cessation and to Whare Ora, but has yet to engage with either service, despite their efforts to connect with her. Nevertheless, she appreciated being referred and the way in which the Harti RA made services accessible for her:

Interviewer: So since your [twins] have been born no one has connected you in with the quit smoking or the Whare Ora or anything like that, even though he has been in and out of hospital?

Anahera: Not until the last time. The quit smoking one they tried to, but it is like my only stress release so I was like no. And being at the hospital, no I'm not going to stop smoking while I'm up there, hell no! Otherwise I'll yell at all of yous! But then this time I don't smoke as much as I did then, so it will be maybe easier to give it up this time around.

Interviewer: Do you reckon it was because it was [Harti RA] going through it with you?

Anahera: Yeah and she made it seem more fun. Not so official. Not "yes/no" questions.

Anahera's previous life experiences means that she can be reluctant to engage with services, particularly where she feels under threat of judgement or coercion. Indeed, any perceived slight her parenting resulted in strong pushback by Anahera. Her son had been instructed to have nil by mouth due to his feeding tube. Anahera noted that her son was fussing and behaving like he was hungry, so she proceeded to feed her son a bottle:

They don't get fed a certain amount when they are on that thing, but you know your kid is starving. That is the hardest part. Then they look at you like, I told you don't do that [feed your child]. But that is my kid and I'm not going to let him starve because

you said no! That is the only hard part I feel, is that you can't feed your kid when you want to. Like he was having a tube but my baby was still starving. Then they will walk in and I'm feeding him the bottle and then they'll look ... My baby is hungry, I'm going to feed him, I don't care! ... I found that when I started feeding him the way I wanted to, he was slowly getting better faster. He would just cry and cry and you would give him a bottle and then he was alright again. Then they would walk in and they were like [makes disparaging noise]. I don't care, look at me sideways, I don't care. You look at me sideways when I starve my kid so I'm not listening to you.

In the above quote, Anahera is well aware of the judgement of others, even when it is unspoken. She is also determined to do what is best for her child, even where this conflicts with “the rules”. Anahera’s pushback response is entirely understandable when considered in the wider context of her life, particularly her early experiences of violence and abuse, and that the authoritarian-style actions of medical professionals likely mirror and/or trigger difficult memories.

Everyday health

Anahera is well versed in the creams and medicines her son needs to keep his eczema under control, rattling them off in quick succession:

We have Locoid and sorbelene. Sorbelene is the moisturiser so that when his cream thingy doesn't crack. The eczema started getting really, really bad and then the doctor gave us Crystaderm, and we were using it but then it started burning his face and it was just like really raw and weepy. We have calmed it down with the Locoid thingy. It is hard because they both got it in their ears too, so that is worse because their ear is always bleeding and stuff. That is hard to see. Any little bit of blood that comes off my kids I cry. It is hard to see that. It makes me feel like I'm not a good parent because my kid is bleeding or my kid has got eczema. You can't help it ... Yesterday they had a bath and then we went for a ride to town and in the space from here to town he had clawed his whole face up. His hand was covered in blood and there was like blood smears like that on his face. I cried.

Despite trying multiple creams and assorted recommended items, the only thing that makes a difference is the Locoid cream. However, Anahera worries about the long-term effects of using steroid creams on the face:

I know with the Locoid thing you have to stop using it at 5. I know that because my brother in law had bad eczema like that too and he was still using it at 15 and a side effect of it is blindness and now my brother in law is blind. So that got put down to medical misadventure, because they were up north when he got the cream and he just carried on getting refill thingys.

Despite having an intimate knowledge of the medicines her son needs, and being highly active in ensuring that he receives the medically-prescribed care he needs, the ongoing prevalence of her son’s facial eczema leaves Anahera feeling distressed: “I feel like a bad mum”.



Figure 14: Twins playing on the lawn.

Prior to being placed in a Housing New Zealand house, Anahera was homeless: Work and Income placed her in a motel as Anahera could not afford a private rental. She is aware of her low-priority status as a private renter, noting that it was her 'bad credit' that led to her being unable to procure a home in this sector. She is very thankful to be in a Housing New Zealand house, and is hopeful that as her children grow that she will be able to move into a larger home with enough room for everyone. Below Anahera comments on the stressful and difficult nature of such temporary accommodation:

When I went into the hospital when they both had bronchiolitis was the first time they ever got it. Manaaki was on day two, and he was on day one, but we went home and he stopped breathing for about ten seconds because he was having a crying coughing splurting fit thing. He went really purple and stopped breathing for a while...I smacked him really hard and then he did the gasp thing. It was pretty hard. We were in a motel and I think I was going through the pregnancy...blues thingy.

The people I was talking to they put it down to situational depression. As soon as we got our own house everything changed because the space was a lot better. But at the motel there was just nothing to do, so all I had to do was think about shit stuff. That wasn't helping. But now that we have our own house it is better.

The one that we were at, [the manager] didn't like kids, but everybody had kids. There was nowhere for the kids to play ... [the manager] can hear them running around at maybe 7 o'clock and then he will come out of his room and yell at the kids. It is like, no, you can't yell at them, there is nowhere for them to play and then when they do find somewhere to play you growl them because you are not allowed over there. They had a pool and the kids weren't allowed to swim in it...It was bullshit.

But it is all better now. Well, for us it is. I'm not sure about the other families that are there.

In the above comment Anahera is making the links between having a stable, secure home to live in versus the distress of surviving in transient housing with unfriendly people, and the impact that had on her mental health. While the current house is not perfect, with Anahera noting a tendency towards cold and damp, she is far less stressed and worried now that her family is settled in their own place.

During this interview, Anahera also shared photographs of family outings, including trips to the Hamilton Lake and Hamilton Gardens (see *Figure 15* and *Figure 16*). Both of these places are civic spaces, and are available free of charge to all. They are designed as pleasant, fun spaces for children and adults alike, and Anahera enjoyed being able to take her children and to participate together in enjoying these spaces.



Figure 15: Family outing to Hamilton Gardens

Additionally, these spaces are designed to encourage active movement. Anahera's older boy particularly enjoys the playground facility at the Hamilton Lake, listing the slide and monkey bars as favourite items to play on. Anahera keeps her babies in their capsules at the Hamilton Lake, and worries that it may be "too boring" for them just to watch their brother play:

There wasn't much to do and the parks were practically there. Even though it is cool for [older boy], they [twins] don't get to have any fun, so we went for a walk where we all could do it. But then they went to sleep so we should have just taken him to the park!



Figure 16: Babies in capsules at the Hamilton Lake

Nevertheless, both the Hamilton Lake and the Hamilton Gardens were equally enjoyable as a family outing for everyone. Being able to access civic spaces such as gardens and playgrounds as equal and participating citizens is important in creating an equitable society, as well as being excellent for children's development, and for contributing positively to mental and physical health.

Having had a fractured upbringing, it is important to Anahera that her children are able to spend time with their wider family. *Figure 17* shows time spent with her partner's family, celebrating her niece's birthday. Anahera comments

I was at his cousin's birthday last night, she turned ten. We went over there for that. That is an unhealthy photo, because they just got junk food all night ... Jelly, ice cream, cream, cake, chips, donuts ... I was like, make the most of this because this ain't happening at home.



Figure 17: Cousins 10 year birthday party

While the food at birthday celebrations is considered highly unhealthy, being able to participate in important familial rituals such as cake and ice-cream for a 10-year old's birthday are healthy in other ways, nourishing a sense of belonging and connectedness. This feeling is particularly poignant given Anahera's childhood where such taken-for-granted occurrences were disrupted, leaving Anahera isolated, angry, and alone.

Kiri (Greater Waikato)

Overview

Kiri lives with her partner, his two children (his previous partner passed away in a car accident when the children were pre-schoolers; the children are now teenagers), and the three children they have together (aged 3, 5, 7). They rent a villa-style home in a small rural township; evidence of the children's residence is visible in the plethora of children's toys scattered on the lawn. A healthy looking vegetable garden grows in the sunny back yard. On the morning I visited it was the day of the primary teacher's strike; subsequently all children were home from school, and rotated in and out of the lounge as their mother and I conversed. Their youngest child 3, has ongoing respiratory challenges, necessitating regular trips to the local doctor and to Waikato Hospital. She was the child most recently admitted to hospital (with shortness of breath/asthma). Her ethnicity is listed as Māori and NZ European. Due to the end of the year fast approaching and the associated increased busyness, we were unable to arrange a time to meet for our second interview.

