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Determining barriers and facilitators to engagement for families in a family-based multicomponent healthy lifestyles intervention for children and adolescents: a qualitative study

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3 **Determining barriers and facilitators to engagement for families in a family-based**
4 **multicomponent healthy lifestyles intervention for children and adolescents: a qualitative study**
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ABSTRACT

Objectives: Recruitment and retention in child and adolescent healthy lifestyle intervention services for childhood obesity is challenging, and inequalities across social groups are persistent. This study aimed to understand the barriers and facilitators to engagement in a multicomponent assessment-and-intervention healthy lifestyle programme for children and their families, based in the home and community.

Design: Qualitative interview-based study of past users of a family-based multicomponent healthy lifestyle programme in a mixed urban-rural region of New Zealand. Semi-structured, home-based interviews were conducted and thematically analysed with peer debriefing for validity.

Participants: Families were selected through stratified random sampling to include a range of levels of engagement, including those who declined their referral, with equal numbers of interviews with Indigenous and non-Indigenous families.

Results: Three interactive and compounding determinants were identified as influencing engagement in Whānau Pakari: acute and chronic life stressors, societal norms of weight and body size, and historical experiences of healthcare. These determinants were present across societal, system and healthcare service levels. A negative referral experience to Whānau Pakari often resulted in participants declining further input or disengaging from the programme. A fourth domain, respectful and compassionate healthcare, was identified as a mitigator these three themes, facilitating participant engagement despite previous negative experiences.

Conclusions: While participant engagement in healthy lifestyle programmes is affected by determinants which appear to operate outside immediate service provision, the programme is an opportunity to acknowledge past instances of stigma and the wider challenges of healthy lifestyle change. The experience of the referral to Whānau Pakari is important for setting the scene for future engagement in the programme. Respectful, compassionate care is critical to enhanced retention in multidisciplinary healthy lifestyle programmes and ongoing engagement in healthcare services overall.

Strengths and limitations of this study

- Large sample size (64 interviews)
- Sample included wide range of participants with varying levels of engagement, including non-service users
- Equal representation from families with Māori and non-Māori children
- Lack of child and adolescent voice
- Participants may not have fully disclosed their experiences to interviewers

Introduction

Excess weight in childhood and adolescence affects physical, psychological and social health and well-being, and is a known risk factor for comorbidities both in childhood and adulthood.¹ Children with weight issues in Aotearoa/New Zealand (henceforth referred to as New Zealand) demonstrate a high prevalence of weight-related comorbidities, as well as low physical activity, suboptimal eating behaviours, and low health-related quality of life.²⁻⁵ One of the key recommendations of the World Health Organization's Report of the Commission on Ending Childhood Obesity is to "provide family-based, multicomponent lifestyle weight management services for children and young people who are obese".⁶ A systematic review and meta-analysis found that a minimum of 26 hours of contact time in lifestyle interventions is associated with improvements in weight status in children and adolescents.⁷ However, as with any service attempting to facilitate lifestyle change, success relies on continued family engagement.⁸ It is also important that such multidisciplinary services – and other health professionals addressing childhood obesity in a primary care setting – are able to engage with groups most affected by obesity, namely those living in the most deprived areas and ethnic minorities.⁹

Improving *engagement* with childhood obesity services requires addressing both initial recruitment and ongoing retention.⁸ Service, system and society-related factors may *enable* or *inhibit* initial and ongoing engagement; factors which are also referred to as facilitators and barriers.^{10, 11} Kelleher and

1
2
3 colleagues' review of the factors affecting attendance at community-based lifestyle programmes
4
5 found that weight stigma, parental reluctance to identify overweight and logistical challenges were
6
7 key barriers to initial and ongoing attendance.¹⁰ Under-represented in the literature are those who
8
9 declined treatment altogether, as many past studies had low recruitment from these families. It is
10
11 therefore important to understand the experiences of families experiencing childhood obesity in order
12
13 to improve initial recruitment and ongoing retention in healthy lifestyle services, particularly for
14
15 groups most affected.¹⁰
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17

18 Whānau Pakari is a family-centred, community-based assessment and intervention programme for
19
20 children and their families, based in Taranaki, a mixed urban-rural region of New Zealand (NZ). The
21
22 name means 'healthy, self-assured families that are fully active'. The focus of the programme is on
23
24 healthy lifestyle change rather than weight loss or obesity, in order to minimise judgement and
25
26 weight-related stigma. The multidisciplinary service involves a home-based medical assessment with
27
28 advice, removing the hospital appointment in order to *demedicalise* care, and includes weekly
29
30 nutrition, physical activity and psychology sessions. This approach takes healthcare outside hospital
31
32 walls and into the community, without compromising quality of care. A randomised clinical trial of
33
34 the Whānau Pakari model of care demonstrated modest reductions in body mass index (BMI) standard
35
36 deviation score (SDS) and improvements in cardiovascular fitness and health-related quality of life.¹²
37
38 ¹³ Greatest improvements in BMI SDS were found in those who attended the recommended $\geq 70\%$ of
39
40 intense intervention sessions.¹³ However, Māori (NZ's Indigenous population) and females were less
41
42 likely to attend $\geq 70\%$ of sessions, with sustained retention in the programme favouring males and NZ
43
44 Europeans.¹³
45
46
47

48 Previous evaluation of the experiences of Whānau Pakari participants and their caregivers has shown
49
50 the programme to be a positive and beneficial experience for those involved, emphasising the
51
52 importance of connectedness, knowledge-sharing and self-determination, the collective journey
53
54 alongside other families and programme deliverers, and the importance of a non-judgemental,
55
56 respectful environment.¹⁴ However, a survey of past participants of Whānau Pakari indicated that
57
58 previous experiences of healthcare may influence subsequent engagement with health services,
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3 particularly for Māori.¹⁵ Therefore, the objective of this study was to understand barriers and
4
5 facilitators to initial attendance and ongoing retention in the Whānau Pakari programme.
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8 *Methods*

9 *Design*

10
11 In NZ, health research is required to be responsive to the needs and diversity of Māori.¹⁶ The study
12
13 design and research approach was informed by Kaupapa Māori theory, which resists persistent power
14
15 imbalances and the continued use of cultural deficit theory (attributing poor health to something
16
17 inherent to a ‘culture’) to explain inequities between Māori and non-Māori.^{16, 17} Kaupapa Māori
18
19 research is an approach which centres Māori voice and experience and is aligned with a social and
20
21 structural determinants of health framework.¹⁸ Subsequently, priority was given to ensuring the voices
22
23 and experiences of Māori participants were understood in this study. In-depth interviews, centring on
24
25 participant experience with Whānau Pakari and wider experiences of the health system, were
26
27 undertaken. A specific focus was to understand the barriers to attendance and retention at varying
28
29 levels of engagement in Whānau Pakari, including those who declined their referral and had no
30
31 further contact with the programme. Factors which facilitated both initial and ongoing engagement
32
33 were explored.
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39 Ethical approval for the Whānau Pakari Barriers and Facilitators study was granted by Central Health
40
41 and Disability Ethics Committee (NZ) (17/CEN/158/AM01). Written informed consent was obtained
42
43 from all study participants.
44
45

46 *Participants*

47
48 Eligible participants were parents and/or caregivers of children and adolescents who had been referred
49
50 to the service from January 2012 to January 2017. Children and adolescents over 11 years of age were
51
52 also invited to participate. The eligibility criteria for referral to the service are children aged 4 to 16
53
54 years, identified as having obesity [body mass index (BMI) $\geq 98^{\text{th}}$ centile], or overweight (BMI $> 91^{\text{st}}$
55
56 centile) with associated weight-related comorbidities.^{12, 19}
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3 Participants were recruited from four different groups of Whānau Pakari service users who had
4 varying levels of engagement (table 1) using stratified random sampling. Recruitment was via
5 telephone call and text message. The sample contained equal numbers of families with Māori and
6 non-Māori children to ensure appropriate representation of Indigenous children's experiences.
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11
12 The interviews were conducted by CW and NR together where possible. NR led the interviews with
13 Māori families when appropriate. Interviews took place in the participant home or alternative
14 locations chosen by the participant (including a hospital, participant workplaces, and a community
15 library) in order to minimise inconvenience and travel barriers. A *koha* (gift, donation or contribution)
16 was offered to participants in acknowledgement of their time and as a sign of reciprocity for the
17 information shared.
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25 *Data collection*

26
27 Informed consent was obtained to record, transcribe and analyse participant data. All participant
28 information was anonymised. Participant ethnicity for both the parent/caregiver and child was
29 confirmed at the time of the interview by using the NZ Census 2006 ethnicity question.²⁰ All
30 interviews were audio-recorded and independently transcribed. Participants were offered their
31 transcripts to review for accuracy and acceptability.
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39 *Analysis*

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41 Interview transcripts were coded and analysed thematically in MAXQDA.²¹ CW developed the
42 coding matrix with peer review from EW, coded the interview data, and identified the initial themes.
43
44 The authors collaborated to finalise the themes and develop the framework. The acknowledgement of
45 different researcher standpoints allowed the authors to debate, challenge, and refine interpretations of
46 the data. Specifically, the researchers agreed to apply the 'Give-Way' rule if there was disagreement
47 over the interpretation of the data concerning Māori participants, with the final decision involving
48 cultural interpretation of Māori participants' experiences passing to a Māori researcher.^{18, 22, 23}
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56 For more detail of this procedure, please refer to the Consolidated Criteria for Reporting Qualitative
57 Research (COREQ) checklist (Appendix One).
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Patient and Public Involvement statement

Participants were first involved in the research at the recruitment stage, although some participants had been involved in an earlier related randomised clinical trial.¹² The research questions were informed by the experiences of participants voiced during clinical assessment and in previous focus group research.¹⁴ The design of the research drew from Kaupapa Māori theory, which informed the research process in order to prioritise the experiences and preferences of participants. The dissemination process to participants was altered as a result of participant preference to receive feedback via a summary video, rather than at a group meeting. Participants were not asked to assess the burden of the time required to participate in the research.

Results

Sixty-four interviews were conducted (out of a potential cohort of 74) with families who had varying levels of engagement, across a six-month period from June to November 2018 (76 participants in total) (Table One). Half of the interviews were with Māori families (families with a Māori child who had been referred to the service), including interviews with non-Māori parents of a Māori child. Full details of interview recruitment rate and reasons for non-participation are included in the COREQ checklist (Appendix One).

Demographics

Table 1. Participant demographics

Interview participants N		76*
Female participant <i>n</i>		65
Ethnicity %†	Māori	32
	NZ European	75
	Asian	7
	Other European	5
Level of engagement <i>n</i>	Attended ≥70% of programme sessions	18

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2		
3	Attended <30% of programme	19
4		
5	sessions	
6		
7	Had one assessment, then discontinued	7
8		
9	with the program	
10		
11	Referred, but chose not to engage	20
12		
13		
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15		

*64 interviews total, 11 interviews involved 2+ family members. †Total ethnicity output (more than one ethnicity selected)

Panel 1: Key determinants of engagement and retention in Whānau Pakari

Domain 1: Adverse life stressors & socioeconomic deprivation

‘I wouldn’t say it was, like, you guys as such – it was just the history behind what she had um, but we come from, so um I came from an abusive marriage, which had split up because of abuse... So this was really hard at the time.’

‘Once she lost her father, well that was pretty much the end of it. She just didn’t want to do nothing. As much as I tried to encourage her to, you know, get with the programme, no she just didn’t want to know about it.’

Competing health priorities

‘...[DAUGHTER] was under [child and adolescent mental health services] for suicide watch and stuff like that... so for us there was that added stuff as well.’

Financial insecurity/socioeconomic status

‘I didn’t have a house and lived in that camper. Yeah, so it just didn’t work out, otherwise she would have

gone.’

Domain 2: Societal norms of weight and body size

Age

‘Like, a weight problem, like, at the time he was only 6 years or 7 years.’

‘... we were kind of shocked because they said that [SON] was, like, obese or something ... I don’t think he’s overweight at all... Because he’s really tall... so I don’t understand, like, what sort of weight should he have been because he was, he’s just like a, he was like a normal kid. So I don’t understand what is overweight and underweight. Because I’ve seen some, not being mean, but overweight kids, and he wasn’t overweight.’

Gender

‘She might develop an eating disorder and I don’t want that. I’d rather, you know, it’s weird, but I’d rather she be overweight than underweight, you know what I mean? I’d hate to deal with an anorexic daughter because that’s hard work.’

Genetic disposition

‘You know... it’s just the way it is sometimes. Some people get good genes, some people get other genes and it means it doesn’t work out.’

Domain 3: Historical experiences of healthcare

Weight stigma and discrimination

‘... having visited for something else entirely different and then being told kind of ‘your child’s obese and we are going to refer you’ and just doing it front of him [...] it was just even in the way that it was delivered and I was kind of not expecting it. I mean, I can see that he’s, he’s a bit chunky, but I just, I don’t know [...] [the referral] was a bit off-putting.’

Racism

‘...people will judge you for what and where, what colour you are or whatever... [it] just made me more determined to get in there and do what I had to do.’

Mediator 1: Respectful, compassionate care mitigated past experiences

‘It was not just the families, but also the, what do you call them, the workers... Very supportive, non-judgmental. I think that made a big difference and ‘yes we are going to go’ because they are not judging you... the staff was very supportive.’

Three major domains and subthemes affecting participant engagement are described in panel 1 in participants’ own words. A fourth domain of respectful, compassionate care was identified as a mediator, which was able to mitigate the effect of the first three themes.

Domain 1: Obesity sits within the context of multiple other complex stressors for families in NZ

Participation in the Whānau Pakari service was affected by the multiple complex stressors of living in contemporary New Zealand. These were acute, one-off adverse events, such as a death in the family, and chronic, ongoing challenges, such as financial insecurity. Childhood obesity and overweight as a health concern sat within the context of multiple other important concerns for families. Participants were often living in ‘crisis mode’ or dealing with multiple challenges at once, including: financial and food insecurity, suicide, abusive relationships, deaths in the family, mental health issues, disability, relocation, marriage & family break-ups, fostering children, children being raised by other caregivers, drug use and significant other illnesses.

For parents of children with multiple health conditions, especially mental health concerns or autism spectrum disorder, addressing weight was often not perceived to be as important compared with other competing family health concerns. Parents and caregivers also reported the challenges of balancing multiple demands such as long work hours, shift work and extracurricular activities alongside attending Whānau Pakari.

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3 'I think he had one of his sporting things on and I was doing 50 hours a week at that time and
4 I was like 'oh, my God, I can't do it', I couldn't do it. I mean, if he needed, if I felt like he
5 needed to be there, I would get him there, like, it's, my work's not that important. Weeds and
6 shit can wait, you know, like, people can wait um if it was a, if I felt like it was serious. I
7 would have got him there, but I just yeah.'

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13 Similarly, socioeconomic deprivation and food insecurity was perceived to be a more immediate and
14 pressing concern than childhood overweight or obesity. Both initial attendance and ongoing retention
15 were affected by a lack of participant resources, even if participants expressed a desire to attend.
16 Participants who engaged with Whānau Pakari and other services despite the impact of adverse
17 stressors appeared to have more resources.

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25 *Domain 2: Societal norms of weight and body size affect how people experience seeking care for*
26 *weight*

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30 *Age*

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32 The age of the child involved in the service affected the degree to which families chose to engage, due
33 to a perception that children were too young to have weight problems, which was a key reason for
34 both dropping out of the service early or declining input altogether. Children who were clinically
35 overweight or had obesity were perceived to be a normal weight in early childhood and increasingly
36 beyond. Some participants felt that while their child might not fit into a set of assessment criteria, this
37 did not necessarily equate to their child being unhealthy.

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46 'When he got put in the [...] 'oh, he's overweight' box. And when you're, like, 'he's not that
47 overweight', because it was just he wasn't in their little boxes. I think that more annoyed me,
48 is that they've got these sort of, like, 'this is the normal weight for a 5 year old'. Well, there's
49 all sorts of different 5 year olds. He's now 10 years and he is my height [...] he's a big guy.'

