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Knowledge, attitudes and practices towards fetal alcohol spectrum disorder among healthcare workers in New Zealand

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ABSTRACT

Background: Fetal alcohol spectrum disorder (FASD) is a highly prevalent neurodevelopmental disability caused by prenatal alcohol exposure (PAE). Healthcare professionals (HCP) are key in prevention, diagnosis, and supporting individuals with FASD. This study explored the FASD knowledge, attitudes, and practices among HCP in Aotearoa, New Zealand (NZ).

Methods: We conducted an online survey of HCP working in NZ. The survey measured knowledge of FASD, beliefs and attitudes about FASD, experiences and practices with FASD and future training.

Results: Of the 96 participants, more than 90% self-reported a good or very good understanding of FASD, and around half had a patient with FASD. However, less than half felt prepared to support someone with FASD. Participants identified lack of professional training, services, and funding as barriers to support individuals with FASD.

Conclusion: We identified a need to provide training and promote awareness and recognition for HCP to support individuals with FASD.

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Fetal alcohol; knowledge; attitudes; practices; healthcare professionals

Fetal alcohol spectrum disorder (FASD) is a diagnostic term that describes the neurological and physical effects of prenatal alcohol exposure (PAE) (Cook et al., 2016). The global prevalence of FASD is estimated at 7.7 per 1,000 births (95% CI 4.9-11.7); however, the prevalence of FASD varies considerably by country, with high estimates in countries with pervasive drinking populations (Lange et al., 2017). In Aotearoa New Zealand (NZ) the prevalence is estimated to be 1–2.7% of the total population (Romeo et al., 2023). However, this is likely to be an underestimate of prevalence as it is based on national survey data on self-reported alcohol use during pregnancy (Romeo et al., 2023), yet PAE is highly stigmatised and therefore, often undisclosed and underreported (Corrigan et al., 2017; Corrigan et al., 2019; Dozet et al., 2023). The odds of alcohol consumption (Rossen et al., 2018) during pregnancy and estimated FASD prevalence (Romeo et al., 2023) are higher for Māori (indigenous people). Māori may be disproportionately affected by FASD due to the

historical, political and socio-economic determinants of health inequities and the failure by governments to implement policies aimed at preventing and mitigating alcohol-related harms.

FASD is associated with a broad range of behavioural, cognitive, emotional, and adaptive functioning deficits (Cook et al., 2016). These impairments can manifest into daily challenges for people living with FASD, such as disengagement at school, substance misuse, poor mental and physical health (Temple et al., 2021). People living with FASD may require support across multiple areas of their daily life, including support from healthcare professionals (HCP) (Petrenko et al., 2014).

HCP are well positioned to raise awareness around PAE and FASD (Mukherjee et al., 2006), and have a crucial role in the prevention, diagnosis and support for individuals with FASD (Okurame et al., 2022). Diagnosis of FASD requires the input of multiple HCP experts, diagnostic tests and decision-making (Cook et al., 2016).

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A diagnosis often involves a multi-disciplinary of specialists, such as paediatricians or physicians, psychiatrists, speech language pathologists and neuropsychologists (Mukherjee et al., 2006) and is dependent on the ability of HCP to recognise and facilitate diagnosis of FASD. Beyond diagnosis, people with FASD can experience ongoing physical and mental health challenges throughout life (Cook et al., 2016), that for some individuals will require the ongoing input from HCP to support favourable outcomes and promote well being. Therefore, it is important that HCP are informed about FASD and can provide individualised and culturally competent care.

Despite the importance of HCP in supporting individuals with FASD, the disability is poorly understood by HCP (McCormack et al., 2022). A systematic review of knowledge, attitudes and practices (KAP) of FASD showed in general, HCP had poor knowledge about the clinical features and prevalence of FASD (McCormack et al., 2022). For instance, only 8% of family physicians in a US study correctly identified the clinical features of FASD (Nevin et al., 2002). Less than 30% of HCP correctly estimated the prevalence of FASD, with most participants underestimating the prevalence of FASD (Howlett et al., 2019; Landgraf et al., 2018; McCormack et al., 2022). Furthermore, HCP often feel unprepared to support individuals with FASD (Payne et al., 2005) due to a lack of training and professional support (Wilson et al., 2024). Many allied health workers (e.g., midwives, mental health, rehabilitation professionals) reported not receiving any professional training related to FASD (McCormack et al., 2022), which may contribute to lack of knowledge and awareness. Training and information about FASD are essential for ensuring that HCP have the necessary skills and knowledge to support individuals with FASD and their families.

