“It's more personal if you can have that contact with a person”: Qualitative study of health information preferences of parents and caregivers of children with obesity in New Zealand

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Abstract
The objective of this study was to understand how participants referred to a childhood obesity intervention programme prefer to receive health information, and secondly, to determine acceptability of digital technologies such as a social media platform or IT application for programme engagement. This study includes a subset of interviews (n = 64) of a wider study of the barriers and facilitators of engagement in a multidisciplinary healthy lifestyle programme for childhood obesity, based in Taranaki, Aotearoa/New Zealand. The topics of health information and social media and/or app use were covered in 53 and 30 interviews, respectively. Participants were parents and caregivers of children and adolescents referred to the programme, and interviews were mostly conducted in family homes. Findings showed that participants consulted a range of people, places and resources for information about their health, notably the internet, health professionals, and family and friends. Participants reported using the internet to complement or supplement information from health professionals. A strong relationship with health professionals built on trust was important. Use of digital technologies such as an IT application or social media platform for engagement with the programme was generally acceptable, with the caveat that this did not replace face-to-face communication with their primary care provider. In conclusion, the high usage of digital sources of health information requires accurate and reliable information. Digital technologies such as IT applications or social media platforms may have a role in terms of supplementing the patient journey; however, the importance of in-person communication and an ongoing relationship with a health professional or practice remains paramount.

KEYWORDS
behavioural/lifestyle intervention, health information, health services, Interaction in Health Care and Community Settings, qualitative research, technology
1 | INTRODUCTION

While health professionals have traditionally served as primary sources of health information, increased access to the internet has meant that a large amount of health information is readily available to the general public, allowing patients to obtain and share health information via websites and online social networks (Sarasohn-Kahn, 2008). In Aotearoa/New Zealand (hereafter New Zealand), 90% of those aged 18 years and older have internet access at home (Grimes & White, 2019). This widespread access to the internet means that many people receive a large proportion of their new health information via the internet. Thus, it is important that the information available is valid, usable and accessible (Clarke et al., 2016).

A systematic review of patient health information needs and sources found that the internet and physicians were the most frequently consulted sources of health information (Clarke et al., 2016). The use of technology in healthcare is becoming ubiquitous; not only are families seeking health information using technology, but health professionals are also utilising digital tools to assist with consultations. While the unregulated nature of internet-based information poses challenges to reliability of information, this widespread information seeking also provides an opportunity for health professionals and providers to support patients and their families in being active participants in their health care journey, especially those dealing with complex chronic conditions, such as obesity. For example, effective management of childhood obesity requires addressing a wide range of weight-related conditions (comorbidities), such as sleep apnoea, type 2 diabetes, prehypertension, and raised blood markers (Anderson et al., 2016). Nine percent of children aged 2–14 years in New Zealand are affected by childhood obesity, and the prevalence is higher for Māori (New Zealand’s Indigenous population; 13%), Pacific peoples (29%) and those living in the most deprived areas (17%) (Ministry of Health, 2020). However, current health care for childhood obesity management nationally is minimal, with limited access to World Health Organization-recommended multidisciplinary intervention programmes (Anderson et al., 2015) and increasing demand on limited health care resources (Lal et al., 2012).

One such multidisciplinary programme in New Zealand is Whānau Pakari, a family-centred assessment and intervention healthy lifestyle programme for children and adolescents experiencing childhood obesity. Families are supported by a multidisciplinary team including a healthy lifestyle coordinator, dietitian, physical activity specialist, clinical psychologist and a paediatrician, and can also attend weekly activity sessions (Anderson et al., 2015). Whānau Pakari takes a non-judgemental, non-stigmatising approach with a focus on achieving healthy lifestyle change rather than on weight loss. The programme involves comprehensive home-based assessments that screen for weight-related comorbidities and other health and wellbeing indicators. This removes the need for a hospital appointment while retaining the ability to address complex weight-related conditions.