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55 There was a strong belief that if children were 'big but active', then their weight was not a concern.

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3 ‘...he’s always been big, but he’s really active. Like he wins the triathlons and the cross-
4
5 country and he bikes and swims... it’s not like he can’t exercise or is held up, you know what
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7 I mean? And so we just thought well, and it’s not like he wasn’t healthy eating.’
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10 *Gender*

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13 Families appeared more reluctant to engage their female children in services that are characterised as
14
15 weight-related, both at initial recruitment and throughout the programme, for fear of their child
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17 developing self-esteem issues. Parents also reported their daughters were often reluctant to attend
18
19 themselves.
20

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22 ‘To me it’s like you don’t need to involve her because she’s already self-conscious, soft-
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24 hearted, already upset about it sort of thing and, like, to me it was like more of a trigger. So, I
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26 was, like, no. I will do it my way. So I pulled back because it wasn’t worth it for her, you
27
28 know what I mean? Like, her self-esteem and stuff is worth more than, you know, going to a
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30 dietitian where at home I can just stop giving her all that stuff to make her healthier. So that’s
31
32 where it comes across wrong.’
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35 *Genetics*

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38 Overweight and obesity was often associated with genetics by participants. This was sometimes
39
40 specifically linked to ethnicity, and specifically that Māori and Pacific Island peoples are ‘naturally
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42 big’. A familial propensity towards overweight resulted in participants reportedly acting in two ways:
43
44 either they did not want to engage because they felt that there was no point, given their weight was
45
46 genetic (panel 1), or they were compelled to engage more in order to counteract their genetics:
47
48

49 ‘My side of the family is really obese so weight has always been an issue, so if you are trying to
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51 diet everyone gets behind you because they know what the challenge and the battle is. No, we
52
53 don’t really care what other people say, we just get on with it.’
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3 *Domain 3: Historical experiences of healthcare affect future perception and engagement with*
4 *services*
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7 Past experiences of healthcare influenced participants' opinions, perceptions and behaviour in relation
8 to seeking care again. This was a multidimensional phenomenon, acting across both weight and
9 ethnicity. If participants had had negative experiences in the health system in relation to their weight
10 or ethnicity, then they were less willing to engage with Whānau Pakari and other health services. This
11 was especially important if the referral experience to Whānau Pakari was negative, given that this
12 may have been the first instance of being confronted about their child's weight.
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21 'Basically they told her she was obese [at the B4 School Check] ... Yeah, that she was obese
22 for her age and they said this in front of her, and she was like "what is obese"? And they said,
23 "you're bigger than any other child your age" but she's not the only one [...] So they say it in
24 front of a child, it sort of knocks their self-esteem and their confidence right back.'
25
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30 While weight stigma was experienced across all groups of participants, there were few feelings of
31 stigma about attending Whānau Pakari for those participants who engaged highly ($\geq 70\%$ of sessions):
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33

34 'There was nothing to be embarrassed about. You know, like secretive about it. It was
35 something that I was doing for my kid, to help her get better in herself and if someone else
36 had a problem then that was their problem, not mine. At the end of the day it is about her. Not
37 about what anyone else thought.'
38
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44 Experiences of racism in the healthcare system and in wider society affected how participants
45 reengaged with health services. This included a wide range of race-related experiences from
46 interpersonal to institutionalised racism. Likewise, participants recounted a variety of responses to
47 these experiences from renewal of engagement and wanting to 'prove them wrong', to disengagement
48 with outside entities and organisations, to internalised racism.
49
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53

54 '... we have been through so much stigmatisation that nothing more than one thing matters
55 [...] because for us it's about the betterment of our children and our whānau [family] as a
56 unit.'
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3 *Mediator 1: Respectful, compassionate care mitigated past experiences*
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5 Conversely, positive and respectful care received in both the Whānau Pakari programme and in other
6 areas of the health system mitigated the effect of the first three determinants, particularly against the
7 impact of past negative experiences of healthcare. A positive referral experience generally set a
8 positive tone for interacting with the Whānau Pakari service itself.
9
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13
14 ‘So we decided yes, this would be an awesome programme for our daughter, because we
15 wanted her to just have some stability at the time because she was just starting High School,
16 going into a phase where people were judging and things like that, you know, building her
17 self-esteem [...] It’s helped her with her confidence and just building a life that’s easy for her,
18 you know. So, yeah, I thank [referrer] for that and for putting us onto that programme too
19 because it was really awesome. We, as a whānau, we enjoyed it, and just being able to support
20 her in that programme.’
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30 Participants who did engage with Whānau Pakari reported that the care received in the programme
31 was ‘different’ from previous care received and that the programme deliverers were ‘like a family’.
32 For these families, the respectful and compassionate care countered some of the negative effects of
33 past experiences.
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39 ‘It was just the people, that’s all it was. It was just the approach of the people to be honest um
40 and that made us comfortable, and I go by my children a lot because if they’re uncomfortable
41 well then they’re not the right people to be around for us. And they were comfortable.’
42
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46 The social and team aspects of Whānau Pakari were beneficial for families, as well as the perceived
47 extra care received
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49

50 ‘I liked it. I didn’t think I was going to. I thought ‘oh, this is going to be stupid’, but no it
51 wasn’t. It was actually a bit of an eye opener. I actually learnt something. And then we just
52 recently got her blood tests and all that done again because through the doctors they didn’t do
53 no diabetic tests or anything like that. Through Whānau [Pakari] they did. They did heaps
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3 more than the doctors did. So I think that's pretty much why we stayed with them, it was like
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5 'aha, we can get some serious help here'.
6
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8 Figure One summarises the interacting and mitigating domains affecting participant engagement.
9

10 11 Discussion 12 13 14 15

16 This study found that engagement in Whānau Pakari was determined by the degree to which
17 participants were affected by three interactive domains: complex adverse life stressors, societal norms
18 of weight and body size, and past experiences of healthcare. These complex mechanisms operated at
19 multiple levels including at the service, health system and wider societal levels, so that experiences at
20 the seemingly distal societal level could still have an impact on participant engagement at the service
21 level. While the impact of these factors was evident across all four groups, some participants appeared
22 to be resilient to the impact of these determinants. Additionally, respectful and compassionate care
23 appeared to act as a positive mediator. Conversely, participants who declined further input after their
24 referral were more likely to be experiencing greater life stressors without the resources to overcome
25 them. Participants also appeared to be affected by societal norms of weight with regards to age,
26 gender and the perceived impact of genetics, and negative experiences of healthcare often resulted in
27 complete disengagement.
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41 We were surprised that clear recommendations for specific changes to internal programme aspects
42 were not forthcoming from participants across all levels of attendance, as this was a specific intent of
43 the project. Although factors such as the difficulty of attending programme sessions with shift work
44 and other stressors were identified as a barrier by some participants, there was no clear consensus on
45 factors such as timing and location. While forces external to the service affected engagement, our
46 study indicates that there are opportunities at the service level to facilitate initial and continued
47 engagement in Whānau Pakari, and potentially other services. Despite the negative experiences of
48 participants in the health system (both weight and non-weight related), the care received in Whānau
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3 Pakari by deliverers was generally seen as ‘different’, and a key reason for wanting to continue with
4
5 the service.
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8 In our study, many participants who declined further engagement after their referral were reluctant to
9
10 identify their young children as having weight issues and requiring assistance. Past research has
11
12 identified multiple reasons for parental reluctance to identify overweight in their children,²⁴ including
13
14 not recognising obesity as a ‘disease’ and therefore not warranting the same attention as other health
15
16 concerns, and wanting to avoid further stigmatising their child. Our data suggests that families are
17
18 especially concerned with the mental health of their children, which was often perceived to be more
19
20 important than identifying and addressing overweight and was a key reason for declining referrals.
21

22 There appears to be a disconnect between the focus on early life intervention due to the growth
23
24 trajectories of young children with overweight or obesity into adolescence and adulthood,^{25,26} and the
25
26 concerns and priorities of parents with young children.
27

28
29 Research indicates that parents of girls with overweight or obesity are more likely to enrol them in
30
31 healthy lifestyles programmes than families with boys with overweight or obesity.¹⁰ The contrasting
32
33 findings of our study, which also included participants who declined their referral, show clear parental
34
35 concern for the mental health and self-esteem of their daughters, which may reflect a desire to focus
36
37 on positive body image, self-esteem and mental health and avoid increasing body dissatisfaction.²⁷
38

39 The findings of this study would suggest that the differences in how males and females experience
40
41 weight in society contributes towards the differing retention rates between male and female
42
43 participants at the service level. It is concerning that two important health issues – overweight and
44
45 mental health – are pitted against each other as perceived incongruent concerns, given that both are
46
47 significant causes of ill-health among children and adolescents, and suboptimal health-related quality
48
49 of life was identified in a previous cohort with weight issues.²
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51

52 Puhl and colleagues argue that message framing with regards to terminology is vital in childhood
53
54 obesity programmes, in order to prevent further stigmatisation of families seeking help for weight.²⁸
55

56 While the Whānau Pakari *programme* aims to be non-judgemental and non-stigmatising, it is equally
57
58 important that the *referral* to the service is perceived to be non-stigmatising by families in order to
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3 encourage engagement. Given the impact of the referral experience to Whānau Pakari on initial and
4 continued engagement with the service, the referral process must be respectful and compassionate,
5 with an acknowledgement of past instances of stigma and discrimination. The sensitivity of weight as
6 a discussion topic requires non-judgemental language, compassion, and an acknowledgement of the
7 wider context and potential pressures on the family.²⁸
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14 As in previous studies,²⁹ many participants in this study had experienced weight stigma, blame and
15 judgement from health professionals as well as a societal culture of weight bias. Indigenous
16 participants often experienced this in addition to varying forms of racism. The impact of racial
17 discrimination on health care use in NZ is well-documented,^{30, 31} and the compounding impact of
18 multiple stigmas is likely to contribute towards differential attendance rates between Māori and NZ
19 Europeans. Previous weight bias and racism which occurs outside the service may play a role in
20 participant reluctance to engage with Whānau Pakari. Further research should investigate the role of
21 racism and weight stigma in engagement with healthcare for weight issues among ethnic minorities.³²
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32 **Strengths and Limitations**

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34 The strengths of this study include the large sample size across participants with varying levels of
35 engagement which allowed for in-depth and broad analysis. In addition, this study included data from
36 a targeted group of participants (those who declined further contact after referral) whose lack of
37 contact with the service limits the power of quantitative methods in drawing conclusions, and who are
38 typically difficult to recruit, as recognised in previous studies.¹⁰ Finally, there was good representation
39 from families with Māori children who comprised approximately half of the interviews, allowing us to
40 draw conclusions for a group whose voice is historically absent from obesity research.
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50 The main limitation of this study was the lack of child and adolescent voice with regards to their
51 experiences with Whānau Pakari. While it was intended to conduct interviews with families, many
52 parents at recruitment were reluctant to involve their children due to the sensitivity of material
53 discussed or were unable to involve them due to timing issues. This meant that children's experiences
54 have only been explored through their parents' accounts, rather than through their own voice. It is
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3 possible that participants were discretionary in what they chose to share; however, the disclosure of
4 extremely personal and sensitive experiences suggests that any researcher-participant power dynamics
5 were overcome by steps the interviewers took to mitigate this difference (Appendix One).
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10 **Conclusions**

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13 In conclusion, this study found that much of the difference between Whānau Pakari participants who
14 engaged highly and those who did not engage appeared to be due to the degree to which participants
15 were affected by the impact of factors at the system and societal levels. Focusing purely on weight in
16 multicomponent interventions does not acknowledge the complexity of contemporary family life.
17 However, family-based multidisciplinary intervention programmes such as Whānau Pakari are an
18 opportunity to acknowledge the wider societal challenges affecting achievement of healthy lifestyle
19 change. Health professionals and providers can engage in respectful and compassionate care to help
20 counteract past negative experiences of healthcare. Referral pathways for healthy lifestyle change
21 programmes need to be as flexible as possible to remove any barriers to engagement, and referrers
22 need to develop a deeper understanding of the importance of the referral conversation in relation to
23 weight. Respectful, compassionate care is critical to enhanced retention in programmes, and ongoing
24 engagement in healthcare services overall.
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39 *Acknowledgements*

40
41 The authors acknowledge Dr Donna Cormack (Te Kupenga Hauora Māori) for her contribution to the
42 research and critical appraisal of the manuscript.
43
44
45

46 Numerous authors within our research group are increasingly aware that the use of terms such as
47 obesity are contested and increasingly problematic, partly due to the experiences of participants in
48 terms of weight stigma. We have therefore used this term where it relates to referenced works,
49 prevalence, and to communicate to the biomedical community, but have used alternate terms
50 wherever possible to ensure a person-centred approach, prioritising the experience and voice of those
51 working towards achieving healthy lifestyle change
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Declarations of interests

We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests. All authors have completed the Unified Competing Interest form (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

Ethics committee approval

Ethical approval for the Whānau Pakari Barriers and Facilitators study was granted by Central Health and Disability Ethics Committee (NZ) (17/CEN/158/AM01). Written informed consent was obtained from all study participants.

Transparency statement

The lead author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as originally planned have been explained.

Contributorship statement

CEKW was involved in study design, data collection, analysis, interpretation, and writing of the manuscript. NR contributed towards study design, data collection and manuscript appraisal. EW contributed towards study design, oversaw analysis and interpretation, and was involved in writing of the manuscript. PH was involved in study design and critical appraisal of the manuscript. YA was involved in study design, analysis, interpretation, and writing of the manuscript.

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Data sharing statement

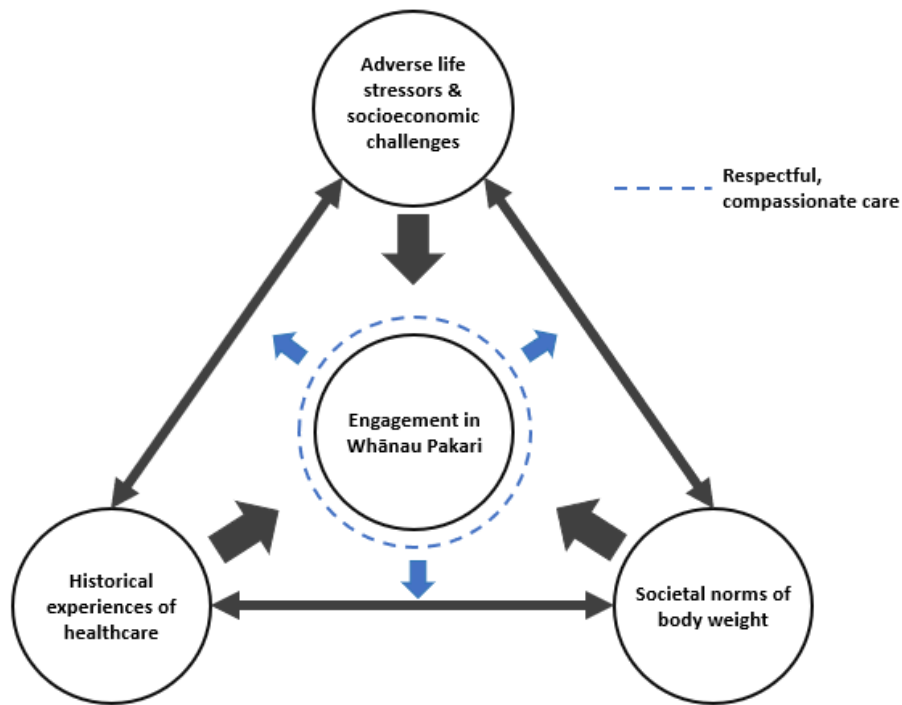
No additional data available.

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COREQ (Consolidated criteria for reporting qualitative research)

Domain 1: Research team and reflexivity

Personal characteristics

1. Interviewer

Cervantée Wild & Ngauru Rawriri conducted the interviews.