In NZ, a qualitative study with HCP found HCP were concerned with the mixed messaging regarding safe levels of PAE in society, particularly from media, despite the increased awareness of FASD (Bagley & Badry, 2019). HCP felt they were not sufficiently aware of FASD despite frequently working with expectant mothers and wanted more information about the effect of PAE (Wouldes, 2009). However, no studies have explored the general KAP of HCP working in NZ. The KAP of lawyers (Chu et al., 2024), educators (Chu et al., 2022), social and community workers (McCormack et al., 2023) has been surveyed in NZ, in general professionals reported some knowledge of FASD but had gaps that need to be addressed. Therefore, this research aims to understand FASD knowledge, attitudes, practices, and awareness among HCP in NZ and identify gaps in knowledge and training to develop

resources and build workforce capacity for HCP working with children and families impacted by FASD.

Method

Design

We conducted an online KAP survey with HCP in NZ. The survey consisted of true and false, multiple-choice, and open-ended questions. The questionnaire was adapted from similar KAP surveys designed for educators, social workers, and lawyers, based on previous questionnaires on FASD for health workers (Chu et al., 2022; Mutch, 2013; Payne et al., 2011). The development of this survey is described in (Chu et al., 2022). The survey questions were adapted to the health context and reviewed by FASD experts working in healthcare settings. The survey consisted of 45 questions presented in three sections: knowledge and awareness, attitudes and experience, and current and future training needs. The survey also included questions about participants demographics, profession, type of work setting, and work location. Several different types of response options were used including, multiple choice, yes/no, true/false/unsure and free text.

Study population

Individuals were eligible to participate if they were currently working as a HCP and had regular contact with patients for their work. Participants were required to be older than 18 years old, be able to read and speak English and reside in NZ.

Recruitment

Participants were recruited over six months, from November 2022 to May 2023, through social media platforms (Facebook, Twitter, LinkedIn) and e-newsletters for professional groups. Also, recruitment occurred through advocacy networks, including the FASD Care Action Network (FASD-CAN), and the Australia New Zealand FASD Clinical Network (ANZFASD-CN). All participants were informed of the survey before taking part via the participant information sheet. As the survey was anonymous, submission of survey responses was taken as consent to participate in the research. We obtained ethics approval from the Auckland Health Research Ethics Committee [Ref:AH23200].

Analysis

An online survey was created and distributed on Qualtrics in which the data was collected and managed, then

exported to SPSS version 28 for analysis (IBM Corp, 2017). To be included in the final analysis, HCP had to report if they were currently working as a HCP and provide sufficient information by completing the knowledge and awareness items. Continuous variables were summarised as frequencies, means with their standard deviation, medians and interquartile range. Categorical variables were displayed as frequencies and percentages.

The responses from the open-ended questions were exported to NVivo (QSR International Pty Ltd, 2020) for analyse using reflexive thematic analysis methods (Braun & Clarke, 2022). Two researchers [SP, HW] independently familiarised themselves with participants' responses to the open-ended questions and generated initial codes (Terry & Hayfield, 2020). After coding was completed, the codes were reviewed to identify overarching themes with a shared meaning, these codes were reviewed by three members of the research team [JTCW, HW, SP]. Any disagreements were discussed by the entire research team.

Results

A total of 123 participants responded to the invitation to complete the survey. Nineteen of those respondents who did not complete the survey were excluded from the analysis. An additional eight participants were excluded because they did not report being employed in a healthcare profession. The final sample consisted of 96 participants (mean age = 47).

Most respondents were either allied health workers ($n = 25$, 26.0%) or psychologists ($n = 25$, 26.0%). The other professions were nurses ($n = 15$, 15.6%), specialist physicians ($n = 13$, 13.5%), general practitioners ($n = 5$, 5.2%) and midwives ($n = 1$, 1.0%; Table 1). Examples of allied health workers include occupational therapist and speech language therapist. The remaining participants reported working in the "other" category, which included roles such as support worker and behaviour specialist.

Most participants were female (83.3%), identified as NZ European (70.8%), were from urban areas (60.4%), and worked in the sector for five years or more (81.3%), with 57.3% reporting working in the health sector for 11 years or more. Most healthcare workers worked in community healthcare (35.4%) or hospitals (33.3%; Table 1).

