Barriers to accessing assisted reproduction for diverse and minority groups in Aotearoa New Zealand: Findings from a qualitative study

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ABSTRACT

INTRODUCTION: There is now an extensive body of international research on fertility help-seeking. While this body of work has historically centred the experiences of dominant ethnicities and heterosexual and cisgender couples and families, our study attends to the experiences of individuals and couples from diverse and minority groups in Aotearoa New Zealand, for which, to date, there is little research. In the article, we report delays and disparities accessing assisted reproduction for these groups to advocate for fertility care based on reproductive justice.

METHODS: The article draws on semi-structured interviews and talanoa from a qualitative study conducted during 2020 and 2021 with 39 Māori, Pākehā, and Pacific people residing in Aotearoa New Zealand who have experienced fertility issues for social or medical reasons and have sought reproductive assistance, using a range of procedures and treatments, to create families.

FINDINGS: To better understand the reproductive journeys of people from these groups we report the challenges identified by study participants in the process of decision-making around accessing assisted reproduction and fertility treatment help-seeking. Importantly, we document a range of situational and structural fertility barriers that point to stratified reproduction relating to affordability, delays and long wait times for resources and services, discrimination, and non-inclusive care.

CONCLUSION: To address these issues, we recommend improvement to fertility treatment services and delivery that is culturally accessible, responsive, and equitable. This entails attending to the structural constraints that prevent people from accessing and obtaining the resources needed to realise their family building goals.

KEYWORDS: Aotearoa New Zealand; assisted reproduction; fertility barriers; qualitative research; structural infertility

AOTEAROA NEW ZEALAND SOCIAL WORK *35(4)*, 102–111.

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There is now an extensive body of international research on the use and uptake of assisted reproductive technologies (ART) in the social sciences. Much of this research has centred on high- and middle-income nations in the Global North such as the USA,

United Kingdom, and parts of Europe (Shaw, 2022), and continues to focus predominantly on low fertility and ART access for heterosexual and cisgender couples and individuals (Tam, 2021). Unlike these studies, the focus of our project is on the fertility

experiences of people from diverse and minority groups in Aotearoa New Zealand, stories that have been largely missing in the international literature. To address this gap—particularly in relation to the paucity of global research documenting Indigenous and ethnic minorities' experiences of infertility (Inhorn, 2020)—we contribute to burgeoning research in the local context with diverse and minority groups who have accessed assisted reproduction for the purpose of family building (see Foaese, 2017; Glover et al., 2007; Glover et al., 2009; Melville, 2016; Reynolds & Smith, 2012; Surtees, 2022). Our discussion includes a comparative overview of data from a qualitative study with samesex couples, single people, older people, and Māori and Pacific peoples—individuals and groups who have historically experienced compromised or denied access to assisted reproduction. As our approach draws on a reproductive justice framework, briefly outlined below, the article concludes with recommendations for policy and practice. The recommendations build on discussion initiated in the "Expert views of assisted reproduction" study undertaken by the first author, which includes interviews with social work and psychology trained fertility clinic counsellors (Te Herenga Waka-Victoria University Human Ethics Committee approval 0000024373).

Literature

Reproductive justice calls for an analysis of the economic, regulatory and sociocultural constraints on people's reproductive choices, enabling advocates "to make connections between the forces that shape [people's] opportunities, the conditions that affect [their] decisions, and the societal impact of the availability and use of certain technologies and practices" (Galpern, 2007, p. 5). To present our findings, we utilise a reproductive justice framework to address reproductive health and reproductive rights through the lens of structural infertility. Our approach highlights the importance of culturally competent and safe information about fertility treatment and services, the

question of affordability and equity of access to reproductive services, and the ways people navigate the tensions between individual autonomy and socio-cultural norms relating to decision-making around family building and assisted reproduction.

Accordingly, we posit that compromised access to fertility treatment and ART renders participants in our study socially infertile under current policy, law, and practice. As Shaw (2022) defined it, social infertility is "an outcome of life chances and circumstances", encompassing a range of situational fertility barriers (Johnson et al., 2014) over and above factors such as delayed childbearing due to educational attainment and career success (Boddington & Didham, 2009). So, even where people experience medical infertility, they may also experience social infertility because their access to assisted reproduction is denied or compromised by structural, ideological, regulatory, and biological factors and constraints.

