

Exploring Epistemic Injustice Through Feminist Social Work Research

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Abstract

This article explores women's experiences of assisted reproduction (AR) and epistemic injustice. Using feminist theory and qualitative data from a social work research project, I argue that the dominant discourse in AR is partial and inadequate and that these epistemological oversights are not accidental; the oversights are actively maintained to preserve power relationships and this constitutes epistemic injustice. Yet women are not completely silenced; elements of resistance and attempts to restore epistemic agency are also presented. The need for an epistemologically inclusive approach to AR and epistemic justice through social work research is reinforced.

Keywords

assisted reproduction, epistemic injustice, feminist social work, feminist research

Introduction

In this article, I use Fricker's (2007) concept of epistemic injustice to explore qualitative data from a feminist social work research project. Epistemic injustice occurs when the value of a marginalized group or individual's knowledge is diminished by a more powerful group or individual resulting in a partial knowledge base (Fricker, 2007, 2008). I argue that the dominance of the biomedical discourse in assisted reproduction (AR) often results in service users' experiential knowledge being devalued constituting epistemic injustice. Qualitative data are used to explore some women's experiences of epistemic injustice, in particular, the injustices experienced through processes of testimonial quietening and testimonial smothering (Dotson, 2011). In addition, data that indicate participants' resistance and efforts to reclaim epistemic agency are explored. Further, I argue, social work research has the potential to "study the negative space of epistemic injustice" in order to explore "the positive space of epistemic justice" and enhance the knowledge base in this (and other) service delivery context(s) (Fricker, 2008, p. 71).

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Context of the Research and Background Literature

There has been sustained interest in reproductive technologies since the birth of the world's first "IVF baby" in the United Kingdom in 1978 (Bell, 2006). Internationally, the provision of reproductive technology services is "big business" characterized by high profits and lucrative growth in an increasingly "globalized bioeconomy" (Gupta, 2012, p. 25). It is underpinned by powerful, commercial interests with significant growth in private equity investment in biotechnology, with staff and shareholder registers dominated by medical practitioners (Gupta, 2012; Winston, 2007; Zoll, 2013). The medical, social, ethical, and legal possibilities and potential of the technology have been the focus of much academic and general discussion. Yet despite the procreative possibilities and collective concerns relating to AR's societal impact, the dominant paradigm remains traditional, conservative, biomedical, and individualistic.

There has been sustained feminist critique since the 1980s (e.g., Corea, 1988; Greer, 1988; Klein, 1989; Rapp, 1988; Rowland, 1988), through the 1990s (e.g., Ginsburg & Rapp, 1995; Greer, 1999; Klawiter, 1990; Rapp, 1999; Shildrick, 1997) and into the 21st century (e.g., Gaard, 2010; Inhorn, 2003; Rapp, 2001, 2004; Thompson, 2005) and yet women's experiential knowledge of AR typically remains marginalized and conventional biomedicine continues to dominate.

The conventional biomedical model underpins all aspects of AR, from practices enacted at the level of direct service delivery through to regulation, evaluation, and knowledge production. Within this model, the epistemic practices of conventional Western biomedical science effectively marginalize women as "patients" and their epistemic agency is largely unrecognized (Bell, 2012a). The lack of recognition of experiential knowledge creates a "science of banal dispossession" (Fine, 2012, p. 4). This constitutes a form of epistemic injustice (Fricker, 2007; Mason, 2011; Tuana, 2004, 2006) in that gendered patterns of oppression are reproduced.

The qualitative data in this research project indicate that most participants encountered epistemic injustice during their experience of AR. However, even when epistemic injustice is pervasive, it is important to recognize that often, a nondominant, experiential knowledge base is possessed by the marginalized group. This knowledge base testifies to the resilience and resourcefulness of the women involved and constitutes a form of resistance to the dominant epistemology in the context of AR. Social work research has potential to explore epistemic injustice and advocate for epistemic justice.

The women who participated in this research project provide evidence of a nondominant epistemology in a number of ways; the very act of volunteering to participate in a qualitative research interview is evidence of a desire to share experiential knowledge. As part of the research interview, I asked all of the women involved in this research project what had motivated them to volunteer to participate in the research and various reasons were offered and are elsewhere discussed in detail (Bell, 2013). Major motivations included that participation offered an opportunity to share knowledge of AR, an opportunity to potentially help others, and importantly, the opportunity to be heard and for knowledge to be validated by me, as a researcher as an interested third party. In addition to participation as a form of resistance, women's accounts of their experiences describe epistemic injustice in AR, especially in relation to objectification, gaps in service delivery, and service providers' responses when attempts were made to assert agency and to disrupt the dominant biomedical paradigm.