Knowledge and awareness of FASD

Nearly all participants were aware of FASD before the survey (99.0%). Most participants learned about FASD

through professional training and education (74.0%), education sessions (50.5%) and colleagues (41.7%). Other means of learning about FASD included their own research, social media, and emails via social networks. Just under 60% of participants believed they had a good understanding of FASD and its effects in general or specifically relating to their role, and 40% believed they had a basic understanding (Table 1).

Participants were given a list of characteristics and asked to identify three features of FASD required to be diagnosed with FASD (central nervous system abnormality, neurological impairments, and exposure

Table 1. Demographics and characteristics of participants in survey.

Demographic variables	N (%)
Gender	
Female	80 (83.3)
Male	16 (16.7)
Ethnicity (participants could provide multiple responses)	
NZ European	68 (70.8)
Māori	7 (7.3)
Samoaan	2 (2.1)
Indian	3 (3.1)
Chinese	2 (2.1)
Other	23 (24.0)
Rural or urban setting	
Urban	58 (60.4)
Rural	6 (6.3)
Both	31 (32.2)
Prefer not to say	1 (1.0)
Role within health sector	
Allied health professional	25 (26.0)
Psychologist	25 (26.0)
Nurse	15 (15.6)
Physician	13 (13.5)
General Practitioner	5 (5.2)
Midwife	1 (1.0)
Other	12 (12.5)
Work setting (participants could provide multiple responses)	
Community healthcare	34 (35.4)
Hospital	32 (33.3)
Mental health services	20 (20.8)
Private practice or clinic	14 (14.6)
Community drug and alcohol services	11 (11.5)
General practice	5 (5.2)
Māori services	4 (4.2)
Family planning/sexual health clinic	1 (1.0)
Pacific services	1 (1.0)
Other (e.g., physical health services, family planning and maternal health)	25 (26.0)
Years employed in health sector	
Less than 1 year	2 (2.1)
1–2 years	6 (6.3)
3–4 years	10 (10.4)
5–10 years	23 (24.0)
11–20 years	27 (28.1)
21–30 years	20 (20.8)
30 or more years	8 (8.3)

Table 2. Participants knowledge and practice with FASD.

Knowledge or practice question	N (%)
Self-reported knowledge and understanding	
Aware of FASD but don't know what effect it has	2 (2.1)
Basic understanding of FASD and its effects in general	37 (38.5)
Good understanding of FASD and its effects in general	23 (24.0)
Good understanding of FASD and its effects specifically relating to my role in the health sector	33 (34.4)
Features required for FASD diagnosis (participants could choose three)	
Exposure to alcohol during pregnancy	91 (94.8)
Neurological impairment across multiple domains	79 (82.3)
Central nervous system abnormality or dysfunction	47 (49.0)
Distinctive facial features	36 (37.5)
Growth restrictions	14 (14.6)
Low IQ	10 (10.4)
Exposure to alcohol during breastfeeding	0 (0)
Prevalence FASD in NZ	
1 in 10,000 people affected	18 (18.8)
1 in 1,000 people affected	24 (25.0)
1 in 100 people affected	23 (24.0)
1 in 50 people affected	17 (17.7)
1 in 20 people affected	6 (6.3)
1 in 10 people affected	1 (1.0)
1 in 5 people affected	0 (0)
How common individuals with FASD experience drug and alcohol dependence	
1 in 10,000 people affected	4 (4.2)
1 in 1,000 people affected	10 (10.4)
1 in 100 people affected	15 (15.6)
1 in 50 people affected	13 (13.5)
1 in 20 people affected	15 (15.6)
1 in 10 people affected	19 (19.8)
1 in 5 people affected	13 (13.5)
FASD relevance to work	
Highly irrelevant	20 (20.8)
Irrelevant	0 (0)
Neither relevant nor irrelevant	4 (4.2)
Relevant	21 (21.9)
Highly relevant	44 (45.8)
If change care for someone with FASD	
Yes	76 (79.2)
No	13 (13.5)
Had experience diagnosing FASD	
Yes	32 (33.3)
No	59 (61.5)
Had a client with FASD	
Yes, patient/client diagnosed with FASD	52 (54.2)
Yes, patient/client suspected of having FASD	20 (20.8)
No, but I suspected a patient/client of having FASD	7 (7.3)
No, I have not had a patient/client with FASD	12 (12.5)
FASD or any other neurological or neurodevelopmental disorder (e.g., TBI, autism) training in the last five years (participants could select multiple answers)	
No	26 (27.1)
Don't Know	0 (0)
Yes, FASD related training	49 (51.0)
Yes, other neurological or neurodevelopmental disorders	34 (35.4)
Prepared to support individual with FASD	
Not at all prepared	6 (6.3)
Somewhat prepared	26 (27.1)
Neither prepared or unprepared	15 (15.6)
Moderately prepared	30 (31.3)
Very prepared	8 (8.3)
Prepared to support Māori individual with FASD	
Not at all prepared	12 (12.5)
Somewhat prepared	24 (25.0)
Neither prepared or unprepared	18 (18.8)
Moderately prepared	22 (22.9)
Very prepared	9 (9.4)