Harti tool & hospital experience

Kiri received tea and toast while in the hospital. She was on the ward for 4 days, and spoke of going hungry, and hoping her daughter didn't eat all her meals so that she would at least have something to eat. The Harti RA brought her some soup and buns, which she deeply appreciated. Even so, the absence of food is a major point of stress for Kiri:

They don't feed you. Like they say they only feed mothers with kids under the age of 1. It is like they don't let us leave, you know? How am I supposed to eat? My partner can't just come over and give me food like every day. We will be in there for weeks at a time. I will just have to pack food [to bring] ... I would eat [daughter's] left overs that she didn't eat. She eats all her food. There wasn't much left.

Kiri has little available funds to spend on purchasing food from the hospital cafeteria. While her partner works full-time, when Kiri is in the hospital he has to take unpaid leave in order to provide care for the remaining 4 children at home. This adds additional financial pressure to the family's finances. Subsequently Kiri is reluctant to spend money the family can ill-afford on expensive café food while in hospital.

Kiri also talked about the difficulties she had in getting appropriate healthcare, and in being taken seriously when concerned about her daughter's health:

She has been in and out since she was 6 months old with all different stuff, pneumonia, bronchiolitis, asthma. She had surgery on her head. A moszy bite got infected and it turned into like a big pus ... I kept taking her to the doctor every week and they kept sending me home and then they said that it was an infected moszy bite.

The mosquito bite Kiri refers to eventually required surgery. You can hear Kiri's sense of frustration in "doing everything right" yet being brushed off until the infection required surgery to fix. As well as this, Kiri shared her experiences of discrimination by healthcare professionals, of being accused not giving her child her medication, and of having state child welfare services (Oranga Tamariki, previously CYFS)

contacted by health professionals due to her daughter's persistent and ongoing ill health. Below she mentions how awful it is to see her child so sick, and the unhelpful attitudes she encounters:

The second to last time she was in intensive care, she ended up in intensive care as well. It was horrible ... they think I don't give her her asthma medicine, her preventive medicine and I do. Certain things trigger her asthma and then I'll give her her reliever and then it just doesn't relieve her so they diagnosed her with brittle asthma, so she needs like hospital treatment, like nebulizers and IV treatment. It is horrible.

Despite the accusations from health workers, Kiri is highly involved in her children's wellbeing. She has removed her pre-schooler from kindergarten, as she persistently came home unwell and sick from the other children's infections. Kiri also is well aware of her daughter's medications and continues to seek medical help despite the attitudes she encounters.

Kiri also mentioned her own health and her diagnosis of Type 2 diabetes mellitus. Subsequently, she has decided it would be too risky to have more children. Additionally, Kiri and her partner have "given up drinking and everything because of my diabetes". Being in hospital without access to food has a detrimental impact on Kiri's health. Despite telling the admissions staff that she has diabetes, she did not receive meals during her most recent stay, and the implication from the interviews was that she rarely receives meals while staying on the ward or in the Emergency Department with her daughter. Her previous experiences with healthcare professionals, and their negative perceptions of her parenting ability leaves her reluctant to engage unless absolutely necessary.

In regards to the Harti screening tool, Kiri spoke highly of her interactions with the Harti RA, and was positive about the experience. However, she had yet to access any of the available services. The combination of a sick child, end-of-year busyness, and living some distance away made a second interview ultimately unrealistic.

Discussion

Across all the cases, similarities of experience emerge; financial stressors and strain; hunger and isolation; concern for their child(ren); and families that are actively engaged in caring for their children's health and well-being.

The Harti screening tool, when administered by a culturally competent Harti RA, counteracts previous alienating experiences. Being treated with dignity, respect and value had a positive impact. Participants spoke at length regarding how wonderful it was to be able to engage with the Harti RA's as Māori and in a culturally appropriate way. Further positive engagement with culturally responsive social services had a positive impact on the health and well-being of participating whānau.

1: Barriers to health care

Overall, participants were highly attuned to the negative perceptions of themselves as Māori by health professionals. Sometimes this was more subtle, such as Anahera describing the facial expressions of staff or London's experience of having staff disbelieve her age, and other times more overt, such as Taryn's telling of her negative interactions with a clinician or Penny's memory of a nurse refusing to call her son by his full (Māori) name. Participant experiences align with previously published literature, which notes that Māori patients report more actively hostile experiences such as being treated with scepticism (Penney et al., 2011), experiences of overt racism and discrimination (Reid, Cormack, & Crowe, 2016; Willams et al., 2003; Wilson & Barton, 2012), and staff mispronunciations of names (Arlidge et al., 2009). Participants also shared memories of past experiences of discriminatory treatment. Mere and Aroha both commented on their memories of being treated poorly and in a discriminatory fashion. Feeling culturally alienated in this manner exacerbates feelings of anxiety and worry while in hospital (Arlidge et al., 2009; Kidd, Gibbons, Kara, Blundell, & Berryman, 2013; Wilson & Barton, 2012). Penny had previously had negative experiences with hospital staff and health professionals, but on this stay she noted a difference in approach: all personnel made an effort to speak te reo Māori. This represented a significant change in health professionals attitude for Penny. These memories indicate a need for consistent high-quality experiences in order to overcome past histories of prejudicial and inequitable conduct.

Underpinning participant experiences was a sense that their wider spiritual and cultural practices associated with their cultural identity were devalued within the mainstream health system; Manaia spoke of needing to refresh her wairua after her hospital experience, Celia was still processing her feelings of grief yet her partner was not allowed to stay, Ngaio was dealing with multiple agencies while in the process of undertaking whangai, Whetu wanted to discuss rongoā but didn't feel that anyone at the hospital was available to do so, Taryn would have liked to have her mother stay for support, and London noted that hospital staff were reluctant to let her leave to spend time with her other children. Their experiences reflect previous studies (Kidd et al., 2013; Walker et al., 2008; Wilson & Barton, 2012), and indicate that there is much work to be done in terms of usual care, in that policy ideals have yet to be translated into culturally supportive treatment in everyday hospital life. Of particular note is the desire expressed by participants in the Usual Care group to have wider family present for support, and their aspiration to discuss cultural and spiritual practices with someone more knowledgeable. Both of these expressions of Māori health were left unmet within the clinical-focussed hospital setting

Two participants (Whetu, Anahera) whose children have facial eczema were particularly interested in rongoā use. Both would have appreciated an in-depth discussion with a knowledgeable person regarding the types of rongoā suitable for use with their child's condition. However, neither felt comfortable discussing this with the health professionals they interacted with. This is congruent with other studies considering the experiences of Māori patients and their comments around rongoā use (Tinirau, Gillies, & Tinirau, 2011; Willams et al., 2003; Wilson & Barton, 2012). Typically, rongoā use is not discussed with doctors as the domination of the biomedical approach to healthcare leaves little room for traditional practices. Instead, Māori patients and whānau wait until discharge before accessing traditional healing techniques such as rongoā, karakia, and mirimiri (Tinirau et al., 2011; Willams et al., 2003; Wilson & Barton, 2012).

Participants understood that clinical hospital staff were busy and under pressure, and subsequently were often reluctant to ask for help. Where parents did 'ring the buzzer' it could still take some time for help to arrive (Jodie, Penny). Their comments reflect previous studies which noted that Māori patients and whānau are well-attuned to the stress levels and concerns of health workers, and are subsequently hesitant to disturb staff (Arlidge et al., 2009; Stevenson, Filoche, Cram, & Lawton, 2016), not wanting to "be a nuisance" (Kidd et al., 2013, p. 132), and reluctant to insist on receiving much-needed healthcare (Gilmour, Huntington, & Robson, 2016; Kerr et al., 2010; Nikora et al., 2011; Penney et al., 2011). This form of self-silencing in order to avoid pressuring staff leads to poorer health outcomes for Māori patients. Participants in our study were active in ensuring their child received care, but often minimised or self-silenced their own needs. Indeed, hospital stays were seen as something to be endured for the sake of the health of their child, and to be exited as soon as physically possible.

The caregivers we talked with understood that hospital staff were doing their best to help their child, and appreciated efforts made to include them in communications and care plans. For example, Ngaio felt that individual health workers were kind and thoughtful and she felt included in clinical care conversations. However, the overall set-up in terms of care for the caregivers left her hungry, stressed, and isolated from her whānau. Where a negative comment was made, it was typically regarding interactions with a specific individual. Taryn and Penny both commented on individual interactions that were alienating; both also acknowledged that this was inconsistent with their other, positive interactions with clinical staff. Overall, participants felt that clinical staff had the best interests of their child at heart and were working hard to provide care for all the patients on the ward. However, the bar of expectation was very low. The case of Celia highlights this; having experienced the previous death of her child while in hospital, her expectation of adequate care was, quite literally, is my child still alive? While the other participants had different experiences, the bar of expectation appeared to be that merely receiving adequate clinical care for their child (that is, seeing a doctor or specialist, and having their concerns taken seriously enough to be admitted to hospital) was sufficient.