Before exploring the qualitative data, in order to contextualize the information, the following brief description of the research project is offered.

The Research Project

As part of my doctoral research project into the experiences and support needs of nonmetropolitan women in relation to AR, 28 women from regional Australia volunteered to participate in an in-

depth, qualitative interview about their experiences of AR. My research was undertaken with the approval of the University's Ethics in Human Research Committee. One woman chose to be interviewed at her workplace; the rest chose their own home. Interview duration ranged from 60 to 90 minutes. Each interview was digitally recorded and later transcribed. Thematic coding of each transcript was undertaken, and each participant received a written summary of all participants' responses and offered opportunities to contact me for follow-up comment. Most of the women became aware of the research after seeing an advertisement in their local newspaper. Interviews were conducted using a semistructured interview schedule. They were audiorecorded and later transcribed to facilitate thematic analysis using a phenomenological, grounded theory approach.

It is worth noting at this point that there was an early indicator of the level of epistemological injustice in that I asked several AR clinics to display a notice about the research in their waiting rooms; none of the clinics were willing to do so and they were indeed reluctant to be involved in any way in seeking to gain knowledge from women's experiences of AR. At best, this could be construed as disinterest and at worst, as deliberate, active avoidance of knowledge from outside the dominant paradigm (Bell, 2009).

The focus of this article is on women's testimonies in relation to the impacts of the predominantly biomedical approach to AR and the epistemic injustices this dominance creates. Based on women's accounts of their experiences, examples of how epistemic injustice impacts on women will be explored along with examples of testimonial quietening and testimonial smothering (Dotson, 2011).

Participants' Descriptions of Epistemic Injustice

Many participants spoke about the adequacy of information they received in the preparatory phase before active service use, with most participants indicating that the level of technical, medical, and procedural information was generally adequate. The following comments illustrate that preparation and access to technical information, while important, are not sufficient to prepare women for the actual experience of AR:

It really felt like the clinic only gave you the medical point of view and the medical side of it . . . The doctor isn't a very empathic bloke, it is just, you know, pretty business-like . . . It was not nice to think that that was what you had to do to get a baby when it wasn't supposed to be like that . . . He is very good at what he does; he probably can't afford to get emotionally involved.

It is not just a physical procedure. It is very emotional, you know . . . I think there is a real difference in that. They set you up on the medical side, they set you up for what to expect physically . . . but they don't tell you it's normal to cry for two weeks out of four for some people, for some people it might be four weeks out of four or it might be for a day. They don't explain that part of the process and I think it's important. I am sure it is . . . It wasn't just a scientific, biological process; there was more feeling to it than that.

I think for a lot of people it is very clinical. Clinic is the word. It is a science and that is, I guess, the best way of saying it. It is science and that is it . . . Yes, there is not a lot of humanity in it I guess. You have to find that for yourself and that could make or break some people . . . It is very invasive.

These comments illustrate how the dominant approach in AR service delivery is biomedical, technical, and inadequate to account for the full nature of these women's experiences. These women describe their experience of AR as a major social and emotional experience in their lives. They express frustration that service delivery often seems to avoid addressing the full context of AR.

The following comments indicate experiences of dehumanization in service delivery experienced at some clinics and the marginalization of these women as epistemic agents in their own right, as well as some more positive, humane approaches to AR service delivery:

You were a number on a list . . . at the [metropolitan] clinic we were a number. Even in the waiting room you were called by a number not a name. Whereas here [another clinic] . . . They were interested in us as people, not patients . . . we weren't just another statistic . . . They were genuinely interested in the issues that we were having and working together, working for us to try and find solutions and not just pushing us aside.

. . . it didn't feel like a clinic when you walked in, you didn't feel like you were going into a laboratory . . . it was really quite warm and inviting so that made a big difference.