to alcohol during pregnancy (Cook et al., 2016; Table 2). Most participants identified that exposure to alcohol during pregnancy (94.8%) and neurological impairment across multiple domains are required to be diagnosed with FASD (82.3%; Table 2). Just under half (49.0%) of participants identified central nervous system abnormality.

Respondents were asked to estimate how common FASD is in NZ. The Ministry of Health (MoH) estimated FASD ranges from 3-5% (Ministry of Health, 2022), alongside Romeo et al. (2023) estimation of 1-2.7%, therefore we accepted 1 in 50 (2%) and 1 in 20 (5%) to be correct answers. Only 24% of participants correctly estimated the prevalence of FASD in NZ (Table 2). A significant proportion of participants (25%) believed FASD prevalence to be 1 in 1,000 people (0.1% prevalence). A similar proportion of participants (24%) believed FASD prevalence to be 1 in 100 (1% prevalence). In addition, participants estimated that the prevalence of FASD in people involved with drug and alcohol dependence was higher than in the general population (Table 2).

Attitudes and beliefs towards FASD

In true-false statements, we asked participants to report on the domains that could be affected by FASD. Most participants correctly identified that FASD can affect a person's learning and memory (96.9%), ability to communicate (93.8%), ability to plan ahead (91.7%), and

ability to control their emotions (89.6%; Figure 1). Relatively fewer respondents felt that FASD can affect a person's ability to feel remorse or regret their words and actions (71.9%).

Most participants correctly stated that people with FASD have permanent brain damage (84.4%; Figure 2) and correctly rejected that people can grow out of FASD (92.7%). Moreover, most participants believed diagnosis of FASD may lead to the child or their family being stigmatised (70.8%). When asked about disability services, 37.5% of respondents believed that a diagnosis of FASD would enable an individual to access disability support services, whereas 44.8% of participants reported this statement as false (Figure 2).

Experiences and practices with FASD

Just under half of participants (45.8%) believed that FASD is relevant to their work in the healthcare system and 21.9% believed it was not relevant, while 20.8% of participants stated that FASD is highly irrelevant to their work (Table 2). In addition, less than half of participants felt moderately prepared or very prepared to support someone with FASD if they were assigned to their care (39.6%). The remaining participants were somewhat prepared or neither prepared/unprepared (41.7%) or not at all prepared (6.3%; Table 2).

Participants were then asked if they would change their delivery of care if they were supporting a patient