Previous studies have documented that financial costs (Martins et al., 2015; Slater et al., 2013; Stevenson et al., 2016; Walker et al., 2008), transportation issues (Gilmour et al., 2016; Kidd et al., 2013; Penney et al., 2011; Stevenson et al., 2016; Tinirau et al., 2011), and practicalities such as organising leave and/or childcare (Arlidge et al., 2009; Lee & North, 2013; Nikora et al., 2011; Wilson & Barton, 2012) act as obstacles to accessing clinics, attending appointments, and receiving appropriate levels of healthcare. Participants in this study mentioned the extra expenses associated with a hospital stay, such as reduced work hours (Kiri, Penny), parking and transport costs (Clare, Jodie), the need to pay for additional food

and personal care items (Astra, Kiri, Manaia), being isolated and away from whānau support (Anahera, Aroha, Whetu) and the wider cost of the hospital stay (Mere). This was exacerbated for families from the Greater Waikato Region, particularly where they did not have family locally to provide support for the parent. Current Waikato District Health Board policies on support for families are predicated on the assumption of a nuclear family unit and that families can afford to cover costs while a child is in hospital. Proffered supports are either not offered and/or insufficient for low-income families.

Wider family were often involved in caring for children not in hospital, and/or providing financially, leaving mothers in particular isolated, alone, and without funds for additional items while in hospital caring for their unwell child. The case of Jodie highlights how this cost is borne by families, even up to several weeks after a hospital stay, leaving families on highly constrained incomes without sufficient money for food and/or transport until they are able to financially recover. Prevalent in participant narratives was both the absence of provided food, and the cost of sourcing food. Subsequently, the majority of our participants went hungry while in hospital providing care for their sick child.

Caregivers who had prior negative experiences with State Services were reluctant to call attention to their impoverishment (Mere, Aroha, Anahera, Kiri, Manaia, Celia). The shame and fear associated with poverty and being unable to afford food means that these parents end up hungry, isolated, and alone during their stay. Historical trauma and past incidences of being treated with disdain, negative comments, and feelings of discrimination, result in a reluctance to engage openly and honestly about impoverished realities and individual situations. Being unable to afford food comes with a sense of shame and social stigma; it is not uncommon for parents in such situations to mask their hunger. Recalling our earlier mention of minimising and self-silencing in order to avoid disturbing hospital staff, the fear of punishment by state authorities for seeking help adds another layer of silence to such experiences, leaving Māori patients and whānau even more vulnerable to ill health.

Of particular note is the case of Maegan, who was homeless at the time of her child's hospital admission. Maegan was clearly worried and distressed about her situation, and where she was going to go on discharge. Due to assistance by the Harti RA's, she was eventually discharged to live with family Auckland. However, this shift moved her out of the Waikato region (and the criteria for inclusion in our study). This case highlights the difficulty in documenting the lived reality of the very poor, and that these voices are absent from our study. Nevertheless, each of the cases in this study highlights the different ways that, for low-income families, the extra costs associated with a hospital stay increase their stress levels, add an extra layer of anxiety to their concerns for their sick child, and impact on their family's financial situation.

A note on meal provision on the Paediatrics Ward

The unexpected nature of hospital admissions for acute conditions resulted in research participants being so concerned for their child that they did not think to bring personal items for themselves or food to eat (e.g. Manaia, Whetu). Additionally, being away from partners, children and wider family left mothers in particular, feeling lonely and isolated (e.g. Ngaio, Kiri). For low-income whānau already finding it difficult to make ends meet, purchasing additional hospital café food was an unaffordable luxury. Locating more affordable food required leaving their ill child alone on the ward and going off-site; whānau were reluctant to leave their child alone and became distressed at having no-one to care for their child if they were to leave their room to purchase food.

The absence of sufficient meal provision for caregivers meant that they were reliant on extended family networks to bring them food and meals to eat. This was not always possible due to financial, transport, and time constraints: whānau networks could not always afford to purchase additional food, whānau did not always have suitable transportation networks to facilitate food delivery, and whānau members (including fathers) were often juggling paid work with looking after children (siblings of the sick child), making additional food provision logistically challenging. For low-income Māori whānau in particular, their own financial insufficiency, along with the inability of whānau networks to meet their food-related needs left them feeling embarrassed and ashamed.

The absence of meal provision for caregivers caring for a sick child in hospital contravenes the United Nations Sustainable Development Goals 2 (Zero Hunger) and 3 (Ensure healthy lives and promote well-being for all at all ages). It particularly contravenes Goal 3.4 (which seeks to promote mental health and well-being) and 3.8 (access to quality health-care services). Insufficient food to eat while caring for a sick child heightens the distress, concern and worry that parents face. This in turn influences whānau capacity for recovery to a space of wellbeing. This breaches the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), notably Article 24 (the right to Indigenous health). Additionally, declining to provide sufficient food means that District Health Boards are failing to meet their own legislative requirements, notably the stated objective of “improving, promoting, and protecting the health of people and communities”⁹.

2: Facilitators to access

Having the Harti screening tool administered by a culturally competent Harti RA acts as a facilitator and a way to ‘bridge the gap’ between proffered healthcare and actual need. These gaps take the form of practical support in the provision of car seats, travel assistance, and food from home; emotional wellbeing through mitigating micro-aggressions and providing high-quality, culturally-safe interactions; and assistance with navigating the health system through clear explanations of referral processes and prompt follow-up. Each of these are discussed in turn.

Practical Support

All recipients of car-seats, both those documented in our study (Jodie, Aroha) and anecdotally from non-interviewed Harti participants, were highly enthusiastic about this form of practical support. As documented by our interviews with Jodie and Aroha, sourcing inexpensive, safe care-seats for their children was a source of stress and concern; car-seats for toddlers in particular are expensive and financially out-of-reach for those on heavily constrained incomes. The car-seats were a tangible reminder of care by others for their family’s well-being, transforming them from a utilitarian object into a material artefact representative of care (Olsen, 2003).

As noted by multiple participants in this study (e.g. Clare, Kiri, Jodie, Ngaio), the provision of transport (and associated costs such as parking fees) to and from hospital places additional financial burdens on families. This is consistent with other publications documenting the hidden costs of healthcare (Kerr et al., 2010; Lee & North, 2013; Walker et al., 2008). Where the Harti tool made a difference, was that the

⁹ See full legislation here: <http://legislation.govt.nz/act/public/2000/0091/72.0/DLM80051.html>

Harti RA was better positioned to talk with whānau and empowered to provide transport vouchers as needed. Additionally, parents appreciated the efforts made by the Harti RA to bring in items of food and organise personal cares to ensure that they were able to “have a break”. Sole parents in larger urban centres can be isolated from whānau, with many carrying the full financial and emotional load of care for children in addition to their own healthcare needs (Lee & North, 2013; Reid et al., 2016; Stevenson et al., 2016). Having kindly, practical support in the form of cup of tea or shower paraphernalia is a simple act that makes a significant difference for parents.

Emotional well-being

Engaging with a culturally competent health professional as part of the Harti process acted as a protective layer between negative micro-aggressions of clinical staff, deficit-oriented assumptions by health workers, and previous negative experiences of healthcare. The language that the Harti RA utilised, alongside high-quality interactions and facial expressions, all acted to communicate a non-judgemental, Māori-centred, Māori-positive environment. This in turn contributed towards emotional well-being and worked to counteract past experiences of racism and discrimination.

Our findings are consistent with previous studies that mention the value of relational rapport in culturally appropriate ways, and how exhibiting qualities such as compassion and warmth have a positive impact on emotional well-being (Kidd et al., 2013; Stevenson et al., 2016). Humour (Willams, 2003), dignity (Walker, 2008), and care for the whole person (Kerr et al., 2010) were all seen to foster healthy clinical relationships that resulted in positive outcomes for Māori patients. Participants who had received the Harti screening tool as delivered by the Harti RA spoke positively of their experience, particularly the ability of the Harti RA to engage positively with them “as Māori” (Mere); [she] “made me feel comfortable” (Penny, Astra); “wasn’t going to judge me” (Anahera).

Alongside high-quality interactions, consistency of care and engaging with one key hospital person was recognised as an emotional benefit (Stevenson et al., 2016). Overall, where Māori patients had positive relationships with healthcare practitioners and/or someone they ‘trusted’ in hospital, it made a positive difference to their experiences, engagement, and health outcomes (Masters-Awatere, 2017). Our findings suggest that the Harti RA was able to be that “one key person” for our participants, and that their interactions then worked to empower participants to engage confidently with clinical staff and healthcare workers. This was particularly evident in the case of Aroha, who, subsequent to her engagements with the Harti RA, went on to engage positively with multiple community health groups.

