

In this editorial I consider the social and psychological implications of infertility and in vitro fertilisation (IVF) for nursing and midwifery practice. In doing so I wish to promote both an awareness of the social, emotional and psychological consequences of infertility and IVF for infertile people among clinical nurses and midwives in a range of health settings *and* stimulate a mainstream interest in and a wider critical nursing discourse around infertility and IVF. I also wish to consider the implications of an increased use of IVF to achieve parenthood by same-sex couples, who are of course not infertile per se (although they may have fertility issues) but cannot achieve biological parenthood through their sexual relations.

Infertility affects 9% of those wishing to start a family and is a life-changing event with profound long-lasting emotional consequences (Allan 2007, de Lacey 2002, 2015, Peters 2007, 2008). It is a stigmatised and self-stigmatising condition, which makes disclosure difficult for infertile couples (Letherby 1999) and for same-sex couples who by default cannot have their own biological children through their sexual relations (Patterson et al. 2010).

Over 60,000 cycles of IVF are performed annually in the UK alone (HFEA 2013) and assisted reproductive technologies (ARTs) account for 2% of all live births every year in the UK (HFEA 2013). Unfortunately, only 17,041 IVF cycles result in live births a year, that is a 25.6% positive outcome using a woman's fresh eggs (HFEA 2013). To put it another way, 75% treatment cycles do not result in a live birth. These poor outcomes are increasingly under scrutiny (Kamphius et al. 2014). Infertile people also experience repeated pregnancy loss and repeated experiences of imagined pregnancy loss which is perhaps more difficult to explain to those who conceive naturally (Brian 2011). Any of these experiences may lead to great emotional strain.

The provision of infertility investigations and IVF as a sub-specialism in many health systems, often only available in the private sector (Allan et al. 2009), means there is fragmentation of the patient journey for the infertile person or couples, and a lack of continuity between the infertility, maternity and primary health services.

An increasing number of IVF cycles and IVF births are among fertile single women, older women and same sex couples (Shaw & Giles 2009). Their needs as fertile people are different to heterosexual infertile couples (Wojnar & Katzenmeyer 2014) but they all seek assistance to conceive through IVF and their journey to parenthood is not straightforward. The experiences of lesbians, gay men and same-sex couples are underexplored in the nursing and midwifery literature because of an entrenched and structured heteronormativity across women's health (Peel & Cain 2012). In Wojnar & Katzenmeyer's study of lesbian non-biological mothers, the women found maternity and primary health services particularly challenging. Some staff ignored the lesbian partner altogether or found the co-mother role challenging to their preconceived ideas of biological, heterosexual motherhood. As the authors suggest, 'unlike their heterosexual counterparts, the journeys of lesbians to parenthood comprises several unique steps.' (2014, p. 51).

What all this means is that babies born from IVF and their parents will meet midwives and nurses in primary and maternity health care settings as well as in emergency settings, general medicine and surgery. Yet many of these parents will not share with their nurse or midwife that their babies were conceived as a result of using IVF, that they are infertile and/or that their family is non-traditional. Therefore any health and social needs associated with infertility and parenting after successful IVF may go undetected.

Infertility and any history of assisted conception are important for nursing and midwifery assessments in a range of practice areas: practice and community nurses, health visiting and importantly, the undergraduate curriculum. The need to be attentive to the presence of IVF conception and parenthood, traditional and non-traditional, increases even more once we take account of new developments in science such as epigenetics (Beresford 2014). This is the study of how environmental factors can affect gene activity, and how a person's risk of chronic diseases is "programmed" into them before they are even born. An example of how important epigenetics may become for IVF conceived babies and their parents is described by Massy-Beresford:

*"Much of today's research stems from the Barker hypothesis, which proposes that birth weight may be linked to the likelihood of getting certain diseases. IVF babies are known to have lower average birth weights – even if the difference, at about 20-30 grams, is small. Scientists are now investigating whether IVF conception equates with more hospital admissions, and an increased risk of cardiovascular disease, high blood pressure and diabetes in later life (2014, p.1)*

Three recent events motivated me to write this editorial. None of these events were connected and it was not until the third that I began to consider how I might think about them critically and what the implications were for nursing practice. The first event was an invitation to write an article for Practice Nurse to provide an update on the psychological effects of infertility and suggest practical advice that practice nurses could give patients they meet in primary care. The second was an invitation, this time to the Royal College of General Practitioners, to deliver a lecture to update general practitioners (GPs) on male infertility. I began to see these two events as connected when I read two research reports about management of infertility by practitioners in primary care (Hampton et al. 2014, Payne & van den Akker 2016).