Thus, most recommendations for improved service delivery center on quality of care, respect, client-centeredness, and humane treatment. For some participants in nonmetropolitan areas, often the only accessible clinic operated as a "satellite" clinic whereby there is no full-time, dedicated AR clinic. These satellite clinics typically operate once every 3 months or so with medical specialists from metropolitan clinics visiting to provide the AR services on a "fly-in/fly-out" basis. This model of service delivery necessitates the synchronization of women's menstrual cycles in the lead-up to each active clinic. Thus, in a small regional center, there might be 20–30 women who have been medicated in order to synchronize their menstrual cycles to coincide with the next visit by AR service providers. For many women, this added to feelings of dehumanization and depersonalization:

. . . Like a great big herd of cattle, really. They had to synchronise everybody to the same day because the clinic only runs for a week every three months. Miss one clinic and you have to wait for another three months . . . They had everyone going like clockwork.

It blew my mind to think there were that many women all doing IVF on the same day . . . There were twenty-odd women being done so he [the doctor] was probably thinking "just another cow in the procession."

Synchronised cycles bothered me but you just do that to work towards it—it is one of the many evils for hopefully the long-term benefit.

These comments along with the agricultural imagery further illustrate the inadequacies of the dominant biomedical approach in that these women felt they had been "processed." And while clinic staff may have predominantly approached each individual "patient" as a singular object for their attention, the women's comments indicate their collective concerns about systemic neglect and dehumanization. While the satellite model of service delivery might be the only way to deliver AR options to isolated communities, simple measures could be undertaken to reduce feelings of dehumanization. For example, the 3-month cycle of biomedical service delivery could be seen as an opportunity to offer additional psychosocial support measures, including groups, in the time between each "active" clinic.

Other comments relating to the presence of observers during AR procedures also underline the epistemic injustice and ethical breaches involved in some AR service delivery. For example, some women spoke of a lack of consultation and informed consent in relation to the presence of observers. This raises serious ethical questions, even within a dominant framework where "patients" are cast as passive objects of attention.

There were three or four other people in there [observing AR procedures] . . . I thought there would be the doctor and one other person but yeah, there were quite a few people in there and it wasn't a huge room and with four or five people in there, like they all introduced themselves and said why they were there . . . Well I just sort of figured they've got to be here. There was nothing I could do about it; I just had to bear with it.

. . . There is always a crowd, so you lose your dignity, lose your privacy, you just look at the screen and think of something else.

It was almost an out-of-body experience, where I couldn't let myself get too involved . . . I was too busy trying to handle the uncomfortable-ness of it all . . . He just said "hop up on the table we are going to give you this injection" that was about all . . . he didn't talk much at all . . . We hadn't met him before so we didn't know his name.

One doctor came in while I was getting my eggs taken and he was just standing there talking and talking about doing the procedure to the others. I don't know this doctor. The door was open. I just think it was very unprofessional . . . it was very uncomfortable for me, just the whole feeling of getting the eggs taken it was quite painful. I just thought there should be a sheet over my legs.

There was a cast of thousands in there with me with my legs in stirrups and the spotlight on my privates and I was just totally unprepared for that . . . Then I had, without my consent, which really irked me, I had the other gynaecologist pop in and see how things were going. I wasn't even his patient, he was no-one to me. I had to figure out who he was after the event . . . He didn't introduce himself . . . He was probably thinking "just another cow in the procession" . . . I was quite offended . . . I didn't feel comfortable saying anything . . .

This series of comments is particularly disturbing due to the lack of regard shown to these women by the healthcare practitioners. That anyone seeking the services of a health professional is treated in this way is unacceptable. Ethical practice should involve genuine respect for service users and not a violation of basic human rights to privacy and dignity. Yet all too often for the participants, AR service delivery is enacted with scant regard for women as epistemic agents with valuable experiential knowledge, whose health concerns are multidimensional and complex. The dominant epistemology precludes equal, meaningful exchange between service provider and service user; there is little reciprocity within this paradigm and a "pernicious ignorance" that effectively marginalizes and silences the women, treating them as objects to be observed and manipulated (Dotson, 2011, p. 241). Indeed, one participant with a professional background in the hospitality industry assessed the medical profession's performance in relation to service delivery in AR in the following way:

I had never had anything to do with the hospital system before this . . . and I am absolutely flabbergasted that it operates so . . . Having been in the hospitality industry for so long and being so tuned into other people and what their needs are, I am amazed that the medical profession is not tuned into who people are.