Electronic decision-making support via digital tools has previously been recommended to assist health professionals in managing childhood obesity in primary care (Walsh et al., 2013). Current research underway aims to develop an IT application with pathways for decision-making regarding the investigation of weight-related comorbidities, individualised to the patient at each healthy lifestyle assessment (Karalus et al., 2021). This could potentially improve patient-centred care by individualising recommendations (Karalus et al., 2021). An additional, participant-facing interface to the application is also proposed; however, successful uptake of such an application depends on participant needs and preferences. Therefore, the aim of this study was to understand how participants who had been referred to a childhood healthy lifestyle programme receive their health information, and to determine if, given the option, they would use an IT application (henceforth, an app) or social media platform to engage with the programme.

2 | METHODS

This study reports results from a subset of interviews that were undertaken as part of a wider study exploring participant experiences and engagement in a healthy lifestyle programme (Whānau...
Pakari). The aim of this original study was to identify factors affecting participant engagement and retention in the programme; opportunistically, we also asked about health information and technology use in the interviews. Only methods relating to this paper are presented; full details of the original Whānau Pakari Barriers and Facilitators study design and methods are described in detail elsewhere (Wild et al., 2020) and involved an approach informed by Kaupapa Māori principles. Ethical approval for the original study was obtained from the Central Health and Disability Ethics Committee (New Zealand; 17/CEN/158/AM01). Written informed consent was obtained from all participants at the time of the interview.

2.1 Study location

Whānau Pakari is located in Taranaki, a mixed urban-rural region of New Zealand. 20.2% of the population are Māori (compared with 16.6% of the national population; Ministry of Health, 2021) and 15% live in the most deprived areas (Atkinson et al., 2014). Health care in New Zealand is a combination of public and privately funded services, with publicly funded hospitals and other public health services alongside privately owned general practices with some public funding, and private hospitals (Goodyear-Smith & Ashton, 2019).

2.2 Participants and data collection

Participants were parents and caregivers of children and adolescents referred to the Whānau Pakari programme between January 2012 to January 2017. Participants were recruited via text message and telephone call using stratified random sampling. This ensured approximately equal numbers of interviews with families with Māori and non-Māori children, and a range of participants who engaged with the programme to varying degrees, including those who declined further input after their referral. Sixty-four in-depth interviews were undertaken by CW and NR with predominantly parents and caregivers of children referred to the Whānau Pakari programme. Community-up research values guided the interview process, the full details of which are described elsewhere (Cram & Phillips, 2012; Wild et al., 2021). The researchers were not already involved in the programme and were predominantly not known to participants (Wild et al., 2021). Several interviews contained more than one parent/caregiver. Interviews took place in-person in family homes or in alternative locations chosen by the participant and sought to ascertain the factors affecting engagement for families in the programme (Wild et al., 2020). Interviews were approximately 30–60 min long, were audio-recorded, and were independently transcribed. Participants were offered their transcripts to check for accuracy and to approve the content.

2.3 Analysis

Participant transcripts were included in the analysis if they had discussed health information (n = 53) and/or social media or App use (n = 30) in their interview. Interview transcripts were independently coded by two researchers (CW and VE) in nVivo (version 12). Qualitative content analysis was inductive (i.e. data-driven) and focussed on the content and contextual meaning of each response, both explicit and inferred (see Table S1 for code definitions; Bengtsson, 2016; Hsieh & Shannon, 2005). This analysis method was deemed suitable given the brevity and specificity of the data. Qualitative content analysis was initially undertaken by CW with peer debriefing with VE for validity. Both CW and VE collaboratively developed the categories and overarching frameworks. A coding table with definitions is included in Supporting Information S1.