In the Australian study of awareness of infertility and IVF in GPs and primary care nurses, the biggest barriers to fertility-awareness education in general practice were the short consultations and time constraints faced by general practitioners together with a lack of patient educational materials and remuneration to support fertility awareness for patients in the routine delivery of primary health care (Hampton et al. 2014). GPs and primary care nurses felt that a greater use of nurses trained in fertility-awareness in a collaborative team care arrangement with general practitioners would be a positive enabler to improving fertility awareness in primary care.

In a later UK study, an evaluation of infertile people's experiences of primary care, maternity and infertility services in the UK, (Payne & van den Akker 2016) the authors suggest that there is a lack of awareness of, and a lack of continuity for people who are infertile in primary health and that this affects their experience of health care. 26% of those infertile people responding to the INUK survey said that they felt that their GP provided sufficient information about infertility and treatment compared to 70% feeling that their specialist doctor provided help and support. These two reports suggest to me that my two talks might indicate a dawning awareness among primary care practitioners, both nurses and doctors, that infertility is an issue they ought to be familiar with. And of course, the question that I then asked myself was *'why had it taken so long for nurses and midwives to recognise infertility and IVF as a biological and a social condition?'*

I think part of the answer to this lies in the framing of infertility solely as a *biomedical condition* rather than understanding it at the same time as a social condition. The literature on ARTs is dominated by a perception of infertility as a medical condition with psychological consequences (Griel et al. 2010), with infertile couples as infertile 'consumers' of medicine

rather than as social beings outside the clinic (Griel et al. 2010). In a social model, Griel et al. suggest, we begin to conceptualise IVF as a social as well as a biological process which has significant social, bioethical and psychological implications for individuals, for gendered relations in parenthood, for families including siblings and for society in non-donor as well as donor IVF. Opening up the possibility of different motherhoods achieved through assisted conception also offers a loosening of the heteronormativity of motherhood and pregnancy in nursing practice (Peel & Cain 2012). IVF then becomes more than a taken-for-granted technology, a treatment; we can begin to explore the social consequences of the biomedicalisation of conception through IVF and the nurse's role in both supporting couples through these processes and identifying any potential health and social needs which may arise.

A paper by Kamphius et al. (2014) in the British Medical Journal suggests that the medical profession are beginning to question the overuse of IVF and therefore, in some sense, the biomedicalisation of infertility and IVF. Kamphius et al. (2014) criticise the increase in IVF cycles in older women and in patients with unexplained infertility citing poor outcomes for IVF children. They conclude that resources need to be targeted at improving fertility awareness to prevent older women seeking IVF; in other words they recognise the limitations of the biomedical model as a way of understanding infertility although they do not develop a social model of infertility.

IVF and other assisted reproductive interventions are complex technologies, inducing technologically mediated conceptions if successful; yet they are increasingly portrayed as *routine* (Allan et al. 2009). These technologies are common but not necessarily experienced as routine since they touch on one of the most personal and intimate areas of life – family building (Chodorow 1978, Raphael-Leff 1992) and involve a fundamental area of reproduction *normally* kept private.

In many cases, infertile people continue to consider themselves infertile even when they become parents through successful IVF. The social condition of infertility (Khetarpal & Singh 2012, Van den Akker 2012) may lead to stigma where couples are looked down upon and couples may be avoided. Self stigma may also occur as couples withdraw themselves and find it difficult to disclose to others; the combined effects of stigma and self stigma can lead to social isolation and divorce. Nurses may reinforce the biomedicalisation of the condition because the experience of infertility as a stigmatized and self stigmatizing condition ensures that the effects of infertility are hidden and ignored to preserve privacy (Allan & Barber 2005). Nurses may feel it becomes intrusive to further probe into infertile patients' emotional lives when their privacy has been so abused in the IVF treatment. Recognizing how their responses to infertility as a stigmatized condition may themselves increase stigma is one step to encompassing a recognition of the social condition of infertility and IVF into nursing care (Allan 2009).