One participant described how along with her psychosocial needs, how her basic physical needs were neglected as well:

We were in our gowns, sitting there, you know, it is quite cold in there and we were all saying 'gosh it's cold in here' and we were not offered a warm blanket . . . We were nervous, we didn't know what to expect really. You could feel tension with all the couples sitting in there and you would be wheeled in, in the wheelchair and you could see some of the ladies crying and some not . . . I don't know you just expect when you are wheeled in maybe a hand on your shoulder saying 'it is OK, this is what we're going to do'. I didn't feel it was explained very well . . . We had to sit for half an hour and then go and get changed and off we went . . . I was pretty much an emotional mess and my husband was trying to calm me down. I was in a lot of pain and not even the coordinator or the nurse came to see me, they could see I wasn't joking. They just stuck a [sanitary] pad on the wheelchair—'sit down on that, off you go'. I just felt that, you know, and those gowns are open all the way down the back . . .

The systemic nature of epistemic injustice described in these comments is clear. The biomedical approach by virtue of its ontological foundations in disembodiment, at times results in the unacceptable treatment of women as objects. However, another participant described a more positive, less-

objectified experience of an egg-retrieval procedure; an experience that affirmed her individual humanity as well as the social context of her service use:

A fill-in doctor did an egg retrieval for me once and when I came out he actually drew where all the eggs came from and the sizes, like he'd done these little circles and diagrams and everything and on the bottom of the note he drew a happy, smiley face and wrote 'good luck!'. And I thought, for me, that's great.

Experiences of Testimonial Quietening

Testimonial quietening occurs when there is a failure, usually by the dominant group, to respond to or to validate testimony from a marginalized group. Such quietening can also be the result of the dominant group responding to but undervaluing or failing to recognize and respect the credibility of the marginalized group's knowledge. As such, testimonial quietening is "an active practice of unknowing" (Dotson, 2011, p. 243).

One participant recounted a particularly powerful experience of testimonial quietening. This woman had requested a specific procedure whereby ova and sperm are placed in the woman's uterus, where hopefully conception will occur, rather than conception occurring *in vitro* prior to transfer to the uterus. She described her strong spiritual beliefs that conception should only occur inside her body and she had requested that only gamete intrafallopian transfer (GIFT) or artificial insemination be used. However, this woman felt that her doctor was more interested in using *in vitro* fertilization (IVF) and that he was unenthusiastic about GIFT, disrespectful and disinterested in her preferences:

The doctor basically told me that it wasn't his problem and that I was the biggest moral dilemma he's come across . . . He wasn't interested in where I was at or how I was feeling . . . He basically told me that it wasn't worth the worry or time . . . 'You're going to have the procedure or you're not', which is fairly blunt . . . Every time I tried to bring it up again there was a kind of a roll-the-eyes . . . you know—"we're actually here for this and not that kind of thing". But they're important parts of who I am.

This participant described her overall experience of AR in negative terms and largely attributed this to her reluctance to accept "treatment" passively and to her continued efforts to advocate for herself according to her spiritual beliefs. She believed that her feistiness and persistence in directly debating these issues with the doctor meant that she became a "difficult patient" and her whole experience of service use at this clinic was thereafter defined in this way and her views and needs were not recognizable as legitimate.

The "difficult" patient poses challenges within the biomedical approach and this woman's experience also highlights the inflexibility of the medicalized approach to conception, her ontological exclusion, abuse of power, and the refusal to respect the transactional aspects of assisted conception. This is a clear example of "active unknowing" with a validated knower (the doctor) failing to respect the credibility of the marginalized knower (Dotson, 2011). This "unknowing" reinforces the epistemological disadvantage of the woman and she is assigned as an illegitimate agent in this scenario. The doctor's threat to withhold AR services is a clear indication of power and the level of control in this scenario, as well as his active efforts to erase this woman's agency.

Another participant described her dissatisfaction and disempowerment during AR service use and how as an act of resistance to being cast as an "unknower," she had decided to provide feedback to her clinic on the clinic's own evaluation questionnaire. The evaluation form included an option for "further contact" or "no further contact" in relation to the information provided by service users on the form. She opted for no further contact, but this was breached when the clinic doctor telephoned her to engage in a rebuttal of the comments and complaints about the clinic's service contained in her evaluation:

I was quite embarrassed that he was quoting things that I had said at a very delicate time of my life . . . and if I had known he was going to phone I might not have said the things I said, so he really turned me away from ever going back.