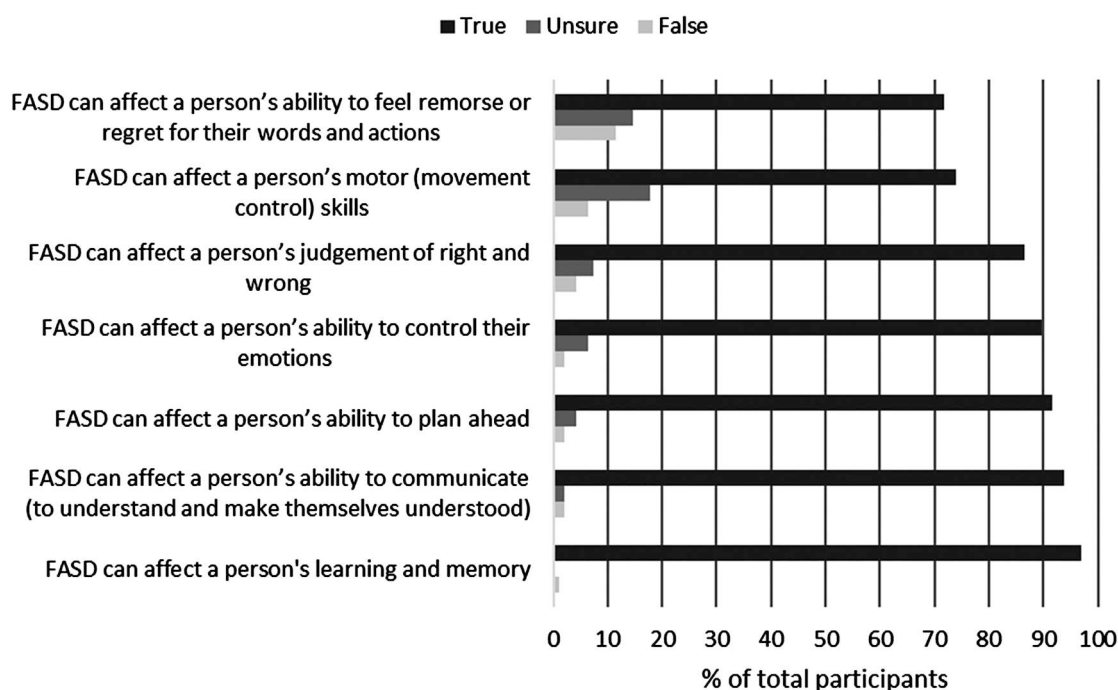


Figure 1. Percentage of participants endorsing the domain as affected by FASD.

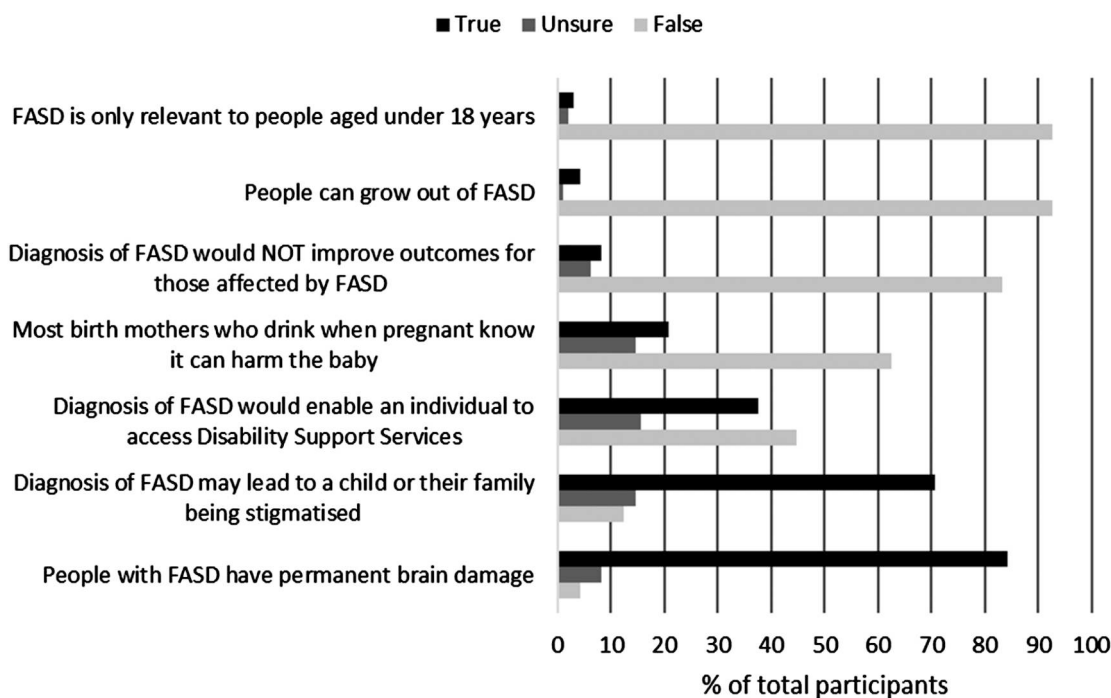


Figure 2. Percentage of participants endorsing statements around attitudes and beliefs towards FASD.

with FASD. The majority (79.2%) of participants reported they would change their care if they were supporting someone known to have FASD (Table 2). Of those who would change their delivery care, several changes were reported. A common theme that emerged was tailored interventions based on need; many participants recognised that they would need to change their approach to care to cater to specific strengths and weaknesses of patients with FASD. For example, many participants would change their communication style. One respondent explained that “information would be simplified and delivered in small increments and I would be checking their understanding of what I have said” (Psychologist). Participants also described that their care of someone with FASD would be “informed by their neurological profile of strengths and struggles” (Psychologist). Additionally, a few respondents expressed that they would incorporate visual aids as a form of communication. A respondent noted that “many have visual strengths and retain words when scaffolded with images” (Paediatrician) and another explained they would “use art therapy” (Alcohol and drug counsellor). Another common theme was the need for multidisciplinary teams and cross-sectoral approaches to care. One participant reported that adults in schools must learn to handle a child with FASD with developed interventions and others expressed the need to connect with other involved professionals to support the patient.