2. Credentials and 3. Occupation

Cervantée Wild (BHSc(Hons), BA) – PhD candidate, Liggins Institute, University of Auckland

Ngauru Rawiri – BHSc student, Te Reo Māori teacher (tertiary level) and interview facilitator, Liggins Institute, University of Auckland

Paul Hofman (MbChB, Dip Obs, FRACP) – Professor and paediatric endocrinologist

Esther Willing (PhD) – Lecturer in Hauora Māori, Kōhatu – Centre for Hauora Māori, University of Otago

Yvonne Anderson (PhD, Dip Paeds, MBChB, FRACP, BSc (Psych)) – Senior research fellow and paediatrician

4. Gender & ethnicity

CW – female, New Zealand European

NR – female, Māori (Ngāti Mutunga, Ngāti Tama, Ngāti Rāhiri o Te Ati Awa me Ngai Tūhoe)

PH – male, New Zealand European

EW – female, Māori (Ngāti Toarangatira, Ngāti Koata me Ngā Ruahine)

YA – female, New Zealand European

5. Experience and training

CW had qualitative research training through the PhD (supervised by PH, EW, and YA). NR had interview experience through her career. PH is an experienced researcher in child health and endocrinology. EW is an experienced qualitative researcher and has extensive experience in Māori health research. YA is an experienced researcher in child health, especially childhood obesity.

Relationship with participants

6. Relationship established

All participants were recruited as described below, and some were already known to NR through relationship networks.

7. Participant knowledge of the interviewer

1
2
3 The participants knew the reasons for conducting the research (detailed in the patient information
4 and consent form), and participants were aware that the study would specifically ask about the
5 factors that contributed to their decisions to engage or not engage, in order to improve the service.
6 Participants were also aware that the interviewers were separate and distinct from the clinical
7 service team.
8

9 10 8. Interviewer characteristics

11 NR is a Māori researcher (of Ngāti Mutunga, Ngāti Tama, Ngāti Rāhiri o Te Ati Awa and Ngai Tūhoe
12 descent) and CW is New Zealand European. This mixed Indigenous – non-Indigenous partnership
13 allowed us to connect and establish rapport with participants, depending on the interview
14 participant and context. NR's role as a parent had the advantage that familiarity with this stage of
15 life helped her understand participants' stories and ask exploratory questions.
16
17

18 **Domain 2: Study design**

19 *Theoretical framework*

20 9. Methodological orientation and Theory

21
22 The research approach was informed by Kaupapa Māori theory. The approach was developed to
23 minimise any perceived power imbalances between the interview team and the participants and
24 make the interview experience as comfortable as possible. We used thematic analysis to analyse the
25 interviews.
26
27

28 *Participant selection*

29 10. Sampling and 11. Method of approach

30
31 We used purposive sampling to identify potential participants who fit the criteria, and then
32 randomised the list of potential participants in each group. We then contacted each participant one
33 by one. Participants were recruited by telephone and interviewed in person over a six-month period
34 from June to December 2018.
35
36
37

38 12. Sample size

39 For funding and resource reasons, we had a maximum total of 74 potential interviews with families.
40 We conducted 64 interviews in total.
41
42

43 13. Non-participation

44 We approached 150 families, of which 40 were uncontactable and 46 declined because they had
45 moved out of the region, were too busy with work, or didn't remember the referral.
46
47

48 *Setting*

49 14. Setting of data collection

50 Participants were interviewed in person at their home, workplace, or at a local community child
51 health centre. All participants chose where they would prefer to be interviewed.
52
53

54 15. Presence of non-participants

55 For most interviews, only the participant and interviewers were present, but there were occasionally
56 other family members present, such as young children (<5 years).
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60

1
2
3 16. Description of sample
4

5 Half the interviews were with families with Māori children. Most (80%) were solely with a female
6 parent/caregiver (13 interviews included male parents and/or caregivers). Eleven interviews
7 involved two or more family members. Five interviews included a child participant.
8

9 *Data collection*
10

11 17. Interview guide
12

13 A semi-structured interview framework was used and adjusted for relevance as each interview
14 progressed. It was not pilot tested.
15

16 18. Repeat interviews
17

18 Repeat interviews were not conducted, but participants were offered their transcripts for review
19 after the interview.
20

21 19. Audio recording
22

23 Interviews were audiotaped digitally and transcribed by a medical typist.
24

25 20. Field notes
26

27 Field notes were made after each interview and kept as part of a reflexive notes.
28

29 21. Duration
30

31 Interview audio recordings ranged from nine minutes to 107 minutes (mean 31 minutes).
32

33 22. Data saturation
34

35 Data saturation was reached in each group of participants in each level of engagement.
36

37 23. Transcripts returned
38

39 Transcripts were anonymised and returned to the participant for checking, including deletions of
40 portions if desired.
41
42

43 **Domain 3: analysis and findings**
44

45 *Data analysis*
46

47 24. Number of data coders
48

49 Eight transcripts were independently coded by CW and EW and discussed for consistency. After the
50 coding matrix was constructed and consensus on codes reached, all transcripts were coded again by
51 CW.
52

53 25. Description of the coding tree
54

55 A 'mind map' was used instead of a coding tree in order to better capture complexity and avoid an
56 artificial hierarchy that did not adequately represent the inter-relationships between the themes,
57 since themes could become more major or minor depending on the context.
58

59 26. Derivation of themes
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3 Themes were derived from the data.
4

5 27. Software

6
7 MAXQDA software was used to manage the data.
8

9 28. Participant checking

10 Participants did not provide feedback on the findings.
11
12
13

14 *Reporting*

15
16 29. Quotations presented

17
18 Participant quotations are presented in Panel 1 and throughout the manuscript. They are not
19 identified by participant number.
20

21 30. Data and findings consistent

22
23 There was good consistency between data and findings, with the two interviewers working to
24 discuss findings and the wider research team providing critique and challenging interpretations of
25 data.
26

27 31. and 32. Clarity of major and minor themes

28
29 A distinction was made between 'major' and 'minor' themes with sub-themes capturing the range of
30 participant experiences under each major theme. However, even major themes could not be cleanly
31 separated, reflecting real-world complexity.
32
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36 (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19, 349–
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40 NB. This checklist has been amended to capture ethnicity and gender breakdown, to reflect the
41 composition of the research team.
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BMJ Open

Determining barriers and facilitators to engagement for families in a family-based multicomponent healthy lifestyles intervention for children and adolescents: a qualitative study

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3 **Determining barriers and facilitators to engagement for families in a family-based**
4 **multicomponent healthy lifestyles intervention for children and adolescents: a qualitative study**
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For peer review only

ABSTRACT

Objectives: Recruitment and retention in child and adolescent healthy lifestyle intervention services for childhood obesity is challenging, and inequalities across social groups are persistent. This study aimed to understand the barriers and facilitators to engagement in a multicomponent assessment-and-intervention healthy lifestyle programme for children and their families, based in the home and community.

Design: Qualitative interview-based study of past users (n=76) of a family-based multicomponent healthy lifestyle programme in a mixed urban-rural region of New Zealand. Semi-structured, home-based interviews were conducted and thematically analysed with peer debriefing for validity.

Participants: Families were selected through stratified random sampling to include a range of levels of engagement, including those who declined their referral, with equal numbers of interviews with Indigenous and non-Indigenous families.

Results: Three interactive and compounding determinants were identified as influencing engagement in Whānau Pakari: acute and chronic life stressors, societal norms of weight and body size, and historical experiences of healthcare. These determinants were present across societal, system and healthcare service levels. A negative referral experience to Whānau Pakari often resulted in participants declining further input or disengaging from the programme. A fourth domain, respectful and compassionate healthcare, was identified as a mitigator of these three themes, facilitating participant engagement despite previous negative experiences.

Conclusions: While participant engagement in healthy lifestyle programmes is affected by determinants which appear to operate outside immediate service provision, the programme is an opportunity to acknowledge past instances of stigma and the wider challenges of healthy lifestyle change. The experience of the referral to Whānau Pakari is important for setting the scene for future engagement in the programme. Respectful, compassionate care is critical to enhanced retention in multidisciplinary healthy lifestyle programmes and ongoing engagement in healthcare services overall.

Strengths and limitations of this study

- Large sample size (64 interviews with 76 total participants)
- Sample included wide range of participants with varying levels of engagement, including non-service users
- Equal representation from families with Māori and non-Māori children
- Lack of child and adolescent voice
- Participants may not have fully disclosed their experiences to interviewers

Introduction

Excess weight in childhood and adolescence affects physical, psychological and social health and well-being, and is a known risk factor for comorbidities both in childhood and adulthood.¹ Children with weight issues in Aotearoa/New Zealand (henceforth referred to as New Zealand) demonstrate a high prevalence of weight-related comorbidities, as well as low physical activity, suboptimal eating behaviours, and low health-related quality of life.²⁻⁵ One of the key recommendations of the World Health Organization's Report of the Commission on Ending Childhood Obesity is to "provide family-based, multicomponent lifestyle weight management services for children and young people who are obese".⁶ A systematic review and meta-analysis found that a minimum of 26 hours of contact time in lifestyle interventions is associated with improvements in weight status in children and adolescents.⁷ However, as with any service attempting to facilitate lifestyle change, success relies on continued family engagement.⁸ It is also important that such multidisciplinary services – and other health professionals addressing childhood obesity in a primary care setting – are able to engage with groups most affected by obesity, namely those living in the most deprived areas and ethnic minorities.⁹

Improving *engagement* with childhood obesity services requires addressing both initial recruitment and ongoing retention.⁸ Service, system and society-related factors may *enable* or *inhibit* initial and ongoing engagement; factors which are also referred to as facilitators and barriers.^{10 11} Kelleher and colleagues' review of the factors affecting attendance at community-based lifestyle programmes

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2
3 found that weight stigma, parental reluctance to identify overweight and logistical challenges were
4 key barriers to initial and ongoing attendance.¹⁰ Under-represented in the literature are those who
5 declined treatment altogether, as many past studies had low recruitment from these families. It is
6 therefore important to understand the experiences of families experiencing childhood obesity in order
7 to improve initial recruitment and ongoing retention in healthy lifestyle services, particularly for
8 groups most affected.¹⁰
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15
16 Whānau Pakari is a family-centred, community-based assessment and intervention programme for
17 children and their families, based in Taranaki, a mixed urban-rural region of New Zealand (NZ). The
18 name means 'healthy, self-assured families that are fully active'. The focus of the programme is on
19 healthy lifestyle change rather than weight loss or obesity, in order to minimise judgement and
20 weight-related stigma. The multidisciplinary service involves a home-based medical assessment with
21 advice, removing the hospital appointment in order to *demedicalise* care, and includes weekly
22 nutrition, physical activity and psychology sessions. This approach takes healthcare outside hospital
23 walls and into the community, without compromising quality of care. A randomised clinical trial of
24 the Whānau Pakari model of care demonstrated modest reductions in body mass index (BMI) standard
25 deviation score (SDS) and improvements in cardiovascular fitness and health-related quality of life.¹²
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¹³ Greatest improvements in BMI SDS were found in those who attended the recommended $\geq 70\%$ of
intense intervention sessions.^{13 14} However, Māori (NZ's Indigenous population) and females were
less likely to attend $\geq 70\%$ of sessions, with sustained retention in the programme favouring males and
NZ Europeans.¹³

Previous evaluation of the experiences of Whānau Pakari participants and their caregivers has shown
the programme to be a positive and beneficial experience for those involved, emphasising the
importance of connectedness, knowledge-sharing and self-determination, the collective journey
alongside other families and programme deliverers, and the importance of a non-judgemental,
respectful environment.¹⁵ A survey of past participants of Whānau Pakari indicated that previous
experiences of healthcare may influence subsequent engagement with health services, particularly for
Māori,¹⁶ although this was not elaborated on further by participants. These findings were limited by

1
2
3 the survey's relatively small sample size and the lack of representation from participants who declined
4
5 intervention. Therefore, the objective of the present study was to understand barriers and facilitators
6
7 to initial attendance and ongoing retention in the Whānau Pakari programme.
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9

10 *Methods*

11 *Design*

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14 In NZ, health research is required to be responsive to the needs and diversity of Māori.¹⁷ The study
15
16 design and research approach was informed by Kaupapa Māori methodological principles. Kaupapa
17
18 Māori theory is a methodology which resists persistent power imbalances and the continued use of
19
20 cultural deficit theory (attributing poor health to something inherent to a 'culture') to explain
21
22 inequities between Māori and non-Māori,^{17 18} and is aligned with a social and structural determinants
23
24 of health framework.¹⁹ As a methodological approach, Kaupapa Māori research centres Māori voice
25
26 and experience, and prioritises understanding people within their contexts and whānau (families).¹⁹ It
27
28 was hoped that this approach would reduce many of the known barriers to research participation for
29
30 Indigenous peoples, and enable participants to engage positively in the research process.²⁰ While
31
32 Kaupapa Māori research can use both quantitative and qualitative methods, in this study, a qualitative
33
34 research design was chosen in order to ensure that priority was given to ensuring the voices and
35
36 experiences of Māori participants were understood in this study.
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40 In-depth interviews, centring on participant experience with Whānau Pakari and wider experiences of
41
42 the health system, were undertaken. A specific focus was to understand the barriers to attendance and
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44 retention at varying levels of engagement in Whānau Pakari, including those who declined their
45
46 referral and had no further contact with the programme. Factors which facilitated both initial and
47
48 ongoing engagement were explored.
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51 Ethical approval for the Whānau Pakari Barriers and Facilitators study was granted by Central Health
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53 and Disability Ethics Committee (NZ) (17/CEN/158/AM01). Written informed consent was obtained
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55 from all study participants.
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Patient and Public Involvement statement

Participants were first involved in the research at the recruitment stage, although some participants had been involved in an earlier related randomised clinical trial.¹² The research questions were informed by the experiences of participants voiced, unsolicited, during clinical assessment during the previous trial and in previous focus group research.²¹ The design of the research drew from Kaupapa Māori theory, which informed the research process in order to prioritise the experiences and preferences of participants. The dissemination process to participants was altered as a result of participant preference to receive feedback via a summary video, rather than at a group meeting. Participants were not asked to assess the burden of the time required to participate in the research.

Participants

Eligible participants were parents and/or caregivers of children and adolescents who had been referred to the service from January 2012 to January 2017. Children and adolescents over 11 years of age were also invited to participate. The eligibility criteria for referral to the service are children aged 4 to 16 years, identified as having obesity [body mass index (BMI) $\geq 98^{\text{th}}$ centile], or overweight (BMI $> 91^{\text{st}}$ centile) with associated weight-related comorbidities.^{12 22}

Participants were recruited from four different groups of Whānau Pakari service users who had varying levels of engagement (Table 1) using stratified random sampling. Recruitment was via telephone call and text message. The sample contained equal numbers of families with Māori and non-Māori children to ensure appropriate representation of Indigenous children's experiences.