This woman experienced the consequences of resisting her “place” as a passive object within the dominant paradigm in that the doctor was actively attempting to “quieten” her testimony and to put back in her place. Her participation in this research project could thus be seen as a further act of resistance to the dominant epistemological frame—an act of amplification and validation of her testimony. The medical doctor in this instance is clearly operating from the position of epistemic advantage afforded to him by the conventional biomedical approach (Code, 1993) and his telephone call to this woman could be regarded as an aggressive ethical breach, designed to silence the wayward testimony.

Other disturbing examples of epistemological injustice via systemic testimonial quietening can be found in some participants’ descriptions of experiences of ovarian hyperstimulation syndrome (OHSS). OHSS is a very serious adverse outcome of the ovarian hyperstimulation regime necessary for most assisted conception procedures. It occurs when ovaries have been overstimulated and can cause fluid accumulation in the abdomen, gastrointestinal symptoms, respiratory distress, pain, and the risk of thromboembolism, as well as disrupted cardiac, renal, liver function (Australian Reproductive Technologies Review Committee [ARTRC], 2006). It can be life threatening. OHSS was experienced to some degree by several women (14% of participants) and all of these women had used the same satellite clinic in a regional town. They reported remarkably similar experiences of OHSS. They were all told to go home and manage this potentially very serious complication themselves or else it was carefully managed within the clinic, and hospital admission was actively avoided. One woman was so badly affected that she had to take 2 weeks leave from work:

The clinic nurse coordinator basically told me to go home and rest, to only get up to go to the toilet, otherwise bed rest. She said that way it will resolve itself . . . She rang every day and asked “you are not nauseous, you are not vomiting?” Just double-checking that I knew how serious it was, which really didn’t do much to alleviate my discomfort . . . My ovaries would feel like rockmelons I was carrying around.

Another woman was also sent home to manage by drinking lots of water and resting. She told -

. . . I could end up in hospital on a drip and that kind of stuff and then . . . we went home and my husband didn’t work for three days and I spent all that time in bed and he was force feeding me water . . . The nurse would ring each day and see how I was.

These descriptions of “in-house” management OHSS highlight issues raised by many authors and regulating bodies (e.g., ARTRC, 2006; Wang, Sullivan, Healy, & Black, 2008, p. 51) on the probable underreporting of undesirable outcomes such as OHSS. In the absence of a hospital admission for OHSS or other AR-related complications, there is no mechanism in place for recording such incidents and outcomes and the official data remain incomplete representations of many women’s actual experiences of the technology. Surely this seriously undermines the evidence base of Australia’s data collection and annual reporting system (the Australia and New Zealand Assisted Reproduction Database [ANZARD]) and its stated purpose to provide evidence for the improvement in the quality of service provision. And surely this is epistemic injustice on a systematic level. The gaps in knowledge left by such epistemic neglect undermine the completeness and complexity of scientific knowledge in this regard. What purpose is served by this epistemic neglect? This systematic failure to recognize and record events is certainly at odds with “good science” (Haraway, 2004).

There is clearly a need for further systematic investigation of such experiences to explore, *inter alia*, whether such responses are characteristic of certain satellite clinics or satellite clinics in general or whether there is a broader pattern across the whole sector in relation to serious adverse outcomes like OHSS. There is a wider political significance arising from this epistemic gap in that the status quo in AR in terms of broader social and governmental support is maintained if adverse outcomes are minimized and if the total costs of reproductive technology are not accurately recorded, perhaps questions about the efficacy of the technology and funding support will likewise be smothered. This demonstrates how epistemic injustice operates in multidimensional ways, impacting on day-to-day interactions between service users and service providers, through to macro levels of policy, funding, and regulation of AR.

Testimonial Smothering

Testimonial smothering is a practice generally undertaken by marginalized groups in order to “edit” and curtail communication to increase the likelihood that some of what is being said will be “heard” by the dominant group. Smothering is more likely to occur if the marginalized group believes that the dominant group lacks the testimonial competence to accurately appreciate the content. Also if the marginalized group perceive content as too risky, unsafe or different from what is seen to be acceptable to the dominant group, testimony is also likely to be smothered resulting in coerced silence. Smothering or self-editing can also be the result of cumulative micro invalidations, micro aggression, and micro insults experienced by a marginalized group (Dotson, 2011).