A few respondents (13.5%) reported they would not change their care; when asked to explain their answers participants often cited a lack of capacity and resources as a contributing factor. A nurse explains “If there were value added to getting a diagnosis, I would be more invested, however, at present our service does not provide any further treatment for people diagnosed with FASD” (Nurse).

Some participants (33.3%) have diagnosed a patient with FASD or been part of a team that diagnosed a client with FASD. Over half (54.2%) of participants have had a patient diagnosed with FASD and one-fifth (20.8%) of participants have had a patient suspected of having FASD. In other words, over 70% of the participants have come across a patient or client with FASD at work.

We asked what support was provided for the patients with FASD or suspected FASD. Many respondents stated their patients were provided referral to other existing services. For example, patients were provided with a Needs Assessment and Service Coordination (NASC) referral, social worker support, resources from Oranga Tamariki (government organisation responsible for care of vulnerable children), individual therapy or diagnostic assessment of FASD. However, several respondents expressed that there was a lack of support for FASD and support could only be provided from different diagnoses. One respondent explained that their patient did not have “support available from

NASC until he was diagnosed with ID [intellectual disability] also” (Physiotherapist). Another respondent said, “very limited additional support – difficult to get neuro-psychological assessment and a six month wait time for this” (Nurse).

Education and training related to FASD

Half (51.0%) of the participants received FASD-related training and around one-third (35.4%) received training for other neurological or neurodevelopmental disorders in the last five years (Table 2). Most received FASD-related training from professional training through the form of webinars and workshops (26%). A few participants also received training from Canadian resources (e.g., Asante Centre) or Australian resources (e.g., The University of Western Australia). Moreover, 27.1% of participants did not receive any training in FASD or neurodevelopmental disorder in the last five years.

Information on FASD was self-directed with some participants carrying out their own research with online resources and reading (11%). The most commonly referenced NZ resource that supported the participants with patient care was Fetal Alcohol Spectrum Disorder Care Action Network (FASD-CAN), which is a non-profit organisation that educates about FASD and provides support for individuals with FASD. Additionally, we asked what diagnostic guidelines or criteria were used to diagnose FASD. The most common diagnostic guideline was Canadian guidelines (18.8%), followed by Australian guidelines (7.3%) and DSM-5 diagnostic guidelines (7.3%).

When asked which resources would be helpful for their work, most participants reported online resources (75.0%), FASD-informed interventions and strategies (74.0%) and information for families and caregivers (72.9%) would be helpful resources. Other important resources included protocols to support people with FASD (64.6%), written material about FASD (63.5%) and training workshops (60.4%).

When asked what specific information would help prepare work with people with FASD, participants expressed the need for clear referral pathways and services available. One participant wanted “a list of support services, who families could talk to, grief counsellors, disability sector on board with providing supports” (Nurse). Other respondents agreed for the need of specific services but included the need for a unified approach for services for FASD across NZ, as one participant wanted “specific services available to support so we are not working in such an isolated way” (Psychologist). Many participants wanted professional

training support to understand symptoms and diagnosis of FASD. Specifically, one respondent explained “I would like to receive specific training that would allow me to diagnose children and youth with FASD as part of my role at the hospital where I am employed” (Psychologist).

Participants further explained what support they needed to work with Māori (Indigenous people of NZ) patients with FASD. Many participants wanted support for culturally tailored interventions and information (23%). One participant explained “I feel like really clear consideration of Māori values when working alongside Māori people with FASD and their whānau would be useful for me and my SLT [Speech Language Therapist] colleagues. Like something that prompts us to ensure we’re considering things like whanaungatanga [relationship] and rangatiratanga [autonomy to make decisions] as part of our practice” (Speech Language Therapist). A few participants were more specific by wanting support in learning Te Reo (Māori language), using Māori health models (e.g., Te Whare Tapa Wha and Te Wheke) and working with whānau (family). Several participants also expressed the need to have more Māori practitioners to be involved with providing care to Māori patients: “All Māori clients are better served when Māori staff are involved in their care. I would try to work with the whānau and Māori liaison team and Māori colleagues, to be guided in my work with these clients” (Midwife).