It is important to note that the term *social infertility* is often used in opposition to medical infertility by Aotearoa New Zealand fertility clinic websites and specialists (Fertility Associates, 2023a; Gillett, 2017). Drawing on the World Health Organisation classic clinical definition (WHO, n.d.), medical infertility is diagnosed as the inability to conceive after one year of unprotected sexual intercourse, or the inability to carry a live pregnancy to term. Social infertility, by contrast, is popularly conceptualised as a voluntary fertility outcome; thereby signalling a person's relationship status as single and/or their gender and sexuality as LGBTQ as a lifestyle choice or a personal preference. Defining medical infertility according to the WHO definition implicitly frames it as a planned event that affects cisgender women and heterosexual couples, potentially ignoring the experiences of cisgender men and LGBTQ people who form single- or multiparent families outside the two-parent norm. In addition to being single or in a

same-sex or gender diverse relationship, a person may be socially infertile due to financial insecurity, labour market precarity or unequal gender distribution of housework and childcare, which leads to low fertility rates and delayed childbearing. In this rendering, social infertility, which is impacted by age-related factors, is structural and not a choice (Shaw, 2022).

The concept of structural infertility, initially coined by Briggs (2018), takes us beyond the limitations of the medical-social binary. Building on Colen's (1995) notion of "stratified reproduction", which refers to obstacles hindering access to reproductive health, we use structural infertility to show how the interlocking effects of class, ethnicity, gender, generation, language, religion, and sexuality shape people's reproductive decision-making along stratified lines. This approach shows how the fertility issues and experiences of people in our study are structured by social and cultural constraints that limit or restrict their reproductive choices, thereby preventing them from accessing and obtaining the resources needed to realise their family building goals.

Method and ethics

The perspectives we present in this article are from 39 in-depth, semi-structured interviews of 45 to 120 minutes conducted in-person or via Zoom during 2020 to 2021. To ensure community safety and cultural sensitivity, our research approach followed the ethical guidelines outlined by the Pūtaiora Writing Group in Te Ara Tika (Hudson et al., 2010). This includes a combination of western ethical principles (consent, beneficence, non-maleficence and justice) alongside key elements of the Te Ara Tika framework: paying specific attention to whakapapa (building relationships and engagement between researchers and the community), tika (ensuring Māori participation, good research design and outcomes), manaakitanga (culturally safe behaviour, social responsibility and respect for persons),

and mana (equity and distributive justice, including ownership of data and consent and reciprocity with Māori). Our research team includes members who identify as Māori, Pacific. Pākehā. and Tauiwi.

Because talking with people about infertility is a sensitive topic, one that is not openly discussed in Māori or Pacific communities, we were aware of the challenges around participant recruitment. To invite potential interviewees to participate in the study we used a variety of recruitment methods: social media platforms, university websites, a fertility consumer website, snowballing sampling, and word-of-mouth. Prior to recruitment, the team elected to interview participants from groups and communities with whom we had proximal identification. The focus on different cohorts in the study was therefore based on agreement about each of the researchers' personal and sociocultural familiarity with specific groups and their positionality with respect to data collection (Bourke, 2014). We surmised that facilitating recruitment, cultural safety, rapport, and relationship-building with participants in these respective cohorts would assist inclusiveness. At the same time, because people's identities are fluid and relational it was important to recognise class, ethnicity, gender, language, religion, sexuality, and other categories of difference as inherently interconnected when representing participants' experiences accessing ART. The comparative aspect of the study meant that, within each of the cohort groups, participants occupy multiple intersecting identities. So, while the research team was sensitive to their own insider/outsider status from the perspective of study participants, we were also open to kōwhiringa (options) about who participants were comfortable talking with. Pacific participants were interviewed by the second author, who identifies as the team's Pacific researcher, but there were times when lesbian, bisexual, queer and Māori participants were interviewed by team members who identified as heterosexual, Pākehā and Pacific.