2.3.1 Findings

Participant demographics are presented in Table 1. The majority of participants were female and of New Zealand European ethnicity. A categorical framework summarising the findings is depicted in Figure 1. All quotations are presented as they directly appear in

| Interview participants | N % |
|------------------------|-----|
| **Health information question** | |
| Gender n % | Female | 50 (83) |
| Ethnicity n % | Māori | 22 (37) |
| NZ European | 35 (58) |
| Asian | 2 (3) |
| Other European | 1 (2) |
| **App/social media question** | |
| Gender n % | Female | 31 (84) |
| Ethnicity n % | Māori | 13 (35) |
| NZ European | 23 (62) |
| Asian | 1 (3) |

*Prioritised ethnicity output.

The data presented here are a convenience sample of responses to two interview questions: (1) how do you prefer to receive information about your health? and (2) would you use a Whānau Pakari social media group or App? Why/why not? Due to the semi-structured nature of the interviews, not all participants were asked questions around their health information and social media use in the course of the interview if the discussion had reached its natural conclusion.
the transcript; however, names and identifying features have been removed to ensure confidentiality. Definitions of New Zealand-specific resources or services are provided in parenthesis and are not italicised.

2.3.2 | Health information sources

The question, “how do you prefer to receive information about your health?” elucidated responses centred around people, places and resources (presented in Figure 1). Participants reported that they consulted multiple sources of information about their health, often having a range of options available such as the Healthline phone service (free health advice and information phone line), the internet, family and friends, and health professionals:

Oh, I go to the Healthline if I’m stuck. Google [...] Oh, and I ask people. And I’ve got friends who are Rongoā Māori (traditional Māori medicine) [practitioners]—

KB (female, Māori).

When they were younger I used to use the Healthline. But as they got older it was more I would ring my Doctor. Maybe if my Doctor wasn’t on I would ring the Nurse and say ‘hey look, this is what’s going on, is it worth me bringing him in?’ If worst came to worst I would ring A & E (the accident and emergency department at the hospital)—

VB (female, NZ European).

Participants frequently mentioned using the internet for their health information, notably using generic search engines such as Google to guide searches rather than directly consulting health information websites. Participants spoke of occasions where the internet was consulted secondary to receiving an initial diagnosis from the doctor or prior to going to an appointment.

Dr Google, or at the Doctors’, they go to Dr Google too! That’s funny that [...] I go online a lot—

MN (female, Māori).

[I] looked on YouTube, and it comes up, you know, what cures diabetes and, you know, what to eat right and how to exercise, and I thought, “oh, this is great”, so I started doing that and exercising and eating the right foods—

JB (male, NZ European).

I still go to the doctor, get some blood tests or whatever, but I do then try and research it so that I can understand a bit more about what’s likely to happen [...] diagnoses for the doctors, but I research it myself now—

NV (female, NZ European).

However, multiple participants reported that they avoided using the internet as they did not feel it was trustworthy:

Online is not always the best way to find out information—

RC (female, Māori).

I have Googled about myself, but then I don’t rely on that, it’s just rubbish—

VB (female, NZ European).

I don’t like um doing Google and all that because they tell you a lot of crap—

KW (female, Māori).

Print resources such as books, magazines and newspapers were reported to be less frequently consulted:

I see an article in one of the health magazines that refers to [disease] or something like that, then I will buy the magazine—

NV (female, NZ European).
Friends and family were frequently cited as reliable sources of information, especially if they had experienced similar situations.

Mums know everything. I know. Naughty aye! Healthline and everything, but no, 0800 Mum.— TJ (female, NZ European).

Firstly Mum, my mum. She’s a teacher and ah maybe there’s Plunket Nurse (Plunket is a free nurse health services for children aged under five years). But, [DAUGHTER] now is bigger, not like close to baby age or toddler, but yeah maybe I go to [general practice] and ask Nurse for the problem if I’ve got some questions, yeah— AE (female, Other European).

Sometimes I talk to my friend that already have kids […] so I always ask her about what’s going on. Is this normal […]?— CJ (female, Asian).