Finally, participants explained the potential challenges they face when caring for people with FASD. One prominent theme among participants was the limited or inefficient services (47%). One participant explained that there is “very limited staffing/support for staff willing to provide FASD assessments” (Psychologist). Along with lack of services for FASD diagnosis, participants also reported a lack of long-term pathways of support and limited services for families. Moreover, participants highlighted the lack of funding as the main issue stemming from inadequate services. Another important theme was the under-recognition and lack of knowledge of FASD among HCP. For example, one participant explained “staff members not aware of their presentation and challenges in learning, expecting too much from the clients – this sets up the client for failure” (Occupational therapist). Other respondents echoed similar thoughts and explained that FASD can be an invisible disability and thus professionals and the community interpret issues with FASD as behavioural issues that need to be changed rather than symptoms of brain impairment.

Interestingly, two participants reported that some professionals do not believe in FASD; a participant

stated “I lead the team in regard to knowledge of FASD. However, this DHB (District Health Board) does not have a service or recognise it in the paediatric disability service. Many doctors do not believe it is real and call it a Bullshit label to be used as a catch all that do not fit real diagnoses” (Psychologist).

Discussion

This study explored the knowledge, attitudes and practices of HCP towards FASD in NZ. HCP who participated in this study had gaps in knowledge and inaccurate beliefs about FASD, consistent with international studies (McCormack et al., 2022). While most HCP in this study self-reported good understanding of FASD, only around 40% felt moderately to well prepared to support someone with FASD in our healthcare system.

While NZ does not currently have clear diagnostic guidelines for FASD, the MoH specifies a diagnosis of FASD is evidenced by PAE and impairment in at least three domains (Ministry of Health, 2022; Te Whatu, 2023). Most participants identified that FASD could cause neurological effects in multiple domains including communication, memory and ability to plan ahead. However, more than one third of participants believed distinctive facial features are required for a person to be diagnosed with FASD, but in reality less than 10% of individuals with FASD exhibit distinctive facial features (Andrew, 2010). This misconception is problematic as it could result in delayed diagnosis of FASD and subsequent support. Only one-fifth of participants correctly estimated the prevalence of FASD (3-5% as per MoH), with the remaining participants underestimating the prevalence of FASD. Previous studies have found similar results; a UK study of 250 healthcare professionals found that only 22% of participants correctly estimated the prevalence of FASD in the general population (Howlett et al., 2019). Therefore, misunderstanding diagnosis and prevalence of FASD may result in FASD being undiagnosed in NZ.

HCP who participated in this study identified that there were major barriers to attaining a formal diagnosis including high costs, long waitlists and few practices in NZ that offer services to diagnose FASD. Currently, only four centres across NZ exist that can diagnosis FASD and there are substantial wait times to accessing a diagnosis (Health Promotion Agency, 2015). Moreover, FASD is not recognised as a funded disability in NZ and therefore an FASD diagnosis alone does not warrant disability support funding (Human Rights Commission, 2021). Many participants corroborated this by stating that those with intellectual disabilities

(IQ < 70) or other disorders (e.g., ASD) are only able to receive disability support. Therefore, only individuals with FASD and a low level of intellectual ability can receive disability support, which excludes many people with FASD, as only around one-third of those with FASD exhibit an IQ of less than 70 (O’Leary et al., 2013). Despite, some individuals with FASD likely to benefit from ongoing support provide by HCP to protect against adverse life outcomes (Streissguth et al., 2004).

FASD is also a highly stigmatised disability (Corrigan et al., 2017) and when this stigma stems from HCP it can lead to delays in diagnosis and negative experiences (Corrigan et al., 2019; Wilson et al., 2024). Most respondents in this survey believed that diagnosis of FASD would lead to stigma with some reporting that professionals may judge birth mothers. Also, some participants believed that birth mothers were aware of the consequences of PAE. Therefore, some HCP hold beliefs about birth mothers that may contribute to stigma. Stigma can create barriers such as parent disclosure of PAE (Bell et al., 2016), delayed recognition of FASD, failure to understand the consequences of PAE, and subsequent behaviours and inadequate treatment and support being offered (Corrigan et al., 2019). It is worth noting that a small number of participants raised concerns around individuals working in the health sector not recognising FASD as a real disability. This may be due to NZ lack of diagnostic guidelines and recognition of FASD as a funded disability shaping HCP’s attitudes. On the other hand, holding stigmatising beliefs and misconceptions about FASD could contribute to this belief (Choate & Badry, 2019).