All participants were over 18 years of age, living in Aotearoa, and had attempted to create a family using a fertility service provider or assisted reproduction via donor insemination at home. Participants were spread throughout Aotearoa, with the majority located in major cities in the North and South Islands. Participants signed consent forms and completed a short demographic survey prior to their interview. Three interviews were conducted with participants who self-identified as Māori, 27 with Pākehā, and nine interviews, which employed a talanoa research method (Vaioleti, 2006) were conducted with Pacific participants. Some study participants identified multiple ethnicities. In this discussion, we refer to our participants' ethnicities as Māori, Pākehā, and Pacific, as this is the lens most interviewees prioritised when reflecting on their fertility experiences in our conversations with them. A total of 20 cisgender women participants identified as single mothers, two participants identified as cisgender men, and 10 participants identified as lesbian, bisexual, or queer. Participants' ages ranged from 33 to 59 at the time of interview, excluding one participant who was 28 years. Thirty-seven participants consulted a fertility clinic or GP (general practitioner/primary care physician) about fertility concerns at some point during their journey (ranging from one to over 30 visits); the remaining two participants did not consult a clinic.

The interview guide was designed to explore participants' views and experiences of their reproductive journeys, meanings around family and whānau, the significance of genetics for family-building, perceptions of fertility clinics, barriers to accessing treatment and suggestions for support and change when seeking assisted reproduction. Once the audio-recorded interviews were transcribed, they were sent to participants who requested them for checking. The data were then manually coded line-by-line from the transcripts and sorted into codes based on areas of relevance to the research questions and patterns across

the interviews. The lead researcher and a research assistant discussed the relationship between these areas to identify candidate themes and subthemes. They then met to discuss and finalise the themes presented in this article (Braun & Clarke, 2013). In the article, we report aggregated findings relative to three overarching themes that represent key barriers presenting challenges for participants' decision-making and access to fertility treatment: cost, time, and non-inclusiveness. The study received institutional research ethics approval from Te Herenga Waka-Victoria University of Wellington (0000027702) and Auckland University of Technology (19/266 2019).

Study findings

Cost

Ability to pay has been identified in the international literature as one of the key barriers influencing the uptake of fertility treatment and ART (Connolly et al., 2010; Peterson, 2005). In Aotearoa New Zealand all three providers of fertility services (Fertility Associates, Fertility Plus, Repromed) offer private and publicly funded treatment. At the time of writing, Repromed advertises the cost of one in vitro fertilisation (IVF) cycle between NZ\$11,500 and NZ\$17,000, excluding genetic screening tests and donor treatment (egg, embryo, sperm) costs, and the cost of one cycle of intrauterine insemination (IUI) as approximately NZ\$2235 excluding donor sperm (2023).

Cost was frequently noted as a significant impediment for our participants, including for 17 interviewees who had an annual income over NZ\$100,000. One participant explained how they had to choose between accessing private fertility services and saving to buy a house, another mentioned having to use their redundancy pay-out, and one single mother re-mortgaged her house to afford treatment. Several single mothers mentioned that they were financially supported by family to assist with treatment costs, and others drew on savings they had

set aside from established careers. Four Pacific participants (all of whom noted a higher average income on their demographic form than the general Pacific population) commented that it took months and years to save and secure the necessary funds, with one participant noting: "Even my first consultation was like \$200 something dollars. It is expensive for a half-hour consultation." Participants also commented on the hidden costs of fertility treatment such as blood tests, sperm health supplements, preconception tablets, ovulation test kits, donor testing costs, costs of travel to and from the clinic, and time away from work.

While Aotearoa New Zealand offers publicly funded fertility treatment, many of our participants were ineligible due to not meeting Clinical Priority Assessment Criteria (CPAC) (Fertility Associates, 2023b). The criteria for public funding are strict and based on medical infertility. Patients must score 65 or more assessment points to be eligible for placement on the waiting list. The main barriers to public funding our participants discussed included not meeting Body Mass Index (BMI) >35 at first specialist consultation or >32 to receive treatment, age 39 years or younger for women (55 years for men at referral) (Te Whatu Ora, 2023), and lack of evidence trying to get pregnant.

None of the single mothers accessed public funding as they did not easily meet the CPAC. For single mothers and same-sex couples, the most difficult criterion to meet, aside from age, was being able to prove to fertility providers that they had been trying to get pregnant. Proof consists of evidence of 12 cycles of donor insemination, with six treatments at a certified Aotearoa New Zealand clinic, before being considered for funding.