Data collection

The semi-structured interviews were approximately 30-60 minutes in duration and conducted by CW and NR together where possible (see supplementary file for interview schedule). NR led the interviews with Māori families when appropriate. Interviews took place in the participant home or alternative locations chosen by the participant (including a hospital, participant workplaces, and a community library) in order to minimise inconvenience and travel barriers. Most interviews were undertaken with one participant (the parent or caregiver) but a portion included two or more family

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3 members, including children (Table 1). A *koha* (gift, donation or contribution) was offered to
4 participants in acknowledgement of their time and as a sign of reciprocity for the information shared.
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8 Informed consent was obtained to record, transcribe and analyse participant data. All participant
9 information was anonymised. Participant ethnicity for both the parent/caregiver and child was
10 confirmed at the time of the interview by using the NZ Census 2006 ethnicity question.²³ All
11 interviews were audio-recorded and independently transcribed. Participants were offered their
12 transcripts to review for accuracy and acceptability.
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18 *Analysis*

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20 Interview transcripts were coded and analysed inductively in MAXQDA (2018),²⁴ according to Braun
21 and Clarke's method for reflexive thematic analysis,^{25,26} which aligned well with the reflexivity and
22 awareness of researcher theoretical positioning required of research informed by Kaupapa Maori
23 Theory. CW developed the coding matrix with peer review from EW, coded the interview data, and
24 identified the initial themes. The authors collaborated to finalise the themes and develop the
25 framework. The acknowledgement of different researcher standpoints allowed the authors to debate,
26 challenge, and refine interpretations of the data, thereby developing a more nuanced interpretation of
27 the data.²⁶ Specifically, the researchers agreed to apply the 'Give-Way' rule if there was disagreement
28 over the interpretation of the data concerning Māori participants, with the final decision involving
29 cultural interpretation of Māori participants' experiences passing to a Māori researcher.^{19,27,28}
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43 It became clear from our initial appraisal of the data that the degree to which participants engaged
44 with the programme was on a continuum rather than fitting neatly into discrete categories. Therefore,
45 the groups have been analysed together, noting where there may be key differences according to the
46 degree of engagement.
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52 For more detail of this procedure, please refer to the Consolidated Criteria for Reporting Qualitative
53 Research (COREQ) checklist (Appendix One).
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Results

64 interviews were conducted (out of a potential cohort of 74) with families who had varying levels of engagement, across a six-month period from June to November 2018 (76 participants in total) (Table 1). Half of the interviews were with Māori families (families with a Māori child who had been referred to the service), including interviews with non-Māori parents of a Māori child. Participants included parents, grandparents, other caregivers, and the children/adolescents themselves (n=5) and were from a range of socioeconomic backgrounds (deciles 1-10 of the 2013 NZ Index of Deprivation).²⁹ Full details of interview recruitment rate and reasons for non-participation are included in the COREQ checklist (Appendix One).

Demographics

Table 1. Participant demographics

Interview participants N		76 ^a
Female participant <i>n</i>		65
Ethnicity % ^b	Māori	32
	NZ European	75
	Asian	7
	Other European	5
Level of engagement <i>n</i>	Attended ≥70% of programme sessions ^c	18
	Attended <30% of programme sessions ^d	19
	Had one assessment, then discontinued with the programme ^e	7
	Referred, but chose not to engage ^f	20

^a64 interviews total, 11 interviews involved 2+ family members, 5 interviews included a child/adolescent participant in addition to their parent/caregiver Maximum total of 74 potential interviews for funding and

resource reasons. 136 families approached, of which 53 were uncontactable, 7 were living out of the region, and 12 declined (see COREQ checklist for reasons); *b* Total ethnicity output (more than one ethnicity selected); *c* 24 families invited total; *d* 42 families invited total; *e* 15 families invited total; *f* 55 families invited total

Box 1: Key determinants of engagement and retention in Whānau Pakari

Domain 1: Adverse life stressors & socioeconomic deprivation

‘I wouldn’t say it was, like, you guys as such – it was just the history behind what she had um, but we come from, so um I came from an abusive marriage, which had split up because of abuse... So this was really hard at the time.’

‘Once she lost her father, well that was pretty much the end of it. She just didn’t want to do nothing. As much as I tried to encourage her to, you know, get with the programme, no she just didn’t want to know about it.’

Competing health priorities

‘...[DAUGHTER] was under [child and adolescent mental health services] for suicide watch and stuff like that... so for us there was that added stuff as well.’

Financial insecurity/socioeconomic status

‘I didn’t have a house and lived in that camper. Yeah, so it just didn’t work out, otherwise she would have gone.’

Domain 2: Societal norms of weight and body size

Age

‘Like, a weight problem, like, at the time he was only 6 years or 7 years.’

‘... we were kind of shocked because they said that [SON] was, like, obese or something ... I don’t think he’s overweight at all... Because he’s really tall... so I don’t understand, like, what sort of weight should he have been because he was, he’s just like a, he was like a normal kid. So I don’t understand what is

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overweight and underweight. Because I've seen some, not being mean, but overweight kids, and he wasn't overweight.'

Gender

'She might develop an eating disorder and I don't want that. I'd rather, you know, it's weird, but I'd rather she be overweight than underweight, you know what I mean? I'd hate to deal with an anorexic daughter because that's hard work.'

Perceived genetic disposition

'You know... it's just the way it is sometimes. Some people get good genes, some people get other genes and it means it doesn't work out.'

Domain 3: Historical experiences of healthcare

Weight stigma and discrimination

'... having visited for something else entirely different and then being told kind of 'your child's obese and we are going to refer you' and just doing it front of him [...] it was just even in the way that it was delivered and I was kind of not expecting it. I mean, I can see that he's, he's a bit chunky, but I just, I don't know [...] [the referral] was a bit off-putting.'

Racism

'...people will judge you for what and where, what colour you are or whatever... [it] just made me more determined to get in there and do what I had to do.'

Mediator 1: Respectful, compassionate care mitigated past experiences

'It was not just the families, but also the, what do you call them, the workers... Very supportive, non-judgmental. I think that made a big difference and 'yes we are going to go' because they are not judging you... the staff was very supportive.'

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3 Three major interacting domains and subthemes affecting participant engagement are described in box
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5 1 in participants' own words. A fourth domain of respectful, compassionate care was identified as a
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7 mediator, which was able to mitigate the effect of the first three themes. Unique themes according to
8
9 level of engagement with the programme were not generated. While each domain was prevalent in
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11 participant accounts across all recruitment categories, the extent to which a domain affected each
12
13 group determined engagement.
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16 *Domain 1: Obesity sits within the context of multiple other complex stressors for families in NZ*

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18 Participation in the Whānau Pakari service was affected by the multiple complex stressors of living in
19
20 contemporary NZ. These were acute, one-off adverse events, such as a death in the family, and
21
22 chronic, ongoing challenges, such as financial insecurity. Childhood obesity and overweight as a
23
24 health concern sat within the context of multiple other important concerns for families. Participants
25
26 were often living in 'crisis mode' or dealing with multiple challenges at once, including: financial and
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28 food insecurity, suicide, abusive relationships, deaths in the family, mental health issues, disability,
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30 relocation, marriage & family break-ups, fostering children, children being raised by other caregivers,
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32 drug use and significant other illnesses.
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36 For parents of children with multiple health conditions, especially mental health concerns or autism
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38 spectrum disorder, addressing weight was often not perceived to be as important compared with other
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40 competing family health concerns. Parents and caregivers also reported the challenges of balancing
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42 multiple demands such as long work hours, shift work and extracurricular activities alongside
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44 attending Whānau Pakari.
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47 'I think he had one of his sporting things on and I was doing 50 hours a week at that time and
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49 I was like 'oh, my God, I can't do it', I couldn't do it. I mean, if he needed, if I felt like he
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51 needed to be there, I would get him there, like, it's, my work's not that important. Weeds and
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53 shit can wait, you know, like, people can wait um if it was a, if I felt like it was serious. I
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55 would have got him there, but I just yeah.'
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3 Similarly, socioeconomic deprivation and food insecurity was perceived to be a more immediate and
4 pressing concern than childhood overweight or obesity. Both initial attendance and ongoing retention
5 were affected by a lack of participant resources, even if participants expressed a desire to attend.
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9 Participants who engaged with Whānau Pakari and other services despite the impact of adverse
10 stressors appeared to have more resources, and thus were less affected by this domain.
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14 *Domain 2: Societal norms of weight and body size affect how people experience seeking care for*
15 *weight*
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18 Societal norms and beliefs around weight and body size led to the minimisation of obesity and the fear
19 of stigmatisation for participants (see also Domain 3). These manifested differently according to the
20 age, gender and the perceived role of genetics in obesity, and resulted in lower engagement. An
21 exception was participant beliefs around perceived genetic propensity towards obesity, which in some
22 cases led to higher rather than lower participant engagement.
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29 The age of the child involved in the service affected the degree to which families chose to engage, due
30 to a perception that children were too young to have weight problems, which was a key reason for
31 both dropping out of the service early or declining input altogether. Children who were clinically
32 overweight or had obesity were perceived to be a normal weight in early childhood and increasingly
33 beyond. Some participants felt that while their child might not fit into a set of assessment criteria, this
34 did not necessarily equate to their child being unhealthy.
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43 ‘When he got put in the [...] ‘oh, he’s overweight’ box. And when you’re, like, ‘he’s not that
44 overweight’, because it was just he wasn’t in their little boxes. I think that more annoyed me,
45 is that they’ve got these sort of, like, ‘this is the normal weight for a 5 year old’. Well, there’s
46 all sorts of different 5 year olds. He’s now 10 years and he is my height [...] he’s a big guy.’
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52 There was a strong belief that if children were ‘big but active’, then their weight was not a concern.
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55 ‘...he’s always been big, but he’s really active. Like he wins the triathlons and the cross-
56 country and he bikes and swims... it’s not like he can’t exercise or is held up, you know what
57 I mean? And so we just thought well, and it’s not like he wasn’t healthy eating.’
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3 Families appeared more reluctant to engage their female children in services that are characterised as
4 weight-related, both at initial recruitment and throughout the programme, for fear of their child
5 developing self-esteem issues. Parents also reported their daughters were often reluctant to attend
6 themselves.
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12 ‘To me it’s like you don’t need to involve her because she’s already self-conscious, soft-
13 hearted, already upset about it sort of thing and, like, to me it was like more of a trigger. So, I
14 was, like, no. I will do it my way. So I pulled back because it wasn’t worth it for her, you
15 know what I mean? Like, her self-esteem and stuff is worth more than, you know, going to a
16 dietitian where at home I can just stop giving her all that stuff to make her healthier. So that’s
17 where it comes across wrong.’
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26 Overweight and obesity was often associated with perceived genetic propensity to obesity by
27 participants. This was sometimes specifically linked to ethnicity, and specifically that Māori and
28 Pacific Island peoples are ‘naturally big’. A perceived familial propensity towards overweight resulted
29 in participants reportedly acting in two ways: either they did not want to engage because they felt that
30 there was no point, given they perceived their weight to be genetic (panel 1), or they were compelled
31 to engage more in order to counteract their genetics:
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39 ‘My side of the family is really obese so weight has always been an issue, so if you are trying to
40 diet everyone gets behind you because they know what the challenge and the battle is. No, we
41 don’t really care what other people say, we just get on with it.’
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46 *Domain 3: Historical experiences of healthcare affect future perception and engagement with* 47 *services*

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49 Past experiences of healthcare influenced participants’ opinions, perceptions and behaviour in relation
50 to seeking care again. This was a multidimensional phenomenon, acting across both weight and
51 ethnicity. If participants had had negative experiences in the health system in relation to their weight
52 or ethnicity, then they were less willing to engage with Whānau Pakari and other health services. This
53 mostly affected participants who declined further input after their referral or who discontinued after
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3 one assessment. This was especially important if the referral experience to Whānau Pakari was
4 negative, given that this may have been the first instance of being confronted about their child's
5 weight.
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10 'Basically they told her she was obese [at the B4 School Check] ... Yeah, that she was obese
11 for her age and they said this in front of her, and she was like "what is obese"? And they said,
12 "you're bigger than any other child your age" but she's not the only one [...] So they say it in
13 front of a child, it sort of knocks their self-esteem and their confidence right back.'
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19 While weight stigma was experienced across all groups of participants, there were few feelings of
20 stigma about attending Whānau Pakari for those participants who engaged highly ($\geq 70\%$ of sessions):
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24 'There was nothing to be embarrassed about. You know, like secretive about it. It was
25 something that I was doing for my kid, to help her get better in herself and if someone else
26 had a problem then that was their problem, not mine. At the end of the day it is about her. Not
27 about what anyone else thought.'
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33 Experiences of racism in the healthcare system and in wider society affected how participants
34 reengaged with health services. This included a wide range of race-related experiences from
35 interpersonal to institutionalised racism. Likewise, participants recounted a variety of responses to
36 these experiences from renewal of engagement and wanting to 'prove them wrong', to disengagement
37 with outside entities and organisations, to internalised racism.
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44 '...we have been through so much stigmatisation that nothing more than one thing matters
45 [...] because for us it's about the betterment of our children and our whānau [family] as a
46 unit.'
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51 *Mediator 1: Respectful, compassionate care mitigated past experiences*

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53 Conversely, positive and respectful care received in both the Whānau Pakari programme and in other
54 areas of the health system mitigated the effect of the first three determinants, particularly against the
55 impact of past negative experiences of healthcare. A positive referral experience generally set a
56 positive tone for interacting with the Whānau Pakari service itself.
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3 ‘So we decided yes, this would be an awesome programme for our daughter, because we
4 wanted her to just have some stability at the time because she was just starting High School,
5 going into a phase where people were judging and things like that, you know, building her
6 self-esteem [...] It’s helped her with her confidence and just building a life that’s easy for her,
7 you know. So, yeah, I thank [referrer] for that and for putting us onto that programme too
8 because it was really awesome. We, as a whānau, we enjoyed it, and just being able to support
9 her in that programme.’

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19 Participants who did engage with Whānau Pakari reported that the care received in the programme
20 was ‘different’ from previous care received and that the programme deliverers were ‘like a family’.
21
22 For these families, the respectful and compassionate care countered some of the negative effects of
23 past experiences.
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27
28 ‘It was just the people, that’s all it was. It was just the approach of the people to be honest um
29 and that made us comfortable, and I go by my children a lot because if they’re uncomfortable
30 well then they’re not the right people to be around for us. And they were comfortable.’
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35 The social and team aspects of Whānau Pakari were beneficial for families, as well as the perceived
36 extra care received
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40 ‘I liked it. I didn’t think I was going to. I thought ‘oh, this is going to be stupid’, but no it
41 wasn’t. It was actually a bit of an eye opener. I actually learnt something. And then we just
42 recently got her blood tests and all that done again because through the doctors they didn’t do
43 no diabetic tests or anything like that. Through Whānau [Pakari] they did. They did heaps
44 more than the doctors did. So I think that’s pretty much why we stayed with them, it was like
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50 ‘aha, we can get some serious help here’.
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53 Figure 1 summarises the interacting and mitigating domains affecting participant engagement.
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Discussion

This study found that engagement in Whānau Pakari was determined by the degree to which participants were affected by three interactive domains: complex adverse life stressors, societal norms of weight and body size, and past experiences of healthcare. These complex mechanisms operated at multiple levels including at the service, health system and wider societal levels, so that experiences at the seemingly distal societal level could still have an impact on participant engagement at the service level. While the impact of these factors was evident across all four groups, some participants appeared to be resilient to the impact of these determinants. Additionally, respectful and compassionate care appeared to act as a positive mediator. Conversely, participants who declined further input after their referral were more likely to be experiencing greater life stressors without the resources to overcome them. Participants also appeared to be affected by societal norms of weight with regards to age, gender and the perceived impact of genetics, and negative experiences of healthcare often resulted in complete disengagement.

We were surprised that clear recommendations for specific changes to internal programme aspects were not forthcoming from participants across all levels of attendance, as this was a specific intent of the project. Although factors such as the difficulty of attending programme sessions with shift work and other stressors were identified as a barrier by some participants, there was no clear consensus on factors such as timing and location. While forces external to the service affected engagement, our study indicates that there are opportunities at the service level to facilitate initial and continued engagement in Whānau Pakari, and potentially other services. Despite the negative experiences of participants in the health system (both weight and non-weight related), the care received in Whānau Pakari by deliverers was generally seen as 'different', and a key reason for wanting to continue with the service.