From past experiences though you kind of know, aye. Yeah, she knows, mother’s instinct knows if it needs to go straight to hospital— TW (male, Māori).

Especially if you know someone who has been through it, it makes it really easy— NP (female, NZ European).

Participants also used Rongoā Māori or consulted people proficient in Rongoā Māori as an alternative to or complementary to visiting the doctor.

I’m right into my Māori rongo […] my Nan is still alive, so I talk with her and we talk about Māori rongo— RD (female, Māori).

For some participants, the cost of seeking medical advice was too high, leading them to find other free alternatives, such as the emergency department.

It’s expensive to go to the Doctor, and that’s probably why I don’t go to the Doctor— RD (female, Māori).

Most participants who talked about seeking medical advice from a health professional emphasised the importance of their ongoing relationship with one health professional or one specific medical practice. The continuity of care received was reported to build familiarity, reliability and trust.

Usually the Doctor… Yeah, real good relationship with the Doctor— NH (female, NZ European).

I think you can’t beat actually talking to a doctor or a nurse about something— LY (female, Māori).

[…] get information from doctors or nurses. I think that would be the most reliable— CE (female, Other European).

I probably would go to [district health nurse]. She was the health nurse that used to do the home visits. If we couldn’t make it to the hospital, [district health nurse] would come to us. She was so cool too— RW (female, Māori).

I just ring the Nurse at [general practice] and talk to her, explain the symptoms at the time and complications, and if she doesn’t know then she will pass me on. Like, just recently I’ve had a medication problem with one of my medications I’ve changed, and I spoke to the Nurse about it, but she couldn’t advise me, so she told me to ring my chemist. So, I sat down and had a talk with my chemist, so she was really good. […] So she passed me onto who she thought would be the better advice— PM (female, NZ European).

I generally will ring my nurse. My Doctor I’ve had since I moved to [region], so that’s a good 25 years ago, and I’ve been with them since then so they’ve been with me since I’ve had the girls and the nurse has been there, [practice nurse] has been there from the word go […] we’re quite good friends— JT (female, NZ European).

2.3.3 Interest in a programme-specific app or social media group

The responses to the question, "would you use a Whānau Pakari app or social media group? Why/why not?" are presented in
Figure 2. Responses were generally positive in terms of whether participants would be interested in using an app or social media group. Negative responses tended to be due to a general aversion to social media.

Social media isn't support. Social media is a place with faceless arseholes who do nothing but bitch and moan about things. Nah. Sorry, I am dead against social media. I hate social media. Personally—

JW (male, NZ European).

However, some participants considered their lack of technical skills to be a barrier to engagement on social media or use of an app.

Probably not. I'm probably a bit of a dinosaur really—

PJ (female, NZ European).

I try to avoid those. Laughing. I am not tech savvy, but the kids will pick it up—

RD (female, Māori).

Probably not for me because I'm not a computer whiz on it—

DS (female, NZ European).

For some participants, an app was preferable to social media due to the perceived ability to control the level of engagement with the platform:

... apps I think probably more for me. I like social media, but I find it has its moments. With social media it can become more of a nuisance, more of a problem, especially if there is a lot of people on it. If people were replying or talking and then it can be quite disruptive. Where if it's your application you can apply it when you want it and it's there, you know, sort of thing—

VB (female, NZ European).

Participants who indicated they would use an app stated they would use it for two purposes: accessing healthy lifestyle content, such as recipes and materials from the programme sessions for reviewing at a later date, and for programme scheduling and location reminders.

You know, if you missed one then it's all up on here—

NP (female, NZ European).

If they were, like, putting regular information about what was happening—

AT (female, Māori).