Participants recalled costs for one cycle of IUI at around \$1500 to \$2000 and IVF between NZ\$11,000 and NZ\$15,000 at the time of procedure. Virtually all participants accessing clinic services needed more than

one cycle of treatment, with several requiring a combination of IUI, ICSI (intracytoplasmic sperm injection), and IVF. All had to fund these services privately. One participant noted the cost of an ECART application for embryo transfer, plus additional counselling and legal fees, in excess of NZ\$6000.

Three single mothers used overseas gamete donors they paid for. One, who accessed treatment in the United States, was able to access private health insurance to assist with costs. For another, the Medicare rebate system in Australia was used to reduce costs. The significance of cost is summed up by a single mother, who commented that investment is more than money, saying: "I've invested so much into this, and said 'no' to relationships and jobs and all of this, so do I just stop and finish with nothing, or give it one last shot?"

Time

Although ART reconfigure how to, when and who can constitute and create a family, temporal limits imposed in Aotearoa New Zealand around age impact access to public funding for fertility treatment as well as the success rate of various treatments (e.g., IVF success for women decreases after the age of 35 (Repromed, 2023a)). Participants drew implicitly on biological clock imagery to describe their reproductive time as "running out". The imposition of external delays such as long wait times for consultations and clinic appointments with wait lists of up to two years for IVF, as well as difficulties finding gamete donors, were therefore negatively connotated in participants' accounts. Clinic wait times for donor testing and consultation were an added stressor. Due to their relationship status, single mothers and same-sex couples in the study had to undergo the process of finding sperm donors. Many of the single parents spoke about their difficulty finding a partner to have children with, explaining how the expectation to have children added pressure on dating and contributed to their reasons for undergoing fertility journeys

alone. One single mother commented, "I can meet a partner anytime but I'm actually running out of time to have a child."

Ten heterosexual, lesbian, and queer-identified participants had pre-existing agreements with relatives, friends, acquaintances, or people they met online who were willing to donate their gametes. Donor insemination at home was not always successful, and some participants turned to clinic-based pathways for assistance. Several participants with known donors used a fertility service provider from the outset. Most participants mentioned long wait times for gamete donors as a barrier. This was significant for participants who sought identity-release clinic donors where age-related fertility decline was a key concern. As reported by MacManus (2017), participants confirmed that the wait time for enrolling and receiving donor sperm was between 1 to 2 years in many cases; although the Fertility Associates website now estimates wait times between 2.5 to 3 years (Fertility Associates, 2023c).

One participant advised starting the journey early if one is single and another said to go on a sperm waiting list by age 34 as waiting times for donors and appointments delay timelines. Some participants noted that the wait time for IVF donors was shorter than the wait time for IUI due to a minimum sperm count needed for IVF success. Those participants who chose to undergo at-home insemination, including participants who had previously sought clinic treatment, endeavoured to avoid costs and wait times for fertility services. Two participants explicitly wanted to create family by side-stepping the clinic and regulatory context. One participant reflected in the following quote: "I wanted to create a whānau with zero state involvement, I didn't want legalities, I didn't want lawyers, I didn't want the state to have any control in how a family looked."

Non-inclusiveness

In addition to anxieties and concerns around wait times impacting diminishing fertility windows, participants commented on the lack of culturally competent and safe fertility treatment in their interactions with administrative staff and healthcare professionals at clinics they attended. Most participants relayed stories about barriers to fertility services that included non-inclusive care, voicing accounts of discrimination they faced on their journey, in the clinic and regarding cultural, social, and professional attitudes. Pejorative comments in relation to age, weight, and sexuality were commonly cited. For example, ageist discourse was described by a participant who faced judgement from friends for having a child later in life. A couple of participants commented on their experiences of polycystic ovarian syndrome, impacting their ability to manage their weight. These, and other participants, spoke of the fatphobic remarks they faced from fertility clinic staff. A Māori participant recalled her GP saying: "Oh, well, it's not hard to lose weight you know, if you just cut out carbs", commenting that the GP regarded weight as the cause of her infertility and losing it as the solution.