In our study, many participants who declined further engagement after their referral were reluctant to identify their young children as having weight issues and requiring assistance. Past research has identified multiple reasons for parental reluctance to identify overweight in their children,³⁰ including not recognising obesity as a 'disease' and therefore not warranting the same attention as other health

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3 concerns, and wanting to avoid further stigmatising their child. Our data suggests that families are
4 especially concerned with the mental health of their children, which was often perceived to be more
5 important than identifying and addressing overweight and was a key reason for declining referrals.
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7 There appears to be a disconnect between the focus on early life intervention due to the expected
8 growth trajectories of young children with overweight or obesity into obesity in adolescence and
9 adulthood,^{31 32} and the concerns and priorities of parents with young children.
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16 Research indicates that parents of girls with overweight or obesity are more likely to enrol them in
17 healthy lifestyles programmes than families with boys with overweight or obesity.¹⁰ The contrasting
18 findings of our study, which also included participants who declined their referral, show clear parental
19 concern for the mental health and self-esteem of their daughters, which may reflect a desire to focus
20 on positive body image, self-esteem and mental health and avoid increasing body dissatisfaction.³³
21 The findings of this study would suggest that the differences in how males and females experience
22 weight in society contributes towards the differing retention rates between male and female
23 participants at the service level. It is concerning that two important health issues – overweight and
24 mental health – are pitted against each other as perceived incongruent concerns, given that both are
25 significant causes of ill-health among children and adolescents, and suboptimal health-related quality
26 of life was identified in a previous cohort with weight issues.²
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40 Puhl and colleagues argue that message framing with regards to terminology is vital in childhood
41 obesity programmes, in order to prevent further stigmatisation of families seeking help for weight.³⁴
42 While the Whānau Pakari *programme* aims to be non-judgemental and non-stigmatising, it is equally
43 important that the *referral* to the service is perceived to be non-stigmatising by families in order to
44 encourage engagement. Given the impact of the referral experience to Whānau Pakari on initial and
45 continued engagement with the service, the referral process must be respectful and compassionate,
46 with an acknowledgement of past instances of stigma and discrimination. The sensitivity of weight as
47 a discussion topic requires non-judgemental language, compassion, and an acknowledgement of the
48 wider context and potential pressures on the family.³⁴
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3 As in previous studies,³⁵ many participants in this study had experienced weight stigma, blame and
4 judgement from health professionals as well as a societal culture of weight bias. Indigenous
5 participants often experienced this in addition to varying forms of racism. The impact of racial
6 discrimination on health care use in NZ is well-documented,^{36,37} and the compounding impact of
7 multiple stigmas is likely to contribute towards differential attendance rates between Māori and NZ
8 Europeans. Previous weight bias and racism which occurs outside the service may play a role in
9 participant reluctance to engage with Whānau Pakari. Further research should investigate the role of
10 racism and weight stigma in engagement with healthcare for weight issues among marginalised ethnic
11 groups.³⁸

22 **Strengths and Limitations**

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25 The strengths of this study include the large sample size across participants with varying levels of
26 engagement which allowed for in-depth and broad analysis. In addition, this study included data from
27 a targeted group of participants (those who declined further contact after referral) whose lack of
28 contact with the service limits the power of quantitative methods in drawing conclusions, and who are
29 typically difficult to recruit, as recognised in previous studies.¹⁰ Finally, there was good representation
30 from families with Māori children who comprised approximately half of the interviews, allowing us to
31 draw conclusions for a group whose voice is historically absent from obesity research.

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33
34 The main limitation of this study was the lack of child and adolescent voice with regards to their
35 experiences with Whānau Pakari, as only five interviews included the child or adolescent as a
36 participant. While it was intended to conduct interviews with families, many parents at recruitment
37 were reluctant to involve their children due to the sensitivity of material discussed or were unable to
38 involve them due to timing issues. This meant that children's experiences have mainly been explored
39 through their parents' accounts, rather than through their own voice. In addition, previous literature
40 has largely focused on the effect of child/adolescent gender rather than parent gender on perceived
41 barriers to engagement.¹⁰ In our study, the majority of participants were mothers or female caregivers,
42 which may have affected the results. Lastly, it is possible that participants were discretionary in what
43 they chose to share; however, the disclosure of extremely personal and sensitive experiences suggests

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3 that any researcher-participant power dynamics were overcome by steps the interviewers took to
4
5 mitigate this difference (see COREQ checklist).
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8 **Conclusions**

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10 In conclusion, this study found that much of the difference between Whānau Pakari participants who
11 engaged highly and those who did not engage appeared to be due to the degree to which participants
12 were affected by the impact of factors at the system and societal levels. Focusing purely on weight in
13 multicomponent interventions does not acknowledge the complexity of contemporary family life.
14
15 However, family-based multidisciplinary intervention programmes such as Whānau Pakari are an
16 opportunity to acknowledge the wider societal challenges affecting achievement of healthy lifestyle
17 change. Health professionals and providers can engage in respectful and compassionate care to help
18 counteract past negative experiences of healthcare. Referral pathways for healthy lifestyle change
19 programmes need to be as flexible as possible to remove any barriers to engagement, and referrers
20 need to develop a deeper understanding of the importance of the referral conversation in relation to
21 weight. Respectful, compassionate care is critical to enhanced retention in programmes, and ongoing
22 engagement in healthcare services overall.
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36 *Acknowledgements*

37
38 The authors acknowledge Dr Donna Cormack (Te Kupenga Hauora Māori) for her contribution to the
39 research and critical appraisal of the manuscript.
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43 Numerous authors within our research group are increasingly aware that the use of terms such as
44 obesity are contested and increasingly problematic, partly due to the experiences of participants in
45 terms of weight stigma. We have therefore used this term where it relates to referenced works,
46 prevalence, and to communicate to the biomedical community, but have used alternate terms
47 wherever possible to ensure a person-centred approach, prioritising the experience and voice of those
48 working towards achieving healthy lifestyle change
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Declarations of interests

We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests. All authors have completed the Unified Competing Interest form (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

Ethics committee approval

Ethical approval for the Whānau Pakari Barriers and Facilitators study was granted by Central Health and Disability Ethics Committee (NZ) (17/CEN/158/AM01). Written informed consent was obtained from all study participants.

Transparency statement

The lead author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as originally planned have been explained.

Contributorship statement

CW was involved in study design, data collection, analysis, interpretation, and writing of the manuscript. NR contributed towards study design, data collection and manuscript appraisal. EW contributed towards study design, oversaw analysis and interpretation, and was involved in writing of the manuscript. PH was involved in study design and critical appraisal of the manuscript. YA was involved in study design, analysis, interpretation, and writing of the manuscript.

Role of the funding source

This research was funded by A Better Start National Science Challenge and Cure Kids. The funders had no role in the conduct of the research, study design, collection, analysis and interpretation of data, in the writing of the manuscript and in the decision to submit the article for publication. The researchers are independent from the funders and all had full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Data sharing statement

No additional data available.

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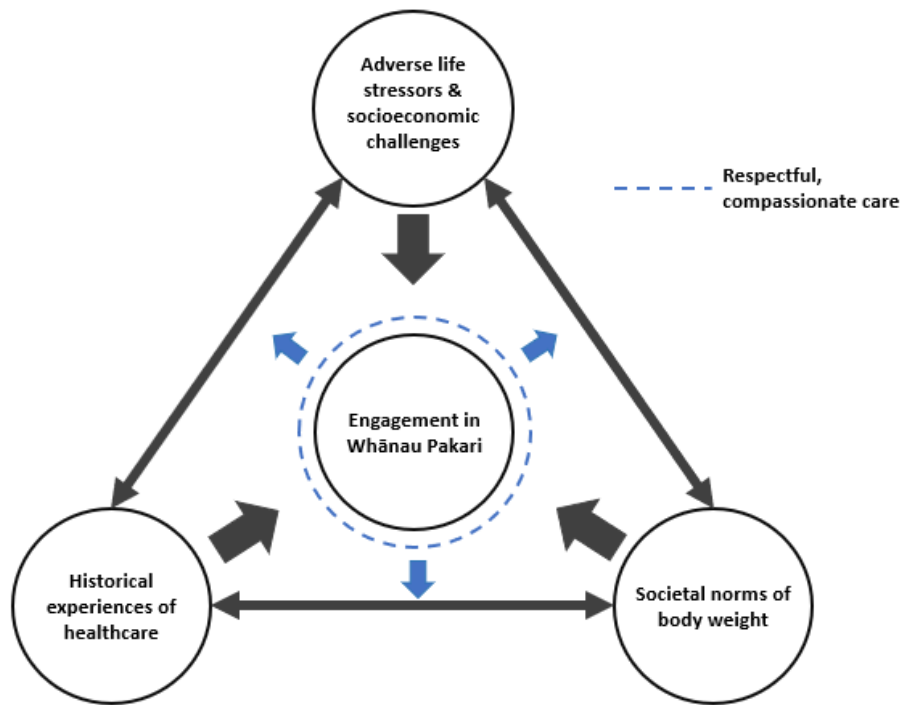
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13 Figure One: The three interacting factors that influence participant engagement in Whānau Pakari.
14 Respectful, compassionate care can partially mitigate the effects of these determinants.
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For peer review only



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COREQ (Consolidated criteria for reporting qualitative research)

This checklist is intended to supplement the manuscript by providing further detail on methodology.

Domain 1: Research team and reflexivity

Personal characteristics

1. Interviewers

Cervantée Wild & Ngauru Rawriri conducted the interviews (page 8).

2. Credentials and 3. Occupation (page 1)

Cervantée Wild (BHSc(Hons), BA) – PhD candidate, Liggins Institute, University of Auckland

Ngauru Rawiri – BHSc student, Te Reo Māori teacher (tertiary level) and interview facilitator, Liggins Institute, University of Auckland

Paul Hofman (MbChB, Dip Obs, FRACP) – Professor and paediatric endocrinologist

Esther Willing (PhD) – Lecturer in Hauora Māori, Kōhatu – Centre for Hauora Māori, University of Otago

Yvonne Anderson (PhD, Dip Paeds, MBChB, FRACP, BSc [Psych]) – Senior research fellow and paediatrician

4. Gender & ethnicity

CW – female, New Zealand European

NR – female, Māori (Ngāti Mutunga, Ngāti Tama, Ngāti Rāhiri o Te Ati Awa me Ngai Tūhoe)

PH – male, New Zealand European

EW – female, Māori (Ngāti Toarangatira, Ngāti Koata me Ngā Ruahine)

YA – female, New Zealand European

5. Experience and training

CW had qualitative research training through the PhD (supervised by PH, EW, and YA). NR had interview experience through her career. PH is an experienced researcher in child health and endocrinology. EW is an experienced qualitative researcher and has extensive experience in Māori health research. YA is an experienced researcher in child health, especially childhood obesity.

Relationship with participants

6. Relationship established

All participants were recruited as described below, and some were already known to NR through relationship networks.

7. Participant knowledge of the interviewer

The participants knew the reasons for conducting the research (detailed in the patient information and consent form), and participants were aware that the study would specifically ask about the factors that contributed to their decisions to engage or not engage, in order to improve the service. Participants were also aware that the interviewers were separate and distinct from the clinical service team.

8. Interviewer characteristics

NR is a Māori researcher (of Ngāti Mutunga, Ngāti Tama, Ngāti Rāhiri o Te Ati Awa and Ngai Tūhoe descent) and CW is New Zealand European. This mixed Indigenous – non-Indigenous partnership allowed us to connect and establish rapport with participants, depending on the interview participant and context. NR's role as a parent had the advantage that familiarity with this stage of life helped her understand participants' stories and ask exploratory questions.

Domain 2: Study design

Theoretical framework

9. Methodological orientation and Theory

The research approach was informed by Kaupapa Māori theory. The approach was developed to minimise any perceived power imbalances between the interview team and the participants and make the interview experience as comfortable as possible. We used thematic analysis to analyse the interviews (page 7).

Participant selection

10. Sampling and 11. Method of approach

We identified eligible potential participants who fit the criteria, and then stratified these participants into groups by engagement level and ethnicity. We then randomised the list of potential participants in each group, and then contacted each participant one by one (stratified random sampling). Participants were recruited by telephone and interviewed in person over a six-month period from June to December 2018 (page 8).

12. Sample size

For funding and resource reasons, we had a maximum total of 74 potential interviews with families. We conducted 64 interviews in total (page 10).

13. Non-participation

We approached 136 families, of which 53 were uncontactable, 7 agreed but were unable to be interviewed as they had moved out of the region, and 12 declined because they were not interested, were too busy with work, or did not remember the referral (page 11).

Setting

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3 14. Setting of data collection
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5 Participants were interviewed in person at their home, workplace, or at a local community child
6 health centre. All participants chose where they would prefer to be interviewed (page 8).
7

8 15. Presence of non-participants
9

10 For most interviews, only the participant and interviewers were present, but there were occasionally
11 other family members present, such as young children (<5 years) (page 8-9)
12

13 16. Description of sample
14

15 Half the interviews were with families with Māori children. Most (80%) were solely with a female
16 parent/caregiver (13 interviews included male parents and/or caregivers). 11 interviews involved
17 two or more family members. 5 interviews included a child participant (page 10).
18

19 *Data collection*
20

21 17. Interview guide
22

23 A semi-structured interview framework was used and adjusted for relevance as each interview
24 progressed. It was not pilot tested. The guide has been included as supplementary material.
25

26 18. Repeat interviews
27

28 Repeat interviews were not conducted, but participants were offered their transcripts for review
29 after the interview (page 9).
30

31 19. Audio recording
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33 Interviews were audiotaped digitally and transcribed by a medical typist (page 9).
34

35 20. Field notes
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37 Field notes were made after each interview and kept as part of a reflexive notes.
38

39 21. Duration
40

41 Interview audio recordings ranged from nine minutes to 107 minutes (mean 31 minutes).
42

43 22. Data saturation
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45 Data saturation was reached in each group of participants in each level of engagement.
46

47 23. Transcripts returned
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49 Transcripts were anonymised and returned to the participant for checking, including deletions of
50 portions if desired (page 9).
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53 **Domain 3: analysis and findings**
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55 *Data analysis*
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57 24. Number of data coders
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3 Eight transcripts were independently coded by CW and EW and discussed for consistency. After the
4 coding matrix was constructed and consensus on codes reached, all transcripts were coded again by
5 CW.
6

7 25. Description of the coding tree

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9 A 'mind map' was used instead of a coding tree in order to better capture complexity and avoid an
10 artificial hierarchy that did not adequately represent the inter-relationships between the themes,
11 since themes could become more major or minor depending on the context.
12

13 26. Derivation of themes

14
15 Themes were derived from the data according to Braun and Clarke's 2006 and 2019 method for
16 reflexive thematic analysis (page 9).
17

18 27. Software

19
20 MAXQDA software was used to manage the data (page 9).
21

22 28. Participant checking

23
24 Participants did not provide feedback on the findings.
25
26
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28 *Reporting*

29 29. Quotations presented

30
31 Participant quotations are presented in Panel 1 and throughout the manuscript. They are not
32 identified by participant number (page 11-12).
33
34

35 30. Data and findings consistent

36
37 There was good consistency between data and findings, with the two interviewers working to
38 discuss findings and the wider research team providing critique and challenging interpretations of
39 data (page 9).
40

41 31. and 32. Clarity of major and minor themes

42
43 A distinction was made between 'major' and 'minor' themes with sub-themes capturing the range of
44 participant experiences under each major theme. However, even major themes could not be cleanly
45 separated, reflecting real-world complexity.
46
47
48

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50 (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19, 349–
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53 NB. This checklist has been amended to capture ethnicity and gender breakdown, to reflect the
54 composition of the research team.
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SUPPLEMENTARY MATERIAL: Interview schedule

NB. Interviews were semi-structured and this schedule is simply a guide to the line of interview questioning. Not all questions were asked if not appropriate. Sections marked with an asterisk () were not asked of participants who declined involvement in the programme.*

Referral & initial thoughts

- Who referred you to Whānau Pakari?
- Do you remember how they told you about the programme? *(if not self-referral)*
- Did they talk with you and your child?
- How did you feel about being referred? How did you talk to your child/children about the programme and referral?
- Why did you decide to accept the referral?
- How did you feel about starting the programme?
- Which part of the programme (if any) were you more interested in, or seemed more relevant for you and/or your family?
- Were you worried about what other people might think about you and your family attending Whānau Pakari?

Overall experience *

- Which parts of the programme were the most helpful?
- Which parts of the programme did you find were more difficult?
- Did Whānau Pakari meet your needs in supporting you to make healthy lifestyle changes as a family? Why/why not?
- Did Whānau Pakari meet your expectations in terms of what you thought the team would provide? How did/didn't they do this?
- Would you recommend Whānau Pakari to other families and why/why not?