Several participants recounted experiences of testimonial smothering, whereby they had curtailed communicating on certain issues with AR service providers due to the perceived inadequacy of providers, operating within the biomedical paradigm, to hear their testimony. For example, one woman spoke of being surprised that there was not more assessment of her psychosocial and general health issues (such as relationships, employment, and nutrition) prior to commencing AR service use:

I thought—they just don’t know people . . . At no time did anyone ask how our marriage was . . . nowhere along the line did they check that . . . no-one asks what is going on in their life, they never asked me what I did . . . So that surprised me when they said ‘just go back and do what you normally do’ when they never asked what I normally do! . . . The medical world has always kept itself aloof from what is going on in heads and what people eat . . . Nature is bigger than all of us.

Everyone’s concentrating on the science of it all, on the medical aspect of it all whereas support needs probably just get overlooked.

Even when service provision included access to psychosocial support and/or professional counseling, many women felt they needed to smother and to self-silence (Dotson, 2011, p. 245) their testimony in order to be “good patients” and to continue service use. For example:

We had to go and see a counsellor and it was just nerve wracking . . . I felt like it was going to be her say whether we were able to continue . . . and it felt like an interview if you know what I mean. I kept thinking ‘say the right thing, say the right thing’ instead of being able to discuss how I really felt . . . It wasn’t comfortable and relaxed . . . you felt like you had to pass. That is how it felt—pressure . . . You don’t want her to fail you . . . She was a really nice lady, she would have been a nice person to talk to and say look I’m just not sure how I’m going to cope but you just go no, I think I’ll be fine . . . They have got to be the right answers that is how it felt . . . I don’t think it was helpful . . . She would have her little clipboard and be

writing down things and it was almost like an exam, it was horrible in that situation I was just keeping myself from really talking to her.

These testimonies represent how exchanges can be curtailed when a marginalized group feels it is unsafe to engage in open disclosure—a form of coerced silence (Dotson, 2011). There is a certain power involved in these acts of curtailment, in that the women here describe their “editing” process and their self-determination in choosing what to disclose and what to withhold from the service provider. However, the silencing of women as a marginalized group operating within the dominant epistemological framework of biomedicine, regardless of whether the silencing is self-induced or enacted by others, serves the same ends; it reinforces the overall lack of epistemic power and maintains marginalization. But while these practices maintain gaps in the dominant epistemology of AR, the women’s testimonies also constitute evidence of a “non-dominant discourses” and can offer alternative interpretations of AR (Mason, 2011, p. 301).

Nondominant Epistemology

As evidenced by the participants’ testimonies, marginalized groups do indeed often resist dominant paradigms and epistemic injustice to offer “non-dominant interpretive resources” (Mason, 2011, p. 295). Just because a dominant paradigm ignores or actively erases some forms of knowledge, the marginalized group’s epistemic agency can survive, even if it is not validated within the dominant frame of reference. Survival occurs in the groups women form, in online networks, in research interviews and other contexts where stories can be shared. Powerful groups can limit the transmission of this knowledge by virtue of their “claim to interpretive authority;” however, nondominant groups can maintain collective knowledge and preserve “non dominant interpretive resources” (Mason, 2011, p. 295). Social work research located in such pockets of resistance has potential to redress epistemic injustice. For instance, during the research interview, I asked each woman what had motivated her to participate in the project. Participants identified the main reasons for participation as to help others, to help themselves to reflect on their experiences, to bring a “private” issue further into the public domain, to provide feedback on service delivery, to connect with other women and, importantly, to be heard—to have their experiential knowledge recorded and legitimated. Reasons for research participation are discussed in more detail in Bell (2013).

The following comments show various other forms of resistance to the dominant paradigm in AR:

The doctor, he said to me ‘it is only going to be like a Pap [cervical] smear . . . I got quite cranky and said well have you ever had a Pap smear?’

I have worked with a lot of specialists and I think it just goes across the board . . . just a little bit too casual about your personal condition, saying things like “huh, I didn’t realise you were such a mess inside” or “if I were a gambling man I’d bet that you wouldn’t get pregnant naturally.” I don’t know, very casual things about something that is so acutely personal to you . . . I was there with my legs up in stirrups with him telling jokes at the other end of me while he is doing the [embryo] transfers and stuff . . . His manner was just very unprofessional.