They could keep track on their kid's weight and all that sort of that stuff, and find recipes on there for their children um so that not only could they be doing it with the groups, but they could also be doing recipes at home together, which would be cool... or even just talks on all the health side of it—

JS (female, NZ European).
There could be advantages to having an app like that. Either, if it’s things like reminders of healthy eating or reminders about exercise or if you want to search up something... it’s a proper, um, evidence-based information in there, then yeah it could be quite helpful [...] Yeah it could be quite interesting. Endless possibilities—

CE (female, NZ European).

Some participants also identified certain conditions for app usage. These included resource and socioeconomic considerations, including access to a smartphone and sufficient mobile data or wifi, and literary considerations in that the material on the app would need to be simple and easy to understand.

Some of them are financially not in a position to have a flash phone, you know—

JS (female, NZ European).

If it was in simple, you know, simplified, to understand... You know, because we have a lot of whānau (families) that don’t understand grammatical English very well—

RD (female, Māori).

Participants also considered the age-appropriateness of an app, suggesting separate material for children and adults might be needed.

It might be something more for the kids’ side of it.—

PJ (female, NZ European).

For some, a social media platform was preferable to an app due to a lack of phone storage space and an abundance of existing apps of which to keep track.

...maybe a social media page. The thing for me is, my phone isn’t very big, sort of, and I find I can’t keep all these different apps on it so, um, I’d probably be less inclined to use it. The kids’ schools are all getting apps for different things and they’re at three different schools and my phone can’t fit them so I just end up going onto the website, just Google and going onto the website and looking at stuff or Facebook notifications—

AD (female, NZ European).

Participants who indicated interest in a social media group similarly stated that access to healthy lifestyle content would be beneficial, as well as maintaining social connections with other members of the group.

You might get a group of them going ‘hey let’s take them to the beach or something good’, and we might have interacted a bit more as a group because we only saw each other once a week. You know, and it’s sort of like you don’t have to tell each other where you live or anything on Facebook, you can pretty much just go ‘well, we’ll just meet at the park’ [...] and that’s the upside of Facebook because it gives you a platform where you can talk without actually face-to-face judgment—

LY (female, Māori).

However, a key concern was privacy considerations, and some participants were reluctant to be connected with other families on social media if they had not connected well in the group session. For example, when asked whether they would feel comfortable being connected with other families on social media, one participant was against this, stating:

Honestly, our group were weird ones... We had some really mental ones in there, so yeah, I wouldn’t have wanted, yeah—KW (female, Māori).

Another participant was aware that some families might not want their ‘faces’ on a social media, implying that privacy should be considered alongside the benefits of being connected:

I know you come across confidentiality and the Privacy Act...—

SS (female, NZ European).

For both options, an underlying caveat was the use of an App or social media group as supplementary to the programme, rather than replacing in-person or face-to-face contact with the programme deliverers.

I think it’s more personal if you can have that contact with a person and that you see face-to-face and talking to them than trying to do it through a computer, yeah—

DS (female, NZ European).

This reflects the trust built over time with health professionals and the importance of continuity of care.

3 | DISCUSSION

This study found that parents and caregivers of participants in a multidisciplinary healthy lifestyle programme consulted a range of sources for their health information, using the internet, family and friends, health professionals, Healthline, rongoā Māori practitioners, print resources and the emergency department. Of these, the first three sources—the internet, family and friends, and health
professionals—were notably most used, and participants emphasised the importance of an ongoing relationship with one health professional or practice as building reliability and trust. When given the hypothetical option of using a programme-specific app or social media group, participants highlighted accessing healthy lifestyle content, programme scheduling reminders and social connection as potential benefits. Important considerations for app usage were resource availability, literacy and age-appropriateness, with privacy being a key consideration for social media usage. Importantly, both forms of technology were perceived as supplementary options to ongoing, kanohi ki te kanohi (face-to-face) relationships with programme deliverers.