Barriers and facilitators *

- What were the things that helped you to or made you want to continue to attend Whānau Pakari sessions, if any?
- What were the things that made it hard for you to continue to attend Whānau Pakari, if any?
- Did you experience any travel barriers to get to the sessions? E.g. location, access to car, parking, petrol, WOF, rego
- The Healthy Lifestyles Coordinator came to you for the assessments. What were the good things about a home visit? (If any) What were the negative things? (If any)
- Do you prefer home-based assessments rather than coming to the hospital/clinic?
- Were you able to involve the rest of your children and family in the programme sessions.

- How much of a priority was Whānau Pakari in relation to your other demands?
- How did other competing demands, obligations or choices impact on your decision to attend Whānau Pakari?
- Can you please describe how Whānau Pakari was (or wasn't) suitable for families like yours?
- Was Whānau Pakari family-friendly, inviting, comfortable? What could be done to improve this?
- Can you please tell me how costs may or may not have been barriers to participation in Whānau Pakari? How?
- Can you tell me about any other barriers to participation in Whānau Pakari that you experienced?
- Can you think of things that might have motivated you or your whānau to participate (or things that kept you from participating)?

Beliefs and feelings around healthy lifestyle programmes

- What do you think about healthy lifestyle programmes in general?

Previous experiences with health system

- In general, can you describe what your experiences with the health system have been like prior to the Whānau Pakari programme?
- Have you ever felt that you or your family have been treated unfairly in the health system? If yes, why do you think that this happened?
- In your experiences with the health system, have you ever experienced discrimination? If yes, can you tell me a bit more about this? Why do you think this happened?
- Have any of you or your family's previous experiences with the health system influenced your decision to attend Whānau Pakari? If yes, how?
- Have you had any previous negative experiences with health providers that made you choose not to attend Whānau Pakari sessions?

Previous experiences with societal stigma

- In your day-to-day life, have you ever been treated unfairly or discriminated against? If yes, can you tell me a bit more about this? Why do you think this happened?
- Have you ever witnessed or heard about other members of your whānau being treated unfairly or discriminated against for any reason? If yes, can you tell me a bit more about this?
- Do you think any of these experiences influenced your decisions or ability to attend, engage, participate or continue participation in Whānau Pakari?

Follow-up prompt guidelines

Prompts are to keep the momentum of the interview by being positive, affirming answers and using active listening without being leading.

- Prompts included:
 - Non-verbal nods
 - Affirming sounds e.g. Mmmm
 - Agreement e.g. yes, that's interesting
 - Questions e.g. "what did you mean by that?", repeat the last word the participant said as a question to prompt more explanation.
 - To get back on track: "Could I ask you about something you said before..."

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BMJ Open

Determining barriers and facilitators to engagement for families in a family-based multicomponent healthy lifestyles intervention for children and adolescents: a qualitative study

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4 **multicomponent healthy lifestyles intervention for children and adolescents: a qualitative study**
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ABSTRACT

Objectives: Recruitment and retention in child and adolescent healthy lifestyle intervention services for childhood obesity is challenging, and inequalities across social groups are persistent. This study aimed to understand the barriers and facilitators to engagement in a multicomponent assessment-and-intervention healthy lifestyle programme for children and their families, based in the home and community.

Design: Qualitative interview-based study of past users (n=76) of a family-based multicomponent healthy lifestyle programme in a mixed urban-rural region of New Zealand. Semi-structured, home-based interviews were conducted and thematically analysed with peer debriefing for validity.

Participants: Families were selected through stratified random sampling to include a range of levels of engagement, including those who declined their referral, with equal numbers of interviews with Indigenous and non-Indigenous families.

Results: Three interactive and compounding determinants were identified as influencing engagement in Whānau Pakari: acute and chronic life stressors, societal norms of weight and body size, and historical experiences of healthcare. These determinants were present across societal, system and healthcare service levels. A negative referral experience to Whānau Pakari often resulted in participants declining further input or disengaging from the programme. A fourth domain, respectful and compassionate healthcare, was identified as a mitigator of these three themes, facilitating participant engagement despite previous negative experiences.

Conclusions: While participant engagement in healthy lifestyle programmes is affected by determinants which appear to operate outside immediate service provision, the programme is an opportunity to acknowledge past instances of stigma and the wider challenges of healthy lifestyle change. The experience of the referral to Whānau Pakari is important for setting the scene for future engagement in the programme. Respectful, compassionate care is critical to enhanced retention in multidisciplinary healthy lifestyle programmes and ongoing engagement in healthcare services overall.

Strengths and limitations of this study

- Large sample size (64 interviews with 76 total participants)
- Sample included wide range of participants with varying levels of engagement, including non-service users
- Equal representation from families with Māori and non-Māori children
- Lack of child and adolescent voice
- Participants may not have fully disclosed their experiences to interviewers

Introduction

Excess weight in childhood and adolescence affects physical, psychological and social health and well-being, and is a known risk factor for comorbidities both in childhood and adulthood.¹ Children with weight issues in Aotearoa/New Zealand (henceforth referred to as New Zealand) demonstrate a high prevalence of weight-related comorbidities, as well as low physical activity, suboptimal eating behaviours, and low health-related quality of life.²⁻⁵ One of the key recommendations of the World Health Organization's Report of the Commission on Ending Childhood Obesity is to "provide family-based, multicomponent lifestyle weight management services for children and young people who are obese".⁶ A systematic review and meta-analysis found that a minimum of 26 hours of contact time in lifestyle interventions is associated with improvements in weight status in children and adolescents.⁷ However, as with any service attempting to facilitate lifestyle change, success relies on continued family engagement.⁸ It is also important that such multidisciplinary services – and other health professionals addressing childhood obesity in a primary care setting – are able to engage with groups most affected by obesity, namely those living in the most deprived areas and ethnic minorities.⁹

Improving *engagement* with childhood obesity services requires addressing both initial recruitment and ongoing retention.⁸ Service, system and society-related factors may *enable* or *inhibit* initial and ongoing engagement; factors which are also referred to as facilitators and barriers.^{10 11} Kelleher and colleagues' review of the factors affecting attendance at community-based lifestyle programmes found that weight stigma, parental reluctance to identify overweight and logistical challenges were

1
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3 key barriers to initial and ongoing attendance.¹⁰ Under-represented in the literature are those who
4 declined treatment altogether, as many past studies had low recruitment from these families. It is
5 therefore important to understand the experiences of families experiencing childhood obesity in order
6 to improve initial recruitment and ongoing retention in healthy lifestyle services, particularly for
7 groups most affected.¹⁰
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13
14 Whānau Pakari is a family-centred, community-based assessment and intervention programme for
15 children and their families, based in Taranaki, a mixed urban-rural region of New Zealand (NZ). The
16 name means 'healthy, self-assured families that are fully active'. The focus of the programme is on
17 healthy lifestyle change rather than weight loss or obesity, in order to minimise judgement and
18 weight-related stigma. The multidisciplinary service involves a home-based medical assessment with
19 advice, removing the hospital appointment in order to *demedicalise* care, and includes weekly
20 nutrition, physical activity and psychology sessions. This approach takes healthcare outside hospital
21 walls and into the community, without compromising quality of care. A randomised clinical trial of
22 the Whānau Pakari model of care demonstrated modest reductions in body mass index (BMI) standard
23 deviation score (SDS) and improvements in cardiovascular fitness and health-related quality of life.¹²
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¹³ Greatest improvements in BMI SDS were found in those who attended the recommended $\geq 70\%$ of
intense intervention sessions.^{13 14} However, Māori (NZ's Indigenous population) and females were
less likely to attend $\geq 70\%$ of sessions, with sustained retention in the programme favouring males and
NZ Europeans.¹³

Previous evaluation of the experiences of Whānau Pakari participants and their caregivers has shown
the programme to be a positive and beneficial experience for those involved, emphasising the
importance of connectedness, knowledge-sharing and self-determination, the collective journey
alongside other families and programme deliverers, and the importance of a non-judgemental,
respectful environment.¹⁵ A survey of past participants of Whānau Pakari indicated that previous
experiences of healthcare may influence subsequent engagement with health services, particularly for
Māori,¹⁶ although this was not elaborated on further by participants. These findings were limited by
the survey's relatively small sample size and the lack of representation from participants who declined

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3 intervention. Therefore, the objective of the present study was to understand barriers and facilitators
4
5 to initial attendance and ongoing retention in the Whānau Pakari programme.
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8 *Methods*

9 *Design*

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11 In NZ, health research is required to be responsive to the needs and diversity of Māori.¹⁷ The study
12
13 design and research approach was informed by Kaupapa Māori methodological principles. Kaupapa
14
15 Māori theory is a methodology which resists persistent power imbalances and the continued use of
16
17 cultural deficit theory (attributing poor health to something inherent to a ‘culture’) to explain
18
19 inequities between Māori and non-Māori,^{17 18} and is aligned with a social and structural determinants
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21 of health framework.¹⁹ As a methodological approach, Kaupapa Māori research centres Māori voice
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23 and experience, and prioritises understanding people within their contexts and whānau (families).¹⁹ It
24
25 was hoped that this approach would reduce many of the known barriers to research participation for
26
27 Indigenous peoples, and enable participants to engage positively in the research process.²⁰ While
28
29 Kaupapa Māori research can use both quantitative and qualitative methods, in this study, a qualitative
30
31 research design was chosen in order to ensure that priority was given to ensuring the voices and
32
33 experiences of Māori participants were understood in this study.
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38 In-depth interviews, centring on participant experience with Whānau Pakari and wider experiences of
39
40 the health system, were undertaken. A specific focus was to understand the barriers to attendance and
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42 retention at varying levels of engagement in Whānau Pakari, including those who declined their
43
44 referral and had no further contact with the programme. Factors which facilitated both initial and
45
46 ongoing engagement were explored.
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50 Ethical approval for the Whānau Pakari Barriers and Facilitators study was granted by Central Health
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52 and Disability Ethics Committee (NZ) (17/CEN/158/AM01). Written informed consent was obtained
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54 from all study participants, or informed assent with proxy parental consent in the case of the child and
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56 adolescent participants aged under 16 years.
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Patient and Public Involvement statement

Participants were first involved in the research at the recruitment stage, although some participants had been involved in an earlier related randomised clinical trial.¹² The research questions were informed by the experiences of participants voiced, unsolicited, during clinical assessment during the previous trial and in previous focus group research.¹⁵ The design of the research drew from Kaupapa Māori theory, which informed the research process in order to prioritise the experiences and preferences of participants. The dissemination process to participants was altered as a result of participant preference to receive feedback via a summary video, rather than at a group meeting. Participants were not asked to assess the burden of the time required to participate in the research.

Participants

Eligible participants were parents and/or caregivers of children and adolescents who had been referred to the service from January 2012 to January 2017. Children and adolescents over 11 years of age were also invited to participate. The eligibility criteria for referral to the service are children aged 4 to 16 years, identified as having obesity [body mass index (BMI) $\geq 98^{\text{th}}$ centile], or overweight (BMI $> 91^{\text{st}}$ centile) with associated weight-related comorbidities.^{12 21}

Participants were recruited from four different groups of Whānau Pakari service users who had varying levels of engagement (Table 1) using stratified random sampling. Recruitment was via telephone call and text message. The sample contained equal numbers of families with Māori and non-Māori children to ensure appropriate representation of Indigenous children's experiences.

Data collection

The semi-structured interviews were approximately 30-60 minutes in duration and conducted by CW and NR together where possible (see supplementary file for interview schedule). NR led the interviews with Māori families when appropriate. Interviews took place in the participant home or alternative locations chosen by the participant (including a hospital, participant workplaces, and a community library) in order to minimise inconvenience and travel barriers. Most interviews were undertaken with one participant (the parent or caregiver) but a portion included two or more family

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3 members, including children (Table 1). A *koha* (gift, donation or contribution) was offered to
4 participants in acknowledgement of their time and as a sign of reciprocity for the information shared.
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8 Informed consent (or assent with proxy parental consent in the case of the child and adolescent
9 participants aged under 16 years) was obtained to record, transcribe and analyse participant data. All
10 participant information was anonymised. Participant ethnicity for both the parent/caregiver and child
11 was confirmed at the time of the interview by using the NZ Census 2006 ethnicity question.²² All
12 interviews were audio-recorded and independently transcribed. Participants were offered their
13 transcripts to review for accuracy and acceptability.
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20 21 *Analysis*

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23 Interview transcripts were coded and analysed inductively in MAXQDA (2018),²³ according to Braun
24 and Clarke's method for reflexive thematic analysis,^{24 25} which aligned well with the reflexivity and
25 awareness of researcher theoretical positioning required of research informed by Kaupapa Maori
26 Theory. CW developed the coding matrix with peer review from EW, coded the interview data, and
27 identified the initial themes. The authors collaborated to finalise the themes and develop the
28 framework. The acknowledgement of different researcher standpoints allowed the authors to debate,
29 challenge, and refine interpretations of the data, thereby developing a more nuanced interpretation of
30 the data.²⁵ Specifically, the researchers agreed to apply the 'Give-Way' rule if there was disagreement
31 over the interpretation of the data concerning Māori participants, with the final decision involving
32 cultural interpretation of Māori participants' experiences passing to a Māori researcher.^{19 26 27}
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45 It became clear from our initial appraisal of the data that the degree to which participants engaged
46 with the programme was on a continuum rather than fitting neatly into discrete categories. Therefore,
47 the groups have been analysed together, noting where there may be key differences according to the
48 degree of engagement.
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54 For more detail of this procedure, please refer to the Consolidated Criteria for Reporting Qualitative
55 Research (COREQ) checklist (Appendix One).
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Results

64 interviews were conducted (out of a potential cohort of 74) with families who had varying levels of engagement, across a six-month period from June to November 2018 (76 participants in total) (Table 1). Half of the interviews were with Māori families (families with a Māori child who had been referred to the service), including interviews with non-Māori parents of a Māori child. Participants included parents, grandparents, other caregivers, and the children/adolescents themselves (n=5) and were from a range of socioeconomic backgrounds (deciles 1-10 of the 2013 NZ Index of Deprivation).²⁸ Full details of interview recruitment rate and reasons for non-participation are included in the COREQ checklist (Appendix One).

Demographics

Table 1. Participant demographics

Interview participants N		76 ^a
Female participant <i>n</i>		65
Ethnicity % ^b	Māori	32
	NZ European	75
	Asian	7
	Other European	5
Level of engagement <i>n</i>	Attended ≥70% of programme sessions ^c	18
	Attended <30% of programme sessions ^d	19
	Had one assessment, then discontinued with the programme ^e	7
	Referred, but chose not to engage ^f	20

^a64 interviews total, 11 interviews involved 2+ family members, 5 interviews included a child/adolescent participant in addition to their parent/caregiver. Maximum total of 74 potential interviews for funding and

resource reasons. 136 families approached, of which 53 were uncontactable, 7 were living out of the region, and 12 declined (see COREQ checklist for reasons); *b* Total ethnicity output (more than one ethnicity selected); *c* 24 families invited total; *d* 42 families invited total; *e* 15 families invited total; *f* 55 families invited total

Box 1: Key determinants of engagement and retention in Whānau Pakari

Domain 1: Adverse life stressors & socioeconomic deprivation

‘I wouldn’t say it was, like, you guys as such – it was just the history behind what she had um, but we come from, so um I came from an abusive marriage, which had split up because of abuse... So this was really hard at the time.’

‘Once she lost her father, well that was pretty much the end of it. She just didn’t want to do nothing. As much as I tried to encourage her to, you know, get with the programme, no she just didn’t want to know about it.’

Competing health priorities

‘...[DAUGHTER] was under [child and adolescent mental health services] for suicide watch and stuff like that... so for us there was that added stuff as well.’

Financial insecurity/socioeconomic status

‘I didn’t have a house and lived in that camper. Yeah, so it just didn’t work out, otherwise she would have gone.’