Several same-sex couples noted the noninclusive language used by clinics (e.g., assuming gender without asking) and the general discomfort they faced when accessing services and interacting with clinicians. Most participants touched on the cultural stigma of IVF and infertility, with two participants noting how they had to keep their journey a secret in the workplace. Some participants spoke about having to exercise self-advocacy with service providers and seek wider community support when they did face discrimination. Pacific participants who were affiliated with a Christian church commented on resistance from church leaders who did not approve nor agree about the use of 'science' to create a child.

Many of the single-mother participants spoke of facing discrimination for undergoing the fertility journey alone. Microaggression and insults came from workplaces, fertility clinic staff and health professionals, and public discourse. One single mother explicitly chose

not to tell their work about the journey, and one mentioned how their co-workers assumed they had been 'knocked up'. One shared how a Plunket nurse had questioned her financial stability due to her single status, and another felt constantly discouraged by the clinic, being told by a nurse they were too old and that they were potentially taking someone else's 'spot' by trying. Another single mother found the antenatal clinic was uninformed about diverse family formations and assumed that all children had two parents. The antenatal clinic also provided misleading information, according to this participant, who filed a complaint. One single mother felt a sense of judgement from others for undergoing IVF and noted that people kept asking about the ethnicity of their child (as they had used an international donor). Two single mother participants noted how cis-heterosexual men are often praised for having children at an older age (e.g., well-known celebrities), yet the same praise is not given to women who have children later in life. A participant, who was over 50 years of age at the time of donorconceived conception, commented:

Some people told me that ... I'll be an older mother and ... I'll be dead before this child gets married, you know, that kind of thing. So, there's quite a lot of, anti-having a child at an older age, that people were quite vocal about.

Most participants commented on the importance of having a strong support network on their fertility journey and were selective about who they confided in as they were aware of how some external views were detrimental to the journey. Many mentioned the lack of support services and follow-up care during clinic treatment and at its conclusion, with some referring to silence around miscarriage and early pregnancy loss as an example (Shaw, 2020), as well as difficulties establishing ongoing contact with clinic-based identity release donors.

Pacific participants shared misunderstandings they received from their families and communities regarding fertility challenges, particularly around sex. For example, almost all encountered assumptions that consummating a marriage and having heterosexual intercourse will result in a pregnancy. One participant reflected on being told to have sex often to increase the chance of conceiving, remarking: "Our people need to be open to addressing infertility in a supportive way instead of just assuming that we pop out kids when we can or after sex. It doesn't work like that."

Discussion

A recent quantitative study concluded that "compared to overseas assessment, NZ fertility care is shown to be patient-centred" (Mourad et al., 2019, p. 271). Accounts from participants in our research confirm positive, patient-centred interactions with fertility counsellors in the local context. We have not presented these findings here. In this article, we focus specifically on a range of barriers impacting access to fertility treatment services in Aotearoa.

One of the most significant issues participants emphasised was the importance of cultural awareness and competency training for fertility clinic staff and GPs, including work on personal skills such as sensitivity and active listening. Several lesbian, bisexual, and queer participants proposed mandatory gender and diversity education for clinic staff as one avenue to achieving this. A few participants said that advocacy and awareness of infertility and social infertility would promote wider social acceptance of diverse forms of family.

Some participants cited informational barriers and suggested improvements to fertility service provision involving diverse language and ethnic representation on clinic websites. Several Aotearoa New Zealand fertility clinics employ doctors who speak Mandarin and Hindi. However, currently only one clinic, Repromed, employs a Māori fertility counsellor. Fertility Associates, which has clinics across the country, is the only provider to employ a Māori fertility

specialist. While each clinic website references commitment to Māori cultural and traditional practices, and two clinics include a link to a Te Reo (Māori language) page, at the time of writing there is no information on these websites in any Pacific language (although there are links to pages in simplified Chinese and French).

Some participants commented on the austere aesthetic of the fertility clinic space and its design and décor as uninviting, uncomfortable, or too 'Pākehā'. While fertility clinic spaces are carefully designed to ensure privacy and discretion between patients and staff, our data indicate a need to 'colour in white walls' of the clinic to ensure people accessing these services feel welcomed and safe.