A lack of training and professional support contributes to HCP feeling unprepared to support someone with FASD. Many participants felt that there was a lack of support to prepare them to support individuals with FASD. Only half of professionals received FASD-related training. Additionally, most participants felt that FASD training, clear professional boundaries, referral pathways and multidisciplinary teams would be important in supporting someone with FASD. These findings are largely consistent with other KAP studies looking at FASD where FASD-informed training is perceived as helpful (McCormack et al., 2022). The lack of professionals training impedes effective prevention, diagnosis and management of FASD, which is already hindered by a lack of NZ diagnostic guidelines and professionals who are trained to diagnose FASD (Gibbs & Sherwood, 2017). Some participants recognised the importance of culturally appropriate training and knowledge, highlighting the importance of developing HCP cultural competency to meet diverse needs.

Compared to other surveys, a relatively high proportion (51%) of participants in our study had received FASD training. In other NZ surveys, only 45% of educators (Chu et al., 2022) and 35% of social and community workers (McCormack et al., 2023) in NZ reported having received training on FASD or any neurodevelopmental disability (Wouldes, 2009). Similarly, a UK study of HCP found previous FASD training ranged from 20–55%, with the highest rates of FASD training reported in paediatricians (Howlett et al., 2019). However, the high proportion of participants reporting FASD training may reflect the sampling methods and self-selection of those with existing FASD knowledge and training rather than FASD education in professional training.

HCP in NZ are working within a system that does not recognise or provide sufficient support (FASD-CAN, n.d.; Human Rights Commission, 2021) for FASD, which makes supporting individuals with FASD in healthcare systems difficult. Several HCP in this study reported that NZ current system lacks cohesion, referral pathways and easy ways to provide support for people affected by FASD. Consequently, there are several barriers within the healthcare system that can contribute to poor quality of care for people with FASD and may contribute to professionals feeling unprepared to support people with FASD (Wilson et al., 2024). Half of the respondents work with FASD patients or with a team involved with FASD diagnoses, but only 45.8% of participants felt that FASD is highly relevant to their work. This may reflect the under recognition of FASD as a significant public health issue and the lack of government actions to address FASD in NZ. Given that over half of HCP in this survey have had a patient with FASD and 70% had interacted with FASD in their workplace, it is critical to provide adequate support to those with FASD, especially as early intervention is key to health and well being (Streissguth et al., 2004). It is vital to recognise FASD as a funded disability in NZ and provide support and resources for individuals affected by FASD and HCP who care for patients with FASD (Streissguth et al., 2004).

Our study is one of the few studies that provides detailed KAP, experiences and opinions of FASD of HCP in NZ that are at the forefront of prevention, diagnosis, support and care of FASD. The KAP survey was adapted from previous KAP surveys of FASD (Chu et al., 2022; Chu et al., 2024; McCormack et al., 2023) and adapted to be used in the HCP context, to enable the KAP to be compared across professional groups. This research has several limitations. Despite using several different recruitment methods, we were only able to recruit 96 HCP, which limits the generalisability of

results. Likewise, HCP is a diverse field with several professions, therefore, this survey may not reflect the KAP of all professions but those who are represented in this survey. Most participants who complete this survey were female, consistent with other KAP surveys in educators (Chu et al., 2022) and social sectors (McCormack et al., 2023) in NZ. Also, due to the small sample size we were unable to compare across professional groups. Respondents self-selected to complete the survey; therefore, participants may already be more FASD-informed or interested in FASD than other HCP. However, recruitment through advocacy networks and other channels was undertaken to reach a diverse sample. Therefore, future research should seek to explore the knowledge, attitudes and practices of all professions towards FASD and explore differences between those who report being FASD informed and those who do not.

Conclusion

Lack of awareness and knowledge of FASD among healthcare professionals can prevent effective and equitable prevention and management of FASD. Evidently, there are gaps in knowledge and misconceptions of FASD that may result from a lack of professional training, support and government recognition and funding of FASD. Therefore, it is crucial for healthcare professionals to receive professional training and development, and government recognition and funding to support people living with FASD to improve the quality of care and outcomes for people living with FASD.

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