Domain 2: Societal norms of weight and body size

Age

‘Like, a weight problem, like, at the time he was only 6 years or 7 years.’

‘... we were kind of shocked because they said that [SON] was, like, obese or something ... I don’t think he’s overweight at all... Because he’s really tall... so I don’t understand, like, what sort of weight should he have been because he was, he’s just like a, he was like a normal kid. So I don’t understand what is

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overweight and underweight. Because I've seen some, not being mean, but overweight kids, and he wasn't overweight.'

Gender

'She might develop an eating disorder and I don't want that. I'd rather, you know, it's weird, but I'd rather she be overweight than underweight, you know what I mean? I'd hate to deal with an anorexic daughter because that's hard work.'

Perceived genetic disposition

'You know... it's just the way it is sometimes. Some people get good genes, some people get other genes and it means it doesn't work out.'

Domain 3: Historical experiences of healthcare

Weight stigma and discrimination

'... having visited for something else entirely different and then being told kind of 'your child's obese and we are going to refer you' and just doing it front of him [...] it was just even in the way that it was delivered and I was kind of not expecting it. I mean, I can see that he's, he's a bit chunky, but I just, I don't know [...] [the referral] was a bit off-putting.'

Racism

'...people will judge you for what and where, what colour you are or whatever... [it] just made me more determined to get in there and do what I had to do.'

Mediator 1: Respectful, compassionate care mitigated past experiences

'It was not just the families, but also the, what do you call them, the workers... Very supportive, non-judgmental. I think that made a big difference and 'yes we are going to go' because they are not judging you... the staff was very supportive.'

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3 Three major interacting domains and subthemes affecting participant engagement are described in box
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5 1 in participants' own words. A fourth domain of respectful, compassionate care was identified as a
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7 mediator, which was able to mitigate the effect of the first three themes. Unique themes according to
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9 level of engagement with the programme were not generated. While each domain was prevalent in
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11 participant accounts across all recruitment categories, the extent to which a domain affected each
12
13 group determined engagement.
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16 *Domain 1: Obesity sits within the context of multiple other complex stressors for families in NZ*

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18 Participation in the Whānau Pakari service was affected by the multiple complex stressors of living in
19
20 contemporary NZ. These were acute, one-off adverse events, such as a death in the family, and
21
22 chronic, ongoing challenges, such as financial insecurity. Childhood obesity and overweight as a
23
24 health concern sat within the context of multiple other important concerns for families. Participants
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26 were often living in 'crisis mode' or dealing with multiple challenges at once, including: financial and
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28 food insecurity, suicide, abusive relationships, deaths in the family, mental health issues, disability,
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30 relocation, marriage & family break-ups, fostering children, children being raised by other caregivers,
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32 drug use and significant other illnesses.
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36 For parents of children with multiple health conditions, especially mental health concerns or autism
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38 spectrum disorder, addressing weight was often not perceived to be as important compared with other
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40 competing family health concerns. Parents and caregivers also reported the challenges of balancing
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42 multiple demands such as long work hours, shift work and extracurricular activities alongside
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44 attending Whānau Pakari.
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46

47 'I think he had one of his sporting things on and I was doing 50 hours a week at that time and
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49 I was like 'oh, my God, I can't do it', I couldn't do it. I mean, if he needed, if I felt like he
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51 needed to be there, I would get him there, like, it's, my work's not that important. Weeds and
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53 shit can wait, you know, like, people can wait um if it was a, if I felt like it was serious. I
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55 would have got him there, but I just yeah.'
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3 Similarly, socioeconomic deprivation and food insecurity was perceived to be a more immediate and
4 pressing concern than childhood overweight or obesity. Both initial attendance and ongoing retention
5 were affected by a lack of participant resources, even if participants expressed a desire to attend.
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9 Participants who engaged with Whānau Pakari and other services despite the impact of adverse
10 stressors appeared to have more resources, and thus were less affected by this domain.
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14 *Domain 2: Societal norms of weight and body size affect how people experience seeking care for*
15 *weight*
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18 Societal norms and beliefs around weight and body size led to the minimisation of obesity and the fear
19 of stigmatisation for participants (see also Domain 3). These manifested differently according to the
20 age, gender and the perceived role of genetics in obesity, and resulted in lower engagement. An
21 exception was participant beliefs around perceived genetic propensity towards obesity, which in some
22 cases led to higher rather than lower participant engagement.
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29 The age of the child involved in the service affected the degree to which families chose to engage, due
30 to a perception that children were too young to have weight problems, which was a key reason for
31 both dropping out of the service early or declining input altogether. Children who were clinically
32 overweight or had obesity were perceived to be a normal weight in early childhood and increasingly
33 beyond. Some participants felt that while their child might not fit into a set of assessment criteria, this
34 did not necessarily equate to their child being unhealthy.
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43 ‘When he got put in the [...] ‘oh, he’s overweight’ box. And when you’re, like, ‘he’s not that
44 overweight’, because it was just he wasn’t in their little boxes. I think that more annoyed me,
45 is that they’ve got these sort of, like, ‘this is the normal weight for a 5 year old’. Well, there’s
46 all sorts of different 5 year olds. He’s now 10 years and he is my height [...] he’s a big guy.’
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52 There was a strong belief that if children were ‘big but active’, then their weight was not a concern.
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55 ‘...he’s always been big, but he’s really active. Like he wins the triathlons and the cross-
56 country and he bikes and swims... it’s not like he can’t exercise or is held up, you know what
57 I mean? And so we just thought well, and it’s not like he wasn’t healthy eating.’
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3 Families appeared more reluctant to engage their female children in services that are characterised as
4 weight-related, both at initial recruitment and throughout the programme, for fear of their child
5 developing self-esteem issues. Parents also reported their daughters were often reluctant to attend
6 themselves.
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12 ‘To me it’s like you don’t need to involve her because she’s already self-conscious, soft-
13 hearted, already upset about it sort of thing and, like, to me it was like more of a trigger. So, I
14 was, like, no. I will do it my way. So I pulled back because it wasn’t worth it for her, you
15 know what I mean? Like, her self-esteem and stuff is worth more than, you know, going to a
16 dietitian where at home I can just stop giving her all that stuff to make her healthier. So that’s
17 where it comes across wrong.’
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25 Overweight and obesity was often associated with perceived genetic propensity to obesity by
26 participants. This was sometimes specifically linked to ethnicity, and specifically that Māori and
27 Pacific Island peoples are ‘naturally big’. A perceived familial propensity towards overweight resulted
28 in participants reportedly acting in two ways: either they did not want to engage because they felt that
29 there was no point, given they perceived their weight to be genetic (panel 1), or they were compelled
30 to engage more in order to counteract their genetics:
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39 ‘My side of the family is really obese so weight has always been an issue, so if you are trying to
40 diet everyone gets behind you because they know what the challenge and the battle is. No, we
41 don’t really care what other people say, we just get on with it.’
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46 *Domain 3: Historical experiences of healthcare affect future perception and engagement with* 47 *services*

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49 Past experiences of healthcare influenced participants’ opinions, perceptions and behaviour in relation
50 to seeking care again. This was a multidimensional phenomenon, acting across both weight and
51 ethnicity. If participants had had negative experiences in the health system in relation to their weight
52 or ethnicity, then they were less willing to engage with Whānau Pakari and other health services. This
53 mostly affected participants who declined further input after their referral or who discontinued after
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3 one assessment. This was especially important if the referral experience to Whānau Pakari was
4 negative, given that this may have been the first instance of being confronted about their child's
5 weight.
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10 'Basically they told her she was obese [at the B4 School Check] ... Yeah, that she was obese
11 for her age and they said this in front of her, and she was like "what is obese"? And they said,
12 "you're bigger than any other child your age" but she's not the only one [...] So they say it in
13 front of a child, it sort of knocks their self-esteem and their confidence right back.'
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19 While weight stigma was experienced across all groups of participants, there were few feelings of
20 stigma about attending Whānau Pakari for those participants who engaged highly ($\geq 70\%$ of sessions):
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24 'There was nothing to be embarrassed about. You know, like secretive about it. It was
25 something that I was doing for my kid, to help her get better in herself and if someone else
26 had a problem then that was their problem, not mine. At the end of the day it is about her. Not
27 about what anyone else thought.'
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33 Experiences of racism in the healthcare system and in wider society affected how participants
34 reengaged with health services. This included a wide range of race-related experiences from
35 interpersonal to institutionalised racism. Likewise, participants recounted a variety of responses to
36 these experiences from renewal of engagement and wanting to 'prove them wrong', to disengagement
37 with outside entities and organisations, to internalised racism.
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44 '...we have been through so much stigmatisation that nothing more than one thing matters
45 [...] because for us it's about the betterment of our children and our whānau [family] as a
46 unit.'
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51 *Mediator 1: Respectful, compassionate care mitigated past experiences*

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53 Conversely, positive and respectful care received in both the Whānau Pakari programme and in other
54 areas of the health system mitigated the effect of the first three determinants, particularly against the
55 impact of past negative experiences of healthcare. A positive referral experience generally set a
56 positive tone for interacting with the Whānau Pakari service itself.
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3 ‘So we decided yes, this would be an awesome programme for our daughter, because we
4 wanted her to just have some stability at the time because she was just starting High School,
5 going into a phase where people were judging and things like that, you know, building her
6 self-esteem [...] It’s helped her with her confidence and just building a life that’s easy for her,
7 you know. So, yeah, I thank [referrer] for that and for putting us onto that programme too
8 because it was really awesome. We, as a whānau, we enjoyed it, and just being able to support
9 her in that programme.’
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18 Participants who did engage with Whānau Pakari reported that the care received in the programme
19 was ‘different’ from previous care received and that the programme deliverers were ‘like a family’.
20 For these families, the respectful and compassionate care countered some of the negative effects of
21 past experiences.
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27 ‘It was just the people, that’s all it was. It was just the approach of the people to be honest um
28 and that made us comfortable, and I go by my children a lot because if they’re uncomfortable
29 well then they’re not the right people to be around for us. And they were comfortable.’
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34 The social and team aspects of Whānau Pakari were beneficial for families, as well as the perceived
35 extra care received
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39 ‘I liked it. I didn’t think I was going to. I thought ‘oh, this is going to be stupid’, but no it
40 wasn’t. It was actually a bit of an eye opener. I actually learnt something. And then we just
41 recently got her blood tests and all that done again because through the doctors they didn’t do
42 no diabetic tests or anything like that. Through Whānau [Pakari] they did. They did heaps
43 more than the doctors did. So I think that’s pretty much why we stayed with them, it was like
44 ‘aha, we can get some serious help here’.
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52 Figure 1 summarises the interacting and mitigating domains affecting participant engagement.
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Discussion

This study found that engagement in Whānau Pakari was determined by the degree to which participants were affected by three interactive domains: complex adverse life stressors, societal norms of weight and body size, and past experiences of healthcare. These complex mechanisms operated at multiple levels including at the service, health system and wider societal levels, so that experiences at the seemingly distal societal level could still have an impact on participant engagement at the service level. While the impact of these factors was evident across all four groups, some participants appeared to be resilient to the impact of these determinants. Additionally, respectful and compassionate care appeared to act as a positive mediator. Conversely, participants who declined further input after their referral were more likely to be experiencing greater life stressors without the resources to overcome them. Participants also appeared to be affected by societal norms of weight with regards to age, gender and the perceived impact of genetics, and negative experiences of healthcare often resulted in complete disengagement.

We were surprised that clear recommendations for specific changes to internal programme aspects were not forthcoming from participants across all levels of attendance, as this was a specific intent of the project. Although factors such as the difficulty of attending programme sessions with shift work and other stressors were identified as a barrier by some participants, there was no clear consensus on factors such as timing and location. While forces external to the service affected engagement, our study indicates that there are opportunities at the service level to facilitate initial and continued engagement in Whānau Pakari, and potentially other services. Despite the negative experiences of participants in the health system (both weight and non-weight related), the care received in Whānau Pakari by deliverers was generally seen as 'different', and a key reason for wanting to continue with the service.

In our study, many participants who declined further engagement after their referral were reluctant to identify their young children as having weight issues and requiring assistance. Past research has identified multiple reasons for parental reluctance to identify overweight in their children,²⁹ including not recognising obesity as a 'disease' and therefore not warranting the same attention as other health

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3 concerns, and wanting to avoid further stigmatising their child. Our data suggests that families are
4 especially concerned with the mental health of their children, which was often perceived to be more
5 important than identifying and addressing overweight and was a key reason for declining referrals.
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7 There appears to be a disconnect between the focus on early life intervention due to the expected
8 growth trajectories of young children with overweight or obesity into obesity in adolescence and
9 adulthood,^{30 31} and the concerns and priorities of parents with young children.
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16 Research indicates that parents of girls with overweight or obesity are more likely to enrol them in
17 healthy lifestyles programmes than families with boys with overweight or obesity.¹⁰ The contrasting
18 findings of our study, which also included participants who declined their referral, show clear parental
19 concern for the mental health and self-esteem of their daughters, which may reflect a desire to focus
20 on positive body image, self-esteem and mental health and avoid increasing body dissatisfaction.³²
21 The findings of this study would suggest that the differences in how males and females experience
22 weight in society contributes towards the differing retention rates between male and female
23 participants at the service level. It is concerning that two important health issues – overweight and
24 mental health – are pitted against each other as perceived incongruent concerns, given that both are
25 significant causes of ill-health among children and adolescents, and suboptimal health-related quality
26 of life was identified in a previous cohort with weight issues.²
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40 Puhl and colleagues argue that message framing with regards to terminology is vital in childhood
41 obesity programmes, in order to prevent further stigmatisation of families seeking help for weight.³³
42 While the Whānau Pakari *programme* aims to be non-judgemental and non-stigmatising, it is equally
43 important that the *referral* to the service is perceived to be non-stigmatising by families in order to
44 encourage engagement. Given the impact of the referral experience to Whānau Pakari on initial and
45 continued engagement with the service, the referral process must be respectful and compassionate,
46 with an acknowledgement of past instances of stigma and discrimination. The sensitivity of weight as
47 a discussion topic requires non-judgemental language, compassion, and an acknowledgement of the
48 wider context and potential pressures on the family.³³
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3 As in previous studies,³⁴ many participants in this study had experienced weight stigma, blame and
4 judgement from health professionals as well as a societal culture of weight bias. Indigenous
5 participants often experienced this in addition to varying forms of racism. The impact of racial
6 discrimination on health care use in NZ is well-documented,^{35 36} and the compounding impact of
7 multiple stigmas is likely to contribute towards differential attendance rates between Māori and NZ
8 Europeans. Previous weight bias and racism which occurs outside the service may play a role in
9 participant reluctance to engage with Whānau Pakari. Further research should investigate the role of
10 racism and weight stigma in engagement with healthcare for weight issues among marginalised ethnic
11 groups.³⁷

22 **Strengths and Limitations**

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25 The strengths of this study include the large sample size across participants with varying levels of
26 engagement which allowed for in-depth and broad analysis. In addition, this study included data from
27 a targeted group of participants (those who declined further contact after referral) whose lack of
28 contact with the service limits the power of quantitative methods in drawing conclusions, and who are
29 typically difficult to recruit, as recognised in previous studies.¹⁰ Finally, there was good representation
30 from families with Māori children who comprised approximately half of the interviews, allowing us to
31 draw conclusions for a group whose voice is historically absent from obesity research.