. . . [the doctor was] horrible . . . no bedside manner . . . I often wonder what he’s even doing helping women because . . . He takes an abrupt manner so that he doesn’t get involved, he doesn’t want to get emotionally involved but he’s very abrupt, probably even rude I think. I used to think “gosh, I hope we don’t see him today” . . . I don’t think he likes women. So I think it is an odd career choice for somebody who is a bit of a chauvinist to be doing the job that could change the life of someone. But . . . he must be good at what he does . . . But I thought “you’re an idiot” because we’re sitting here thinking ‘what a dickhead’.

... treat people with a bit of humanity ...

These comments illustrate the importance of experiential knowledge and each woman's assessment that the practitioner in question lacked the requisite knowledge and professional competence to offer an acceptable level of human service.

Many participants used online support groups and information sites to access other women's experiential knowledge of AR. This can be seen as an effort to offset the epistemological gaps in the dominant form of knowledge presented to them by service providers:

There were a few testimonials [online] and there was actually one person's diary and their day-to-day experience, which was great ... It was actually a real person, it is not medical, it is not clinical.

I would look at a website as opposed to chatting to people online. I would e-mail someone with a question or something ... Being able to e-mail someone with a question is really helpful because it is not so confrontational and it is personal and takes away those barriers sometimes ... Anything to help ascertain what the experience is like ... I think it is an important step in the process, rather than going on what you read and what you get told by the coordinator, to experience ... I think to hear about someone else's experiences would be the link between those two steps, I really think that, yeah.

I found solace in the Internet, not chat rooms but getting into websites devoted to IVF ... You do generally get positive outcomes, you don't very often hear about the ones that don't succeed.

I think I would use it only for information; I still think there's a lot to be said for face-to-face contact with people. I think it's a little bit more personal that way, so for me face-to-face is more valuable than having something online. But if you're ... living in an isolated town somewhere then the Internet is good for the technical side of it but not I think for the support side of it ... or even a phone line, a help line that you can actually talk to someone who has been through it.

The Internet afforded these women with access to a wider range of information, typically experiential knowledge of other women. Their use of online communities enhances the level of exchange within this otherwise marginalized group and enhances a collective, though nondominant hermeneutic resource (Mason, 2011, p. 299).

Redressing Epistemological Injustice in AR

Arguably, the level of epistemic injustice evident in these experiences of AR is an indication of the centrality of human reproduction (and its control) to the maintenance of masculine domination. This could explain why, despite the huge potential for reproductive technology to disrupt traditional kinship ties and modes of family formation, extraordinarily conventional approaches persist and discipline boundaries are so actively defended and maintained. Klawiter (1990, p. 85) says this desire to control reproduction via technology reveals a fundamental misogyny and states that "we cannot give in to the pressure to individualize and technologize" involuntary childlessness and human reproduction.

Indeed, the epistemic injustices described by participants in this research project certainly provide experiential evidence of the distortions and fragmentations that result from a dominant paradigm based on dualism, disembodiment, and individualism (Klawiter, 1990). Arguably, many other health and social service contexts could be said to mirror these patterns of exclusion and marginalization. Epistemic injustice, testimonial quietening, and smothering are evident in the accounts provided. The women's accounts also indicate some strategies for redressing epistemic injustice. For example, at the micro level, women suggest that holistic assessment of health, social, and psychological factors be conducted prior to active AR service use. At the macro level, holistic data collection should include qualitative, phenomenological

information from service users in order to gain a more complete picture of the impacts of AR. This would enhance the level of complexity and completeness of scientific knowledge in the field of AR and importantly, it would go some way toward validating women's experiential knowledge thereby reducing epistemic injustice. Feminist researchers have a responsibility to honor women's testimonies by communicating findings as widely as possible, so as to amplify nondominant knowledge. In my research, this has been achieved to some extent by providing each participant with a written summary of all participants' responses, media interviews about the research findings (with local radio) as well via publication in academic and professional spheres.

However, a more thorough reenvisioning of AR is required to transform approaches to reproductive technology, and the aim should be for substantial rather than superficial change. A paradigm shift from individualism and disembodiment to collectivism and embodiment is central to a postconventional approach (Bell, 2012). Like Gaard (2010, p. 107), my research supports an approach based on reproductive and epistemic justice "where human beings flourish through interdependence." A sustained effort is needed to provide space and validation for women's experiences of AR via feminist social work research as a form of collective resistance to conventional scientific dissociation with complexity and embodiment (Fine, 2012). Without ongoing efforts toward such a transformation, the repression and partiality will be sustained.

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