Health system navigation

Navigating the health system on behalf of unwell family members is difficult and stressful and requires time, energy and skill (Arlidge et al., 2009; Reid et al., 2016; Wilson & Barton, 2012). Having a trusted whānau member who could interpret information and advocate for their needs makes a positive difference to Māori health outcomes. This is due in part to Māori, particularly low-income Māori whānau, receiving less-than-ideal service in healthcare settings. That is, Māori experience reduced access to social determinants of health (Blakely et al., 2004), higher rates of preventable, adverse¹⁰, in-hospital events

¹⁰ Davis et al defined a preventable adverse event as an unintended injury that resulted in disability or death, with evidence of an error by health-care management due to failure to follow accepted practice.

(Davis et al., 2006), and increased likelihood of inappropriate care and follow-up (Anderson et al., 2016; Jansen & Smith, 2006). Māori patients typically receive inequitable access to interventions and quality of care (Jansen, Bacal, & Crengle, 2009; Westbrooke et al., 2001) and consistently report negative hospital experiences (Adcock, Lawton, & Cram, 2018; McKinny, 2006). Correspondingly, Māori families accessing hospital care for a child have encountered systemic barriers (Bolitho & Huntington, 2006).

It is clear from the existing literature that Māori receive low-quality 'Usual Care'. While this report does not compare the experiences of participants with other groups, from our interviews it was clear that the Usual Care recipients received low-quality, bare-minimum service – and that this form of clinical care was accepted as 'the norm'. The case of Celia highlights how low the bar is set for some families; it is, literally, "Did my baby die?"

Participant experiences of the Harti tool indicate that high-quality system navigation such as ensuring that referrals are made and following through to available services, and ensuring that families are accessing resources to which they are entitled (such as Tamariki Ora, GP enrolment) AND to additional services (car seats, inhalator study) resulted in positive uptake of services and increased engagement with wider healthcare providers (e.g. Aroha, Anahera). In contrast, Usual Care participants were not always referred to culturally appropriate services, or, if they were, this was not followed up and/or the parent was so overwhelmed and demoralised from their hospital experience that they declined to further engage with other services (e.g. Taryn).

For the mothers (both Harti Whānau and Usual Care groups) who had had previous negative experiences with state surveillance (e.g. Anahera, Manaia, Aroha, Kiri), there was a strong reluctance and hesitation to engage with wider state-sponsored services for fear of on-going judgement and potential disciplinary action. Their personal memories of trauma reflect broader cultural memories of historical trauma (Pihama et al., 2014), compounding their reluctance to engage with government-sponsored health workers.

As such, the use of the Harti screening tool, in conjunction with the Harti RA, resulted in health service provision that reflected Māori patient experiences of Māori service providers who were typically described as "being like whānau" (Slater et al., 2013), "so welcoming" (Kidd et al., 2013), and given "high praise" (Walker et al., 2008) due to their provision of clear information, advocacy assistance and/or medication management.

3. Everyday health

Across both Usual Care and Harti Whānau groups, images provided by participating whānau reference healthy food ideals, physical activity, knowledge of medications, and an understanding of the health needs of their children. Existing literature notes health professionals' negative perceptions of whānau Māori (Kerr et al., 2010; Kidd et al., 2013; Penney et al., 2011). These negative assumptions of whānau Māori contribute to reduced quality of care and follow-up events (Anderson et al., 2016; Jansen & Smith, 2006). Of interest to this study is the stereotype that 'Māori don't care about their health'. This trope comes from the misinterpretation of events such as missed appointments, unpaid bills, lack of 'compliance', and an unwillingness to engage relationally with Māori patients. These negative

assumptions by health workers act as a barrier to high quality care for Māori whānau. Nevertheless, Māori patients and whānau continue to do the best they can with the resources available to them.

The whānau interviewed for this study have clear health aspirations for their children. However, as noted by Jodie, Aroha, and Taryn, meeting food-related healthy eating aspirations is challenging with low-incomes. Being unable to meet healthy food ideals is associated with poverty and food insecurity (Boon & Farnsworth, 2011). Food insecurity is defined as the *absence* of “nutritionally adequate and safe foods or the ability to acquire acceptable foods in socially acceptable ways is limited or uncertain” (Coleman-Jensen, 2010). In 2008/09, 7.3% of NZ households experienced severe food insecurity, and 33% of NZ households reported moderate levels of food insecurity (University of Otago and Ministry of Health, 2012). A more recent Ministry of Health report found that just under one in five children (19%) live with severe food insecurity, and this significantly impacts on their health and well-being (Ministry of Health, 2019). A fifth (20.9%) of Māori women aged 21-50 experience severe food insecurity (University of Otago and Ministry of Health, 2012). Effectively, the more deprived the neighborhood, the more severe the food insecurity and associated distress (Carter, Kruse, Blakely, & Collings, 2011).

Whānau Māori are over-represented in low-income New Zealand households and in areas of high deprivation (Salmond, Crampton, King, & Waldegrave, 2006). Highly-deprived areas have reduced access to fresh fruit and vegetables, and residents in these areas are more likely to report eating white bread, hot chips, take-out, and soft drinks (Ministry of Health, 2014). In such circumstances, Māori families turn to places that will provide enough food to feed the family at reduced prices, such as high-fat saturated foods (Jani, Rush, Crook, & Simmonds, 2018). Community groups involved in emergency food support note high demand for accessible fresh fruit and vegetables, yet bread remains the most commonly donated item (Moore, 2019). The poverty cycle that traps whānau Māori in low-nutrition environments with poor access to healthier foods is becoming harder to escape (Hodgetts & Stolte, 2017). The physical health consequences of insufficient food access and poor diet are then transferred to the next generation (Harwood & Tipene-Leach, 2007; Lombe, Nebbitt, Sinha, & Reynolds, 2016). In short, while whānau are aware of healthy food messages and do their best to provide healthy foods for their children, insufficient access to resources creates additional barriers to meeting their food-related aspirations.

Child health is associated with poverty, with the poorest New Zealand families having the worst health outcomes (Turner et al., 2011). Some posit that this correlation is due to poor health literacy and insufficient health knowledge (e.g. White, Reid, & Damiris, 2014). However, interviews with whānau in this study indicate that associated poorer health outcomes are more likely to be a result of insufficient access to resources and/or available supports rather than insufficient health literacy or health knowledge. From medications stored in the fridge (Clare), to kawakawa leaves in the bath (Whetu), to appointment times on the noticeboard (Celia), to follow-up visits with their local GP (Mason), all the caregivers of tamariki Māori interviewed showed both a thorough understanding of their child’s health needs, and engaged in efforts to work with health professionals to ensure that their child had positive health outcomes.

Conversations arising from provided images reference the challenges of healthy homes, including the high cost and poor quality of private rentals, and the impacts that this has on tamariki hauora. Such comments are congruent with the existing literature on housing in Aotearoa New Zealand, which note the poor quality of existing housing stock (Johnson, Howden-Chapman, & Eaqub, 2018), that high-cost

and poor-quality housing exacerbates psychological distress (Pierse, Carter, Bierre, Law, & Howden-Chapman, 2016), and that Māori are more likely to experience housing deprivation (Amore, 2016). Existing research also notes that poor quality housing negatively impacts on the respiratory health of children (Tin Tin et al., 2016), increases the risk of pneumonia and hospitalisation with pneumonia (Grant et al., 2012), and that even simple measure such as retrofitted insulation and new heaters can decrease health service and pharmaceutical costs (Telfar et al., 2011). These are not new findings, but it bears repeating: poor quality housing negatively impacts on the health of children. Even where whānau Māori are eligible for state housing assistance (such as in the case of Mere) they are less likely to receive it, and more likely (as in the case of Anahera) to be placed in temporary housing.

Our findings indicate that both Usual Care and Harti Whānau groups are doing the best they can to provide healthy food, exercise regularly, and keep their homes as dry and healthy as possible. These efforts typically go unrecognised, and health professionals continue to disregard whānau attempts to manage their health. Our findings challenge individualised deficit constructions of health-related behaviours of wāhine Māori and whānau Māori.

Recommendations

Following our series of qualitative interviews with research participants, we have 4 distinct-but-related recommendations to make. These are draft recommendations; the full set of recommendations, along with the full report for the entire Harti Hauora Tamariki project, will be forthcoming at the completion of the project in 2020.

While this research was undertaken at the Waikato Hospital, the issues raised are applicable nationally. Whānau Māori live throughout Aotearoa New Zealand, and face similar issues to those described by participants.