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34 The main limitation of this study was the lack of child and adolescent voice with regards to their
35 experiences with Whānau Pakari, as only five interviews included the child or adolescent as a
36 participant. While it was intended to conduct interviews with families, many parents at recruitment
37 were reluctant to involve their children due to the sensitivity of material discussed or were unable to
38 involve them due to timing issues. This meant that children's experiences have mainly been explored
39 through their parents' accounts, rather than through their own voice. In addition, previous literature
40 has largely focused on the effect of child/adolescent gender rather than parent gender on perceived
41 barriers to engagement.¹⁰ In our study, the majority of participants were mothers or female caregivers,
42 which may have affected the results. While this study included a range of participants from a variety
43 of different backgrounds (table 1), it lacks specific participant demographic information such as age,

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3 socioeconomic status and education level. Lastly, it is possible that participants were discretionary in
4 what they chose to share; however, the disclosure of extremely personal and sensitive experiences
5 suggests that any researcher-participant power dynamics were overcome by steps the interviewers
6 took to mitigate this difference (see COREQ checklist).
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11 **Conclusions**

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15 In conclusion, this study found that much of the difference between Whānau Pakari participants who
16 engaged highly and those who did not engage appeared to be due to the degree to which participants
17 were affected by the impact of factors at the system and societal levels. Focusing purely on weight in
18 multicomponent interventions does not acknowledge the complexity of contemporary family life.
19 However, family-based multidisciplinary intervention programmes such as Whānau Pakari are an
20 opportunity to acknowledge the wider societal challenges affecting achievement of healthy lifestyle
21 change. Health professionals and providers can engage in respectful and compassionate care to help
22 counteract past negative experiences of healthcare. Referral pathways for healthy lifestyle change
23 programmes need to be as flexible as possible to remove any barriers to engagement, and referrers
24 need to develop a deeper understanding of the importance of the referral conversation in relation to
25 weight. Future research should focus on specific strategies to facilitate engagement at different points
26 of contact with family-based multidisciplinary healthy lifestyle services. Respectful, compassionate
27 care is critical to enhanced retention in programmes, and ongoing engagement in healthcare services
28 overall.
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48 research and critical appraisal of the manuscript.
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52 Numerous authors within our research group are increasingly aware that the use of terms such as
53 obesity are contested and increasingly problematic, partly due to the experiences of participants in
54 terms of weight stigma. We have therefore used this term where it relates to referenced works,
55 prevalence, and to communicate to the biomedical community, but have used alternate terms
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3 wherever possible to ensure a person-centred approach, prioritising the experience and voice of those
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5 working towards achieving healthy lifestyle change
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8 *Declarations of interests*

9
10 We have read and understood BMJ policy on declaration of interests and declare that we have no
11
12 competing interests. All authors have completed the Unified Competing Interest form (available on
13
14 request from the corresponding author) and declare: no support from any organisation for the
15
16 submitted work; no financial relationships with any organisations that might have an interest in the
17
18 submitted work in the previous three years, no other relationships or activities that could appear to
19
20 have influenced the submitted work.
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23 *Ethics committee approval*

24
25 Ethical approval for the Whānau Pakari Barriers and Facilitators study was granted by Central Health
26
27 and Disability Ethics Committee (NZ) (17/CEN/158/AM01). Written informed consent was obtained
28
29 from all study participants, or informed assent with proxy parental consent in the case of the child and
30
31 adolescent participants aged under 16 years.
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34 *Transparency statement*

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36 The lead author affirms that the manuscript is an honest, accurate, and transparent account of the
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38 study being reported; that no important aspects of the study have been omitted; and that any
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40 discrepancies from the study as originally planned have been explained.
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43 *Contributorship statement*

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45 CW was involved in study design, data collection, analysis, interpretation, and writing of the
46
47 manuscript. NR contributed towards study design, data collection and manuscript appraisal. EW
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49 contributed towards study design, oversaw analysis and interpretation, and was involved in writing of
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51 the manuscript. PH was involved in study design and critical appraisal of the manuscript. YA was
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53 involved in study design, analysis, interpretation, and writing of the manuscript.
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Data sharing statement

No additional data available.

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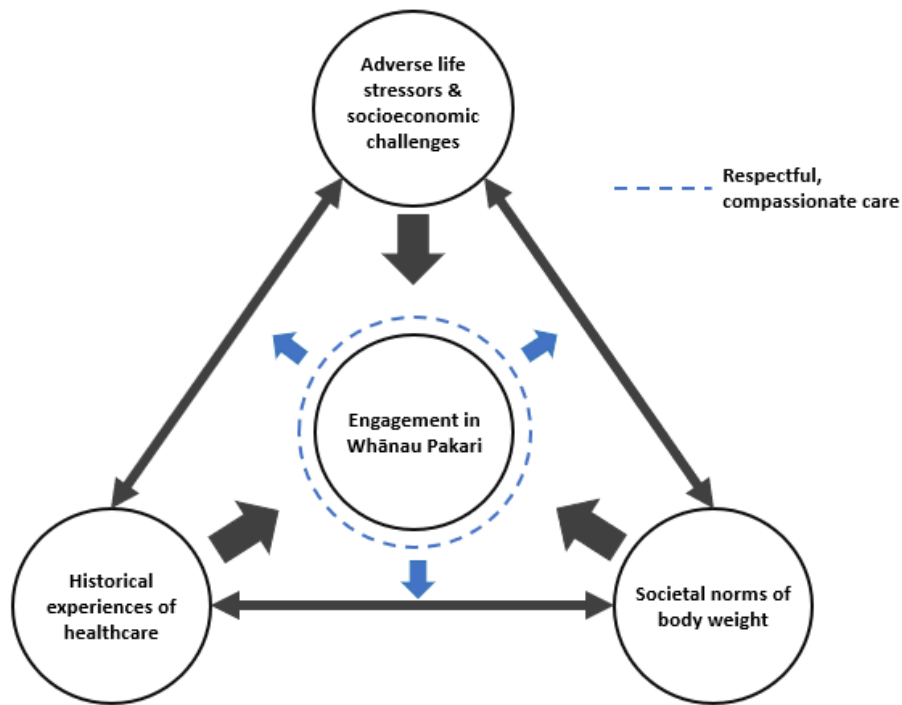
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22 Figure One: The three interacting factors that influence participant engagement in Whānau Pakari.
23 Respectful, compassionate care can partially mitigate the effects of these determinants.
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COREQ (Consolidated criteria for reporting qualitative research)

This checklist is intended to supplement the manuscript by providing further detail on methodology.

Domain 1: Research team and reflexivity

Personal characteristics

1. Interviewers

Cervantée Wild & Ngauru Rawriri conducted the interviews (page 8).

2. Credentials and 3. Occupation (page 1)

Cervantée Wild (BHSc(Hons), BA) – PhD candidate, Liggins Institute, University of Auckland

Ngauru Rawiri – BHSc student, Te Reo Māori teacher (tertiary level) and interview facilitator, Liggins Institute, University of Auckland

Paul Hofman (MbChB, Dip Obs, FRACP) – Professor and paediatric endocrinologist

Esther Willing (PhD) – Lecturer in Hauora Māori, Kōhatu – Centre for Hauora Māori, University of Otago

Yvonne Anderson (PhD, Dip Paeds, MBChB, FRACP, BSc [Psych]) – Senior research fellow and paediatrician

4. Gender & ethnicity

CW – female, New Zealand European

NR – female, Māori (Ngāti Mutunga, Ngāti Tama, Ngāti Rāhiri o Te Ati Awa me Ngai Tūhoe)

PH – male, New Zealand European

EW – female, Māori (Ngāti Toarangatira, Ngāti Koata me Ngā Ruahine)

YA – female, New Zealand European

5. Experience and training

CW had qualitative research training through the PhD (supervised by PH, EW, and YA). NR had interview experience through her career. PH is an experienced researcher in child health and endocrinology. EW is an experienced qualitative researcher and has extensive experience in Māori health research. YA is an experienced researcher in child health, especially childhood obesity.

Relationship with participants

6. Relationship established

All participants were recruited as described below, and some were already known to NR through relationship networks.

7. Participant knowledge of the interviewer

The participants knew the reasons for conducting the research (detailed in the patient information and consent form), and participants were aware that the study would specifically ask about the factors that contributed to their decisions to engage or not engage, in order to improve the service. Participants were also aware that the interviewers were separate and distinct from the clinical service team.

8. Interviewer characteristics

NR is a Māori researcher (of Ngāti Mutunga, Ngāti Tama, Ngāti Rāhiri o Te Ati Awa and Ngai Tūhoe descent) and CW is New Zealand European. This mixed Indigenous – non-Indigenous partnership allowed us to connect and establish rapport with participants, depending on the interview participant and context. NR's role as a parent had the advantage that familiarity with this stage of life helped her understand participants' stories and ask exploratory questions.

Domain 2: Study design

Theoretical framework

9. Methodological orientation and Theory

The research approach was informed by Kaupapa Māori theory. The approach was developed to minimise any perceived power imbalances between the interview team and the participants and make the interview experience as comfortable as possible. We used thematic analysis to analyse the interviews (page 7).

Participant selection

10. Sampling and 11. Method of approach

We identified eligible potential participants who fit the criteria, and then stratified these participants into groups by engagement level and ethnicity. We then randomised the list of potential participants in each group, and then contacted each participant one by one (stratified random sampling). Participants were recruited by telephone and interviewed in person over a six-month period from June to December 2018 (page 8).

12. Sample size

For funding and resource reasons, we had a maximum total of 74 potential interviews with families. We conducted 64 interviews in total (page 10).

13. Non-participation

We approached 136 families, of which 53 were uncontactable, 7 agreed but were unable to be interviewed as they had moved out of the region, and 12 declined because they were not interested, were too busy with work, or did not remember the referral (page 11).

Setting

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3 14. Setting of data collection
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5 Participants were interviewed in person at their home, workplace, or at a local community child
6 health centre. All participants chose where they would prefer to be interviewed (page 8).
7

8 15. Presence of non-participants
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10 For most interviews, only the participant and interviewers were present, but there were occasionally
11 other family members present, such as young children (<5 years) (page 8-9)
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13 16. Description of sample
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15 Half the interviews were with families with Māori children. Most (80%) were solely with a female
16 parent/caregiver (13 interviews included male parents and/or caregivers). 11 interviews involved
17 two or more family members. 5 interviews included a child participant (page 10).
18

19 *Data collection*
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21 17. Interview guide
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23 A semi-structured interview framework was used and adjusted for relevance as each interview
24 progressed. It was not pilot tested. The guide has been included as supplementary material.
25

26 18. Repeat interviews
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28 Repeat interviews were not conducted, but participants were offered their transcripts for review
29 after the interview (page 9).
30

31 19. Audio recording
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33 Interviews were audiotaped digitally and transcribed by a medical typist (page 9).
34

35 20. Field notes
36

37 Field notes were made after each interview and kept as part of a reflexive notes.
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39 21. Duration
40

41 Interview audio recordings ranged from nine minutes to 107 minutes (mean 31 minutes).
42

43 22. Data saturation
44

45 Data saturation was reached in each group of participants in each level of engagement.
46

47 23. Transcripts returned
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49 Transcripts were anonymised and returned to the participant for checking, including deletions of
50 portions if desired (page 9).
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53 **Domain 3: analysis and findings**
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55 *Data analysis*
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57 24. Number of data coders
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3 Eight transcripts were independently coded by CW and EW and discussed for consistency. After the
4 coding matrix was constructed and consensus on codes reached, all transcripts were coded again by
5 CW.
6

7 25. Description of the coding tree

8
9 A 'mind map' was used instead of a coding tree in order to better capture complexity and avoid an
10 artificial hierarchy that did not adequately represent the inter-relationships between the themes,
11 since themes could become more major or minor depending on the context.
12

13 26. Derivation of themes

14
15 Themes were derived from the data according to Braun and Clarke's 2006 and 2019 method for
16 reflexive thematic analysis (page 9).
17

18 27. Software

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20 MAXQDA software was used to manage the data (page 9).
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22 28. Participant checking

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24 Participants did not provide feedback on the findings.
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26
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28 *Reporting*

29 29. Quotations presented

30
31 Participant quotations are presented in Panel 1 and throughout the manuscript. They are not
32 identified by participant number (page 11-12).
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35 30. Data and findings consistent

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37 There was good consistency between data and findings, with the two interviewers working to
38 discuss findings and the wider research team providing critique and challenging interpretations of
39 data (page 9).
40

41 31. and 32. Clarity of major and minor themes

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43 A distinction was made between 'major' and 'minor' themes with sub-themes capturing the range of
44 participant experiences under each major theme. However, even major themes could not be cleanly
45 separated, reflecting real-world complexity.
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49 Reference: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research
50 (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19, 349–
51 357. doi: 10.1093/intqhc/mzm042
52

53 NB. This checklist has been amended to capture ethnicity and gender breakdown, to reflect the
54 composition of the research team.
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SUPPLEMENTARY MATERIAL: Interview schedule

NB. Interviews were semi-structured and this schedule is simply a guide to the line of interview questioning. Not all questions were asked if not appropriate. Sections marked with an asterisk () were not asked of participants who declined involvement in the programme.*

Referral & initial thoughts

- Who referred you to Whānau Pakari?
- Do you remember how they told you about the programme? *(if not self-referral)*
- Did they talk with you and your child?
- How did you feel about being referred? How did you talk to your child/children about the programme and referral?
- Why did you decide to accept the referral?
- How did you feel about starting the programme?
- Which part of the programme (if any) were you more interested in, or seemed more relevant for you and/or your family?
- Were you worried about what other people might think about you and your family attending Whānau Pakari?

Overall experience *

- Which parts of the programme were the most helpful?
- Which parts of the programme did you find were more difficult?
- Did Whānau Pakari meet your needs in supporting you to make healthy lifestyle changes as a family? Why/why not?
- Did Whānau Pakari meet your expectations in terms of what you thought the team would provide? How did/didn't they do this?
- Would you recommend Whānau Pakari to other families and why/why not?

Barriers and facilitators *

- What were the things that helped you to or made you want to continue to attend Whānau Pakari sessions, if any?
- What were the things that made it hard for you to continue to attend Whānau Pakari, if any?
- Did you experience any travel barriers to get to the sessions? E.g. location, access to car, parking, petrol, WOF, rego
- The Healthy Lifestyles Coordinator came to you for the assessments. What were the good things about a home visit? (If any) What were the negative things? (If any)
- Do you prefer home-based assessments rather than coming to the hospital/clinic?
- Were you able to involve the rest of your children and family in the programme sessions.

- How much of a priority was Whānau Pakari in relation to your other demands?
- How did other competing demands, obligations or choices impact on your decision to attend Whānau Pakari?
- Can you please describe how Whānau Pakari was (or wasn't) suitable for families like yours?
- Was Whānau Pakari family-friendly, inviting, comfortable? What could be done to improve this?
- Can you please tell me how costs may or may not have been barriers to participation in Whānau Pakari? How?
- Can you tell me about any other barriers to participation in Whānau Pakari that you experienced?
- Can you think of things that might have motivated you or your whānau to participate (or things that kept you from participating)?

Beliefs and feelings around healthy lifestyle programmes

- What do you think about healthy lifestyle programmes in general?

Previous experiences with health system

- In general, can you describe what your experiences with the health system have been like prior to the Whānau Pakari programme?
- Have you ever felt that you or your family have been treated unfairly in the health system? If yes, why do you think that this happened?
- In your experiences with the health system, have you ever experienced discrimination? If yes, can you tell me a bit more about this? Why do you think this happened?
- Have any of you or your family's previous experiences with the health system influenced your decision to attend Whānau Pakari? If yes, how?
- Have you had any previous negative experiences with health providers that made you choose not to attend Whānau Pakari sessions?

Previous experiences with societal stigma

- In your day-to-day life, have you ever been treated unfairly or discriminated against? If yes, can you tell me a bit more about this? Why do you think this happened?
- Have you ever witnessed or heard about other members of your whānau being treated unfairly or discriminated against for any reason? If yes, can you tell me a bit more about this?
- Do you think any of these experiences influenced your decisions or ability to attend, engage, participate or continue participation in Whānau Pakari?

Follow-up prompt guidelines

Prompts are to keep the momentum of the interview by being positive, affirming answers and using active listening without being leading.

- Prompts included:
 - Non-verbal nods
 - Affirming sounds e.g. Mmmm
 - Agreement e.g. yes, that's interesting
 - Questions e.g. "what did you mean by that?", repeat the last word the participant said as a question to prompt more explanation.
 - To get back on track: "Could I ask you about something you said before..."

For peer review only