Our findings are consistent with research investigating the use of digital and telehealth tools in other complex health journeys; kanohi ki te kanohi relationships were identified as critical, especially for Māori patients, in gout management in primary care (Rolston et al., 2018), perinatal care (Gasteiger et al., 2019), and type 2 diabetes management via the Green Prescription programme (Williams et al., 2017). Our findings provide participant-centred evidence within community child health that can help inform the development of digital infrastructure such as applications to support healthy lifestyle programmes via health promotion and health literacy. This is important given the focus on developing digital infrastructure as part of the upcoming health system reform in order to improve the quality of health service delivery (Health & Disability Review Transition Unit, 2021).

The range of information sources consulted by participants demonstrates the importance of information consistency in appropriate language that supports health literacy across multiple sources. Our study supports previous research findings that the internet and health professionals were commonly used sources of health information (Honey et al., 2014), often being used as complementary or supplementary sources for each other. A survey in NZ of 1783 general practice users found that visiting the doctor (91%), nurse (82%) and using the internet (76%) were perceived to be the most useful sources of information (Honey et al., 2014). A review of patient use of the internet and how this may affect the patient-provider relationship showed that the use of the internet for health information tends to be before the clinical encounter to decide if they need help, or after for reassurance or for Supporting Information S1 (McMullan, 2006). In our study, those seeking advice primarily from health providers highlighted the ongoing relationship built with one health professional, or group of health professionals at a specific health care service, and previous research has emphasised the importance of respectful, compassionate care with programme deliverers in promoting engagement (Wild et al., 2020). This suggests that digital resources could be used effectively, but in conjunction with an ongoing, trusting relationship with health professionals. The prior establishment of a trusting relationship remains paramount.

The recent announcement of a major health and disability system reform in New Zealand brings opportunities for the development of digital technologies to enable better self-management of healthcare (Health & Disability System Review, 2019). Our study suggests there is scope and potential for digital resources such as social media platforms or apps to augment paediatric obesity service provision and potentially additional clinical services for complex health needs. The development of an app to supplement the Whānau Pakari clinical service and healthy lifestyle programme could be an opportunity for enhancing participant engagement in their health journey. Previous qualitative research has emphasised the importance of knowledge-sharing and enabling a family to become self-determining in their process to achieve healthy lifestyle change (Anderson et al., 2021). Given participant concerns around the reliability and trustworthiness of information provided on the internet in our study and others (Honey et al., 2014), the app could also function as a reliable source of information, provided the information is complete, relevant, accurate, understandable and of sufficient depth (Tao et al., 2017). According to participants, a health-literate app, age-appropriateness, and access to resources are key considerations for app development. Privacy concerns and appropriate consent processes would also need to be considered.

A strength of this study was the broad representation from Māori and non-Māori families, which was representative of the wider service. Additionally, having the wider research team involved in analysis and interpretation may have strengthened the confirmability of the findings. However, transferability beyond the New Zealand context may be a limitation. Given the data are also less recent, current perspectives on virtual consultation may not be captured, especially in the wake of the COVID-19 pandemic, which has accelerated the use of digital technologies in clinical consultations (Hutchings, 2020). Additionally, only some participants were asked these questions due to the semi-structured nature of interviews, so the findings may not be representative of the wider cohort. Few male participants and children participated in the original study (Wild et al., 2020), thereby limiting this subset of interviews to those original parents and caregivers. Future research should ensure that any digital resource or application is developed in partnership with patients and their families (i.e. the end-users), as participant agency is vital to ensuring an acceptable, appropriate service that is equitable, compassionate, and respectful.

In conclusion, the variety of health information sources consulted by participants, including both online and in-person resources, suggests that both digitally accessed information and health professionals are used in conjunction with one another to inform participants about information regarding their health. With several caveats, the potential use of an IT application or social media platform to supplement their health journey was positively received by participants, provided this did not replace in-person contact with programme deliverers. There is clear potential for digital technologies to augment clinical service provision moving forward, particularly given the widespread use of digital resources for health information. However, their success is likely to depend on a foundation of trusting relationships with health professionals, primary care practices and a more equitable health system.
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