We are aware of the need to provide healthcare professionals with training in being able to better support whānau as they engage in caring for their health practices. In developing such training, we recommend an approach that emphasizes that whānau Māori do the best they can to manage their health with the resources that they have available, that dominant societal narratives surrounding poverty prevent families from asking for help, and that there is a need for healthcare practitioners to interrogate their own assumptions regarding Māori patients and whānau.

Recommendations for immediate implementation:

- 1) A checklist for whānau leaving the GP office for hospital
 - a. This list would guide first-timers at the hospital, and assist with focus for caregivers while packing appropriate and needed items for a hospital stay

Recommendations for Hospital services

In order to reduce barriers to healthcare and associated services, and to facilitate whānau of tamariki Māori feeling able to access available supports we recommend the following:

1. A **dedicated Harti health professional** who engages with all families of admitted children to the Paediatrics Ward at Waikato Hospital. This person will administer the Harti tool on a full-time basis. Having a dedicated Harti staff member will ensure that there is a systematic approach to

delivering supports, and work to increase awareness of available supports, particularly for low-income families.

2. A **designated Harti administration person/team**. Having allocated administrative hours will help ensure that regular updates of available services occur, that these will be tailored to the local region (in this instance, the Waikato), and keep the Harti screening tool up-to-date. Designated administrative hours will also assist in providing a systematic approach, promote administrative networking across hospital departments, social services, and DHB's, and avoid overloading a single worker.
3. All health professional staff at Waikato Hospital to consistently **provide high-quality experiences for Māori patients and whānau** in order to overcome past histories of prejudicial and inequitable conduct. In order to achieve this, we suggest the following:
 - a. All staff continue learning te reo Māori and to continue to extensively use te reo Māori in engagements with whānau members
 - b. Careful thought be given to ways in which the Paediatrics Ward at Waikato Hospital can incorporate Māori healing practices as part of health treatment procedures
 - c. Staffing levels on the Paediatrics Ward be increased, along with funding, so that ward staff no longer appear stressed, busy and rushed
 - d. Increase staff awareness of the stigma and shame associated with insufficient finances, and how this presents in everyday life
4. **Provide 3 meals a day for at least 1 caregiver** staying with a child who has been admitted to the Paediatrics Ward at Waikato Hospital. Additionally, we recommend that **all** DHB's
 - a. Continue to provide tea and coffee making facilities for caregivers
 - b. Provide cereal, milk, bread and spreads at breakfast time
 - c. Deliver a lunch meal to one caregiver as part of the regular meal delivery service
 - d. Deliver an evening meal to one caregiver as part of regular meal delivery service

In seeking meal provision for caregivers at Waikato DHB we identified multiple barriers:

- Financial cost
- Staff and kitchen capacity
- Hygiene concerns
- Insufficient facility space

These barriers exist across health regions and boards in Aotearoa New Zealand. A Ministry of Health directive with appropriate resource and support would reduce these barriers, making implementation more likely. The current targeted approach at Waikato Hospital requires nursing staff to identify which primary caregivers meet inclusion criteria for a meal and then complete paperwork requirements. This creates additional administrative tasks for already stretched staff. A universal meal provision policy would alleviate this burden, prevent the stigma associated with applying for an exemption due to financial constraints, and implicitly conveys a message of care and concern for whānau well-being that supports positive mental health.

Receiving meals while on the ward means that primary caregivers can stay with their child, alleviating both their hunger and the distress associated with having to leave a sick child alone. The meal delivery service is more cost-effective than purchasing individual hospital café items. Providing meals from the hospital's standard meal services will be more nutritious and healthier than corner-store purchases. Additionally, receiving meals communicates a sense of care for the caregiver and works to counteract previous negative experiences of social stigma and inequitable treatment.

This recommendation supports the United Nations Sustainable Development Goals 2 and 3 through the practical provision of food, and supports UNDRIP Article 24 by acknowledging that whānau Māori face additional barriers to accessing meals which impacts on their well-being. It also brings DHB's into line with their own legislation.

References

- Adcock, A., Lawton, B., & Cram, F. (2018). Experiences of the health care system for young māori mothers: "You know how some people look at māoris like, 'yuck'?" *Journal of Paediatrics and Child Health*, 54(S1), 6-6. doi: 10.1111/jpc.13882_8
- Amore, K. (2016). Severe housing deprivation in aotearoa/ New Zealand: 2001-2013. Wellington: He Kainga Oranga Housing and Health Research Programme, University of Otago.
- Anderson, Y.C., Wynter, L.E., Treves, K.F., Grant, C.C., Stewart, J.M., Cave, T.L., . . . Hofman, P.L. (2016). Prevalence of comorbidities in obese New Zealand children and adolescents at enrolment in a community-based obesity programme. *Journal of Paediatrics & Child Health*, 52(12), 1099-1105. doi: 10.1111/jpc.13315
- Arlidge, B., Abel, S., Asiasiga, L., Milne, S., Crengle, S., & Ameratunga, S. (2009). Experiences of whānau/families when injured children are admitted to hospital: A multi-ethnic qualitative study from aotearoa/New Zealand. *Ethnicity & Health*, 14(2), 169-183. doi: 10.1080/13557850802307791
- Blakely, T., Ajwani, S., Robson, B., & et al. (2004). Decades of disparity: Widening ethnic mortality gaps from 1980 to 1999. *New Zealand Medical Journal*, 117(1199), U995.
- Bolitho, S., & Huntington, A. (2006). Experiences of maori families accessing health care for their unwell children: A pilot study. *Nurs Pract N Z*, 22(1), 23-32.
- Boon, B., & Farnsworth, J. (2011). Social exclusion and poverty: Translating social capital into accessible resources. *Social Policy & Administration*, 45(5), 507-524. doi: 10.1111/j.1467-9515.2011.00792.x
- Bourdieu, P. (1979). *Distinctions. A social critique of the judgement of taste* (R. Nice, Trans.). Boston, MA: Harvard University Press.
- Buck-McFadyen, E.V. (2015). Rural food insecurity: When cooking skills, homegrown food, and perseverance aren't enough to feed a family. *Canadian Journal of Public Health*, 106(3), 140-146. doi: 10.17269/cjph.106.4837
- Burrows, L., Wright, J., & Jungersen-Smith, J. (2002). "Measure your belly." New Zealand children's constructions of health and fitness. *Journal of Teaching in Physical Education*, 22(1), 39-48. doi: 10.1123/jtpe.22.1.39
- Carter, K.N., Kruse, K., Blakely, T., & Collings, S. (2011). The association of food security with psychological distress in New Zealand and gender differences. *Social Science & Medicine*, 72, 1463-1471.
- Chin, M.H., King, P.T., Jones, R.G., Jones, B., Ameratunga, S.N., Muramatsu, N., & Derrett, S. (2018). Lessons for achieving health equity comparing aotearoa/New Zealand and the united states. *Health policy*, 122(8), 837-853. doi: 10.1016/j.healthpol.2018.05.001
- Coleman-Jensen, A. (2010). U.S. Food insecurity status: Toward a refined definition. *Social Indicators Research*, 95(2), 215-230. doi: 10.1007/s11205-009-9455-4
- Collins, F.L. (2008). Of kimchi and coffee: Globalisation, transnationalism and familiarity in culinary consumption. *Social & Cultural Geography*, 9(2), 151-169. doi: 10.1080/14649360701856094
- Cram, F., Smith, L., & Johnstone, W. (2003). Mapping the themes of maori talk about health. *The New Zealand medical journal*, 116(1170), 1p following U353-U353.
- Davis, P., Lay-Yee, R., Dayall, L., & et al. (2006). Quality of hospital care for māori patients in New Zealand: Retrospective cross-sectional assessment. *Lancet*, 367, 1920-1925.
- Douglas, M. (1971). Deciphering a meal. In C. Geertz (Ed.), *Myth, symbol and culture* (pp. 61-82). New York, NY: Norton.
- Flyvbjerg, B. (2006). Five misunderstandings about case-study research. *Qualitative Inquiry*, 12(2), 219-245.