Several interviewees raised concerns around the lack of inclusive signage and the use of outdated terminology on clinic forms, an issue also raised by transgender and non-binary people accessing fertility preservation services in Aotearoa New Zealand (Ker et al., 2022). While some fertility clinics provide useful website glossaries of key treatment-related terms for patients, low fertility knowledge, health literacy and lack of cultural safety suggest these terms may have little meaning for those who do not speak English fluently or are uncomfortable with highly medicalised and clinical language.

Accordingly, participants commented that healthcare providers and policymakers need to consider how culture and ethnicity shape attitudes toward in/fertility to provide quality information, counselling, and procedures that are responsive to the concerns of diverse and minority groups. Given the success other projects have found by both making information accessible and appropriate and providing information leaflets in translated content (see Culley & Hudson, 2009), culture- and languageconcordant care could assist to increase access to fertility treatment for the diverse communities in our study. Several Pacific participants also suggested that fertility

clinics, GPs, counsellors, and religious leaders work together to ensure communities are provided with the information they need to make informed decisions around fertility treatment options.

Most participants were asked about the limits around public funding for fertility treatment services. Five single parents agreed that the age limit for public funding was too low and should be raised to above 40 years, with one participant suggesting 47 or 48 years. One single parent commented that society is shifting to older age of marriage and children, so funding eligibility criteria should shift to accommodate this. Participants also suggested that low-cost clinics, like those in Australia, be set up to accommodate the needs of LGBTQ people, single parents, and those from lower socioeconomic backgrounds.

A key issue for many participants was spuriousness around producing proof of donor insemination for access to public funding. While single parents and same-sex couples must prove they have been trying to get pregnant for a year, GPs and clinics assume that heterosexual couples have done so if they claim this is the case. Our participants questioned this double standard.

While some participants were wary of regulating personal or private sperm donation, one participant supported a centralised system with donor information, including a database to record online sperm donors matched with women who had used at home insemination to ensure open disclosure for donor-conceived persons. Donor-linking recognises the importance of whakapapa connections for Māori, as legislated in the Human Assisted Reproductive Technology (HART) Act of 2004 (Daniels & Douglass, 2008) and aligns with international literature in sociology and social work acknowledging donative acts as relational decisions that not only implicate those immediately involved (donors, intended parents, donor-conceived offspring), but also donors' own families and

social networks (Blyth, 1999; Nordqvist & Gilman, 2022).

Along with the eight Pacific women participants, two Pākehā and one Māori participant criticised the BMI limit, saying it was arbitrary and lacked evidential basis. They commented on the BMI requirements being too low, adding that this was inequitable for Māori and Pacific peoples who do not meet those requirements easily (see Parker & Le Grice, 2022; Shaw & Fehoko, 2023).

All study participants voiced that their reproductive journeys were difficult. While the ability to pay was universally cited as an impediment to accessing treatment, it was not the only barrier. Participants called on policy makers and fertility providers to produce and disseminate culturally appropriate awareness-raising information about fertility treatment, increase efforts to reduce lengthy wait times for consultations and access to donor gametes, improve donor disclosure processes, fund and provide access to counselling services during and after treatment, rethink public funding eligibility criteria, particularly around BMI, and provide mandatory education and training for health professionals working in the field to create non-discriminatory and inclusive care relating to service delivery.

Concluding comment

While trends relating to fertility rates in high income countries like Aotearoa New Zealand have been attributed to delayed childbearing for reasons to do with educational attainment, career success, and lifestyle decisions, the accounts of participants in our study show that involuntary childlessness and access to ART are not simply a product of personal choice. Rather, the reproductive self-determination of participants must be understood more broadly, in relation to structural constraints that prevent people from accessing and obtaining the resources needed to realise their family-building goals. The allyship and contribution of social work

and counselling professionals who provide advice, information, and services to those seeking fertility treatment and assisted reproduction is key if we are to address these inequities and advocate fertility care based on the principles of a reproductive justice framework.

Acknowledgements

The authors would like to thank the study participants and ART experts for generously sharing their experiences and views, Danielle Webb (Ngāpuhi) and Shalomy Sathiyaraj for their research assistance on various aspects of the project, and the Royal Society New Zealand Marsden Fund and Te Herenga Waka–Victoria University of Wellington for supporting the research.

Declaration of interest statement

The authors declare that there is no conflict of interest.

Received: 17 February 2023

Accepted: 5 June 2023

Published: 18 December 2023

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