- Gazso, A., McDaniel, S., & Waldron, I. (2016). Networks of social support to manage poverty: More changeable than durable. *Journal of Poverty*, 20(4), 441-463. doi: 10.1080/10875549.2015.1112869
- Gifford, H., Cvitanovic, L., Boulton, A., & Batten, L. (2017). Constructing prevention programme with a māori health service provider view. *Kōtuitui: New Zealand Journal of Social Sciences Online*, 12(2), 165-178.
- Gilmour, J., Huntington, A., & Robson, B. (2016). Oral health experiences of māori with dementia and whānau perspectives - oranga waha mo nga iwi katoa. *Nursing Praxis in New Zealand*, 32(1), 20-27.
- Graham, R., Hodgetts, D., Stolte, O., & Chamberlain, K. (2018a). Food insecurity in urban New Zealand. The case of the kopa family. *Journal of Poverty*, 1-19. doi: 10.1080/10875549.2017.1419533
- Graham, R., Hodgetts, D., Stolte, O., & Chamberlain, K. (2018b). Hiding in plain sight: Experiences of food insecurity and rationing in New Zealand. *Food, Culture & Society*, 21(3), 384-401. doi: 10.1080/15528014.2018.1451043
- Graham, R., Hodgetts, D., Stolte, O., & Chamberlain, K. (2018c). Sustaining spaces: Community meal provision and mental wellbeing. In L. McGrath & P. Reavey (Eds.), *Mental distress and space: Community and clinical applications*. London, UK: Routledge.
- Gramsci, A. (1971). *Selections from the prison notebooks*. New York, NY: International Publishers.
- Grant, C.C., Emery, D., Milne, T., Coster, G., Forrest, C.B., Wall, C.R., . . . Robinson, E.M. (2012). Risk factors for community-acquired pneumonia in pre-school-aged children. *Journal of Paediatrics & Child Health*, 48(5), 402-412. doi: 10.1111/j.1440-1754.2011.02244.x
- Halbwachs, M. (1950/1980). *The collective memory*. New York, NY: Harper and Row.
- Hamelin, A.-M., Beaudry, M., & Habicht, J.-P. (2002). Characterization of household food insecurity in québec: Food and feelings. *Social Science & Medicine*, 54(1), 119-132. doi: 10.1016/S0277-9536(01)00013-2
- Harris, R., Cormack, D., Tobias, M., Yeh, L.-C., Talamaivao, N., Minster, J., & Timutimu, R. (2012). The pervasive effects of racism: Experiences of racial discrimination in New Zealand over time and associations with multiple health domains. *Social Science & Medicine*, 74(3), 408-415. doi: 10.1016/j.socscimed.2011.11.004
- Harwood, M., & Tipene-Leach, D. (2007). Diabetes. In B. Robson & R. Harris (Eds.), *Hauora: Māori standards of health iv* (pp. 160-167). Wellington, NZ: Te Rōpū Rangahau Hauora a Eru Pōmare.
- Hodgetts, D., Chamberlain, K., Gabe, J., Dew, K., Radley, A., Madden, H., . . . Nikora, L.W. (2011). Emplacement and everyday use of medications in domestic dwellings. *Health & Place*, 17(1), 353-360. doi: 10.1016/j.healthplace.2010.11.015
- Hodgetts, D., Chamberlain, K., Groot, S., & Tankel, Y. (2014). Urban poverty, structural violence and welfare provision for 100 families in auckland. *Urban Studies*, 51(10), 2036-2051. doi: 10.1177/0042098013505885
- Hodgetts, D., Hayward, B., & Stolte, O. (2015). Medicinal commodities and the gift of a caring mother. *Journal of Consumer Culture*, 15(3), 287-306. doi: 10.1177/1469540513498611
- Hodgetts, D., & Stolte, O. (2017). *Urban poverty and health inequalities. A relational approach*. London, UK: Routledge.
- Jani, R., Rush, E., Crook, N., & Simmonds, D. (2018). Availability and price of healthier food choices and association with obesity prevalence in New Zealand maori. *Asia Pacific Journal of Clinical Nutrition*, 27(6), 1357.
- Jansen, P., Bacal, K., & Crengle, S. (2009). He ritenga whakaaro: Māori experiences of health services. Auckland, NZ: Mauri Ora Associates.

- Jansen, P., & Smith, K. (2006). Māori experiences of primary health care: Breaking down the barriers. *NZFP*, 33(5), 298-300.
- Jansen, W. (1997). Gender identity and the rituals of food in a Jordanian community. *Food and Foodways*, 7(2), 87-117. doi: 10.1080/07409710.1997.9962056
- Johnson, A., Howden-Chapman, P., & Eaube, S. (2018). *A stocktake of new zealand's housing*. Retrieved from <https://www.beehive.govt.nz/sites/default/files/2018-02/A%20Stocktake%20Of%20New%20Zealand's%20Housing.pdf>.
- Kerr, S., Penney, L., Moewaka Barnes, H., & McCreanor, T. (2010). Kaupapa maori action research to improve heart disease services in aotearoa, New Zealand. *Ethnicity & Health*, 15(1), 15-31. doi: 10.1080/13557850903374476
- Kidd, J., Gibbons, V., Kara, E., Blundell, R., & Berryman, K. (2013). A whānau ora journey of māori men with chronic illness: A te korowai analysis. *AlterNative: An International Journal of Indigenous Peoples*, 9(2), 125-141. doi: 10.1177/117718011300900202
- Kohn, T. (2013). Stuffed turkey and pumpkin pie: In, through and out of American contexts. *Cultural Studies Review*, 19(1), 50-72.
- Lee, J. (2009). Decolonising māori narratives: Pūrākau as a method. *MAI Review*, 2(3), 1-12.
- Lee, L.Y. (2011). Hungry for peace: Jane Addams and the Hull-House Museum's contemporary struggle for food justice (Vol. 36, pp. 62-79): Wiley-Blackwell.
- Lee, R., & North, N. (2013). Barriers to Maori sole mothers' primary health care access. *Journal of Primary Health Care*, 5(4), 315-321. doi: 10.1071/hc13315
- Lombe, M., Nebbitt, V.E., Sinha, A., & Reynolds, A. (2016). Examining effects of food insecurity and food choices on health outcomes in households in poverty. *Social Work in Health Care*, 55(6), 440-460. doi: 10.1080/00981389.2015.1133469
- Martins, D.C., Gorman, K.S., Miller, R.J., Murphy, L., Sor, S., Martins, J.C., & Vecchiarelli, M.L. (2015). Assessment of food intake, obesity, and health risk among the homeless in Rhode Island. *Public Health Nursing*, 32(5), 453-461. doi: 10.1111/phn.12180
- Masters-Awatere, B. (2017). A game of slides and ladders: Māori health providers and funders. In S. Groot, C. van Ommen, B. Masters-Awatere & N. Tassell-Matamua (Eds.), *Precarity: Uncertain, insecure and unequal lives in aotearoa New Zealand* (pp. 147-162). Auckland, NZ: Massey University Press.
- Matheson, A., Walton, M., Gray, R., Lindberg, K., Shanthankumar, M., & Wehipeihana, N. (2018). Summative evaluation report: Healthy Families NZ. Wellington: Ministry of Health.
- McKinny, C. (2006). *Māori experiences of hospital care in Auckland*. (Masters of Public Health), University of Auckland, Auckland.
- Ministry of Health. (2014). Screening, diagnosis and treatment of gestational diabetes in New Zealand. Wellington, NZ: Ministry of Health.
- Ministry of Health. (2019). Household food insecurity among children: New Zealand health survey. Wellington, NZ: Ministry of Health.
- Moore, R. (2019). Stories from Kirikiriroa Hamilton community houses. Hamilton, NZ: Anglican Action.
- Musarò, P. (2013). Food consumption and urban poverty: An ethnographic study. *Italian Sociological Review*, 3(3), 142-151. doi: 10.13136/isr.v3i3.65
- New Zealand Health and Disability Act, 1994, § 114, 3 Stat. (2000 14 December).

- Nikora, L.W., Hodgetts, D., Carlson, T., & Rua, M. (2011). Māori and medications. *AlterNative: An International Journal of Indigenous Peoples*, 7(2), 87-99. doi: 10.1177/117718011100700202
- Olsen, B. (2003). Material culture after text: Re-membering things. *Norwegian Archaeological Review*, 36(2), 87-104.
- Penney, L., Barnes, H.M., & McCreanor, T. (2011). The blame game: Constructions of maori medical compliance. *AlterNative: An International Journal of Indigenous Peoples*, 7(2), 73-86. doi: 10.1177/117718011100700201
- Pierse, N., Carter, K., Bierre, S., Law, D., & Howden-Chapman, P. (2016). Examining the role of tenure, household crowding and housing affordability on psychological distress, using longitudinal data. *Journal of Epidemiology and Community Health*, 70(10), 961-966. doi: 10.1136/jech-2015-206716
- Pihama, L., Reynolds, P., Smith, C., Reid, J., Tuhiwai Smith, L., & Te Nana, R. (2014). Positioning historical trauma theory within aotearoa New Zealand. *Alternative*, 10(3), 248-262.
- Pitama, S., Ahuriri-Driscoll, A., Huria, T., Lacey, C., & Robertson, P. (2011). The value of te reo in primary care. *Journal of Primary Health Care*, 3(2), 123-127. doi: 10.1071/hc11123
- Radley, A., & Chamberlain, K. (2012). The study of the case: Conceptualising case study research. *Journal of Community & Applied Social Psychology*, 22(5), 390-399. doi: 10.1002/casp.1106
- Reavey, P. (Ed.). (2011). *Visual methods in psychology*. Hove and NY: Psychology Press.
- Reid, J., Cormack, D., & Crowe, M. (2016). The significance of socially-assigned ethnicity for self-identified māori accessing and engaging with primary healthcare in New Zealand. *Health*, 20(2), 143-160. doi: 10.1177/1363459315568918
- Reid, P., & Robson, B. (2007). Understanding health inequities. In B. Robson & R. Harris (Eds.), *Māori standards of health iv. A study of the years 2000-2005* (pp. 3-10). Wellington: Te Rōpū Rangahau Hauora a Eru Pōmare.
- Reinfeld, M., & Pihama, L. (2007). Matarākau: Ngā kōrero mō ngā rongoā o taranaki. Taranaki, NZ: Foundation for research, science and technology.
- Richard, V.M., & Lahman, M.K.E. (2014). Photo-elicitation: Reflexivity on method, analysis, and graphic portraits. *International Journal of Research & Method in Education*, 1-20. doi: 10.1080/1743727X.2013.843073
- Ritchie, J. (2015). Food reciprocity and sustainability in early childhood care and education in aotearoa New Zealand. *Australian Journal of Environmental Education*, 31(1), 74-85. doi: 10.1017/aee.2014.46
- Robertson, N., & Masters-Awatere, B. (2007). Community psychology in aotearoa/New Zealand: Me tiro whakamuri ā kiā hangai whakamua. In S. M. Reich, M. Riemer, I. Prilleltensky & M. Montero (Eds.), *International community psychology: History and theories* (pp. 140-163): Springer.
- Robinson, H. (2019). *Shining a light on food insecurity in aotearoa New Zealand*. (Masters of Social and Community Leadership), University of Auckland, Auckland, NZ.
- Ruddin, L.P. (2006). You can generalize stupid! Social scientists, bent flyvbjerg, and case study methodology. *Qualitative Inquiry*, 12(4), 797-812. doi: 10.1177/1077800406288622
- Salmond, C., Crampton, P., King, P., & Waldegrave, C. (2006). Nzidep: A New Zealand index of socioeconomic deprivation for individuals. *Social Science & Medicine*, 62(6), 1474-1485. doi: https://doi.org/10.1016/j.socscimed.2005.08.008
- Seed-Pihama, J. (2017). *Ko wai tō ingoa? The transformative potential of māori names*. (Doctor of Philosophy PhD), University of Waikato, Hamilton, NZ.
- Seremetakis, C.N. (1994). The memory of the sense: Pts 1 & 2. In C. N. Seremetakis (Ed.), *The senses still: Perception and memory as material culture in modernity* (pp. 1-43). Boulder, WN: Westview Press.

- Simmonds, N., & Gabel, K. (2016). Ūkaipō: Decolonisation and māori maternities. In J. Hutchings & J. Lee-Morgan (Eds.), *Decolonisation in aotearoa: Education, research and practice* (pp. 145-157). Wellington, NZ: NCER Press.
- Slater, T., Matheson, A., Davies, C., Tavite, H., Ruhe, T., Holdaway, M., & Ellison-Loschmann, L. (2013). 'It's whanaungatanga and all that kind of stuff': Maori cancer patients' experiences of health services. *Journal of Primary Health Care*, 5(4), 308-314. doi: 10.1071/hc13308
- Small, M.L. (2009). 'How many cases do i need?' On science and the logic of case selection in field-based research. *Ethnography*, 10(1), 5-38. doi: 10.1177/1466138108099586
- Sobal, J. (2000). Sociability and meals: Facilitation, commensality and interaction. In H. L. Meiselman (Ed.), *Dimensions of the meal: The science, culture, business, and art of eating* (pp. 119-133). Gaithersburg, MD: Aspen.
- Stevenson, K., Filoche, S., Cram, F., & Lawton, B. (2016). Lived realities: Birthing experiences of maori women under 20 years of age. *AlterNative: An International Journal of Indigenous Peoples*, 12(2), 124-137. doi: 10.20507/AlterNative.2016.12.2.2
- Stewart, M.J., Makwarimba, E., Reutter, L.I., Venstra, G., Raphael, D., & Love, R. (2014). Poverty, sense of belonging and experiences of social isolation. *Journal of Poverty*, 13(2), 173-195. doi: 10.1090/10875540902841762
- Stolte, O., & Hodgetts, D. (2015). Being healthy in unhealthy places: Health tactics in a homeless lifeworld. *Journal of Health Psychology*, 20(2), 144-153. doi: 10.1177/1359105313500246
- Sue, C.A. (2014). Hegemony and silence: Confronting state-sponsored silences in the field. *Journal of Contemporary Ethnography*, 44(1), 113-140. doi: 10.1177/0891241614540211
- Telfar, B.N., Preval, N., Howden-Chapman, P., Arnold, R., Young, C., Grimes, A., & Denne, T. (2011). The impact of retrofitted insulation and new heaters on health services utilisation and costs, and pharmaceutical costs *Evaluation of the New Zealand Insulation Fund*. Wellington, NZ: Ministry of Economic Development.
- Teo, T. (2016). Embodying the conduct of everyday life. In C. Højholt & E. Schraube (Eds.), *Psychology and the conduct of everyday life* (pp. 111-123). New York, NY: Routledge.
- Tin Tin, S., Woodward, A., Saraf, R., Berry, S., Atatoa Carr, P., Morton, S.M.B., & Grant, C.C. (2016). Internal living environment and respiratory disease in children: Findings from the growing up in New Zealand longitudinal child cohort study. *Environmental Health: A Global Access Science Source*, 15, 1-10. doi: 10.1186/s12940-016-0207-z
- Tinirau, R., Gillies, A., & Tinirau, R. (2011). Hōmai tō hono: Connecting customary, conventional and spiritual healing practices within a rural-based māori community. *AlterNative: An International Journal of Indigenous Peoples*, 7(2), 163-176. doi: 10.1177/117718011100700208
- Turner, N., Asher, I., Bach, K., Denny, S., Fancourt, N., & Merry, S. (2011). Child health and poverty. In M. C. Dale, M. O'Brien & S. S. John (Eds.), *Left further behind: How policies fail the poorest children in New Zealand* (pp. 122-136). Auckland, NZ: Child Poverty Action Group.
- University of Otago and Ministry of Health. (2012). A focus on nutrition: Key findings of the 2008/09 New Zealand adult nutrition survey. Wellington, NZ: Ministry of Health.
- Waitangi Tribunal. (2001). *The napier hospital and health services report: Wai 692*. Wellington: Legislation Direct.
- Walker, T., Signal, L., Russell, M., Smiler, K., Tuhiwai-Ruru, R., Health Centre, O., . . . Health, T. (2008). The road we travel: Maori experience of cancer. *The New Zealand Medical Journal (Online)*, 121(1279), 27-35.
- Ware, F., Forster, M., & Breheny, M. (2018). Kaupapa kōrero: A māori cultural approach to narrative inquiry *AlterNative*, 14(1), 45-53. doi: 10.1177/1177180117744810

- Weaver, L.J., & Hadley, C. (2009). Moving beyond hunger and nutrition: A systematic review of the evidence linking food insecurity and mental health in developing countries. *Ecol Food Nutr*, 48, 263-284.
- Westbrooke, I., Baxter, J., & Hogan, J. (2001). Are māori under-served for cardiac interventions? *N Z Med J*, 114, 484-487.
- White, C., Reid, S., & Damiris, V. (2014). Māori health literacy research: Gestational diabetes mellitus. Wellington, NZ: Ministry of Health.
- Whiting, E.F., & Ward, C. (2010). Food provisioning strategies, food insecurity, and stress in an economically vulnerable community: The northern cheyenne case. *Journal of Agriculture and Human Values*, 27(4), 489-504. doi: 10.1007/s10460-009-9248-z
- Williams, P.N., Gray, M.A., Ka'ai, T.M., Moorfield, J.C., McPherson, K.M., Weinstein, P., & Nacey, J.N. (2003). Maori men's perceptions and experiences of health seeking for prostate health problems in New Zealand. *Pacific health dialog : a publication of the Pacific Basin Officers Training Program and the Fiji School of Medicine*, 10(2), 71-78.
- Wilson, D., & Barton, P. (2012). Indigenous hospital experiences: A New Zealand case study. *Journal of Clinical Nursing*, 21(15-16), 2316-2326. doi: 10.1111/j.1365-2702.2011.04042.x

Research publications and dissemination

Academic articles

Masters-Awatere, B., & Graham, R. (2019). Whānau Māori explain how the Harti Hauora Tool assists better access to health services. *Australian Journal of Primary Health*. doi: 10.1071/PY19025

Abstract: In this paper, whānau Māori highlight how a Kaupapa Māori-centred intervention (the Harti Hauora Tamariki tool, hereafter Harti tool) has improved interactions with health services. The Harti tool is undergoing a randomised control trial (RCT) at Waikato Hospital in New Zealand. As part of the RCT, the authors engaged in a series of qualitative interviews with whānau members of tamariki Māori (children aged 0–5 years) admitted to Waikato Hospital's paediatric ward. Whānau who met at least one criteria for New Zealand's domains of deprivation were included. Using a Kaupapa Māori approach to the study, participants shared their views on barriers and facilitators to accessing health resources and primary care services. The interviews conducted highlight how the Harti tool, when administered in a culturally appropriate and respectful manner that prioritised relationship-building, enabled better connection to healthcare services. Prevalent in our analysis were connections to wider determinants of health and ways to reduce existing health inequities. To conclude the paper, how the Harti tool has enhanced feelings of being in control of health, with the potential to reduce the likelihood of a hospital readmission, is highlighted.

Graham, R., & Masters-Awatere, B. (In Print). Experiences of Māori of Aotearoa New Zealand's public health system: A systematic review of two decades of published qualitative research. *Australian & New Zealand Journal of Public Health*.

Abstract: Objective: This paper aims to synthesise the broader perspectives of Māori patients and their whānau of their treatment within the public health system. Our research question was "What are the experiences of Māori in the public health and/or hospital system in Aotearoa New Zealand?" Methods: A systematic search using PRISMA protocols and reflexive typology was organised around the categories of Māori, qualitative research, personal experience, and public healthcare. A qualitative meta-synthesis was utilised for the 14 included papers and a critical community psychology approach to thematic analysis undertaken. Results: Māori patients and whānau from the included papers mention both barriers and facilitators to health. The authors of this article have categorised barriers as organisational structures, staff interactions and practical considerations. Facilitators were categorised as the provision of whānau support in the form of practical assistance, emotional care, and health system navigation. Conclusions: For many Māori the existing public health system is experienced as hostile and alienating. Whānau members provide support to mitigate this but it comes as a cost to whānau. Implications for Public Health: Public health providers must find ways to ensure that Māori consistently experience positive, high-quality healthcare interactions that support Māori ways of being.

Masters-Awatere, B. Graham, R., Scott, N., Atatoa Carr, P. (In print). Meal provision needed for caregivers who stay with a child in hospital. *International Perspectives in Psychology: Research, Practice, Consultation*.

Abstract: The provision of meals for primary caregivers when caring for a child in hospital varies across regions in New Zealand. Where meals are not provided, caregivers are expected to bring their own food from home and/or purchase food from on-site (or nearby) vendors. Twenty-four qualitative interviews with 15 Māori whānau (family/families) from one public hospital revealed that caregivers are reluctant to leave their child alone and that financial constraints meant that caregivers were often alone, isolated, and hungry. We recommend implementing a national meal policy to support caregivers who provide much-needed physical and emotional cares for their child during a hospital stay.

Academic Conference Presentations

Masters-Awatere, B. & Graham, R. Human flourishing for caregivers in the context of hospital paediatrics admissions. *New Zealand Psychological Society Annual Conference*, Rotorua, NZ: 27-30 August 2019

Abstract: This research is part of a Randomised Control Trial of the Harti Hauora Tamariki tool (HHTt) delivered at Waikato Hospital. Overall, 1100 tamariki Māori aged 0-4years will be recruited. The intervention (utilisation of HHTt during inpatient care, delivered by a trained Research Assistant) is randomly assigned, with the control group receiving hospital-based care as per usual (no HHTt). Methods: Qualitative interviews (n=24) with whānau members (n=15) of tamariki Māori. Interviews included photo-elicitation activities and occurred in participant's homes. Whānau were interviewed who received the Harti tool (n=7) and usual care (n=8). Prevalent in our analysis were connections to wider determinants of health and ways to reduce existing health inequities. Results: This presentation focuses on an unexpected finding from the qualitative interviews. Namely, that parents caring for young children admitted to hospital go hungry and have inadequate access to food/meals. The absence of enough eat while caring for a sick child in hospital heightens the distress, concern and worry that parents face. Caregivers are often reluctant to leave their child alone. Feelings of hunger intensify parental marginalisation and isolation. Conclusions: A radical re-shift of public health approaches to include the flourishing of all whānau members is much needed. Delivering meals to support caregivers—who provide much-needed physical and emotional cares for the child—is one such radical solution that is struggling to find traction.

Masters-Awatere., B. & Graham., R. Whānau Māori talk about health. *LIME Connection VIII*, Christchurch, NZ: 5-8 November 2019

Abstract: A large proportion of Waikato tamariki Māori (children 0-4yrs) are admitted to hospital every year with diseases of poverty. New Zealanders think the health sector will provide essential preventative care for these children and their whānau. However, an audit found that was not the case and over 1/3 of tamariki were readmitted within 6 months. In response, Harti Hauora Tamariki (HHT) was co-designed and implemented in 2015. In 2017 the Health Research Council of New Zealand agreed to fund a Randomised Control Trial of HHT at Waikato Hospital. The presenters will discuss the findings

from a series of qualitative interviews with whānau members of tamariki Māori who had been admitted to Waikato Hospital's paediatric ward during the July - November 2018 research period. Using a narrative approach, recipients of the HHT tool shared their views on barriers and facilitators to accessing health resources and primary care services. Evidence from our interviews highlight how the HHT tool enabled better connection to healthcare services within the hospital and beyond. Despite the complex issues covered within the tool, interactions of a culturally appropriate and respectful manner, fostered a positive experience for whānau. Observation of the narratives from whānau who received the HHT tool contrast strongly with whānau who did not, highlighting the ways in which usual care was inadequate. While the Harti Hauora Tamariki tool has enhanced feelings of being in control of health with the potential to reduce the likelihood of a hospital readmission, we recognise the importance of decolonising health services from within. Prevalent in our analysis were connections to wider determinants of health, the impact of unconscious bias in the form of racism, classism, and ways to reduce existing health inequities. The importance of continuous quality improvement for both the tool and hospital staff are needed to address structural racism.

Conference Symposium "Harti Hauora Tamariki: Kaupapa Māori research for change" by Scott., N., Masters-Awatere, B., Atatoa Carr, P., Graham, R. & Jones, A. *11th Health Services and Policy Research Conference*, Auckland, NZ: 4-6 December 2019

Abstract: The Harti Hauora Tamariki study aims to evaluate the effectiveness of the Harti tool (a whānau ora based assessment tool designed to reduce health inequities). Utilising a mixed methods approach, this pragmatic Randomised Control Trial (RCT) is a 3-year project funded by the Health Research Council of New Zealand. Altogether, 1100 tamariki Māori under the age of 5 who have been admitted to Waikato Hospital under a paediatric medical team will be recruited. The intervention (utilisation of the Harti tool by a trained Research Assistant during inpatient care) is randomly assigned, with the control group receiving usual care; that is, hospital-based care as per usual (no Harti tool). This symposium explores the development and delivery of the Harti tool, highlights important opportunities to achieve sustainable health equity, presents initial findings from the qualitative component, and comments on the challenges and opportunities for Māori and non-Māori health professionals, academics, and researchers to work collaboratively in order to affect change at all levels of health care. In doing so, we provide opportunity for feedback at all levels and invite discussion on ways of continuing to facilitate communication between researchers and policymakers and to ensure sustainable capacity in health services research.

DHB Presentations

Findings from interviews with participating whānau were presented throughout the qualitative phase.

Groups presented to include the following:

- **Iwi Maori Council** (Waikato DHB). This includes iwi representatives from Ngāti Maniapoto, Hauraki, Waikato-Tainui, Raukawa, Ngāti Tuwharetoa, Whanganui, Te Rūnanga O Kirikiriroa (Urban Māori Authority) as well as the Kaunihera Kaumātua (cultural advisory committee).
- **Te Puna Oranga**. (Māori health service at Waikato DHB). Presentation to Māori staff team within Te Puna Oranga at Waikato Hospital.
- **Advisory Group** (Harti Hauora Tamariki tool trial advisory group, meets twice annually)
- Presentation to medical personnel at Waikato District Health Board as part of the programme by Waikato Postgraduate Medicine Incorporated (WPMGI) to advance medical education, quality assurance and research in the Waikato. This included a one-hour presentation at the **Grand Round** series in the Bryant Education Centre.
- **Midlands District Public Health Team**. The Midlands District groups together representatives from 4 health boards: Lakes, Waikato, Tairāwhiti and Bay of Plenty. This presentation was to the Population and Public Health teams from each of these areas.