The stigma associated with a non-traditional family life has long been experienced by same-sex couples historically excluded from parenthood and thus 'normal' family life. This was exacerbated by historical restrictions on adoption and access to IVF for lesbians when there was initially a 'father' requirement. It is still a problem for gay men who need a surrogate. In this sense they are multiply stigmatized. For lesbians, gay men and same sex couples, the dynamic of parenthood after IVF is experienced differently to infertile people. Lesbians, gay men and same-sex couples find IVF an empowering route to parenthood, given biological parenthood is not their default norm. For example, gay men who become fathers via surrogacy reported greater closeness with their families of origin and heightened self-esteem as a result of becoming parents and raising children (Bergman et al. 2010).

Nurses and midwives in maternity services, health visiting, primary care and education must focus on both the effects of biomedicalisation *and* the processes of stigma and stigmatising behaviours towards infertile people as well as self-stigma. The strength of stigma in infertility as a live issue for infertile people is revealed in early findings from a current UK study, Taking part; this is a NIHR funded study by the National Perinatal Epidemiology Unit (<https://www.npeu.ox.ac.uk/taking-part-study>). Taking pART explores the reasons why over 50% of infertile patients undergoing IVF refuse to give consent for their personal data stored by the Human Fertilisation Embryology Authority to be used in future research. Early data analysis suggests couples seek to maintain privacy over the whole IVF experience even requesting that their GPs be given restricted amounts of information in any communication from fertility clinics. As continuity of care is recognised as a significant factor in better outcomes in pregnancy, this patient initiated discontinuity is concerning and worthy of further and wider critical thought, investigation and dissemination to clinical practice. Finally it occurs to me that these data might reveal the structured heteronormativity Peel & Cain (2012) argue is prevalent in women's health research and practice. Given that an increasing number of cycles, people seeking IVF are not infertile but fertile single women or same sex couples, a further complexity to these early findings may be whether in fertile same sex couples or single women, the desire to keep their data private is driven by the stigma of IVF rather than infertility.

Shining a light onto infertility, IVF and same-sex parenthood after IVF reveals complexities, which will be difficult to address in daily nursing practice. Nevertheless, we cannot afford to ignore these complexities as we integrate technology into nursing care if we are to deliver person-centred care.

## References

- Allan HT (2007) Liminality and the experience of infertility: the role of the clinic in creating a liminal space. *Nursing Inquiry* **14**(2), 132-139
- Allan HT (2009) *Managing intimacy and emotions in advanced fertility care: the future of nursing and midwifery roles*. M&K Publishing, London
- Allan HT, De Lacey S & Payne D (2009) The socio-cultural context of assisted reproductive technologies: the shaping of 'routine practices'. *Nursing Inquiry* **16**, 241-250
- Bergman K, Rubio R J, Green R J, Padrón E (2010). Gay men who become fathers via surrogacy: The transition to parenthood. *Journal of GLBT Family Studies*, 6(2), 111-141
- Chodorow N (1978). *The reproduction of mothering: Psychoanalysis and the sociology of gender*. University of California Press, Berkeley, CA
- De Lacey S, Peterson K, McMillan J (2015) Child interests in assisted reproductive technology: how is the welfare principle applied in practice? *Human Reproduction* **30**(3), 616-624
- De Lacey SL & Sandelowski M (2002) The use of a 'disease': infertility as a rhetorical vehicle. In *Infertility around the globe. Thinking on childlessness, gender, and reproductive technologies*. (Inhorn M & van Balen, F eds), University of California Press, Berkeley, CA. pp. 33-51.
- Griel AF, Slausen-Blevins K & McQuillan J (2010) The experience of infertility: a review of recent literature. *Sociology of Health & Illness* **32**(1), 140-162
- Hampton KD, Newton JM, Parker R, Mazza DA (2014) Qualitative study of the barriers and enablers to fertility-awareness education in general practice. *Journal of Advanced Nursing* **72**(7), 1541-1551
- Kamphius EI, Bhattacharya S, Van Der Veen F, Mol BWJ & Templeton A (2014) Are we overusing IVF? *British Medical Journal* **348**(g252), doi:10.1136/bmj.g252.
- Letherby G (1999) Other than mother and mothers as others: The experience of motherhood and non-motherhood in relation to 'infertility' and 'involuntary childlessness'. *Women's Studies International Forum* **22**(3), 359-372
- Massy-Beresford H (2014) What's next for the world's 5 million IVF babies? <https://www.theguardian.com/society/2014/nov/23/whats-next-for-worlds-5-million-ivf-babies>
- Patterson, C. J., & Riskind, R. G. (2010). To be a parent: Issues in family formation among gay and lesbian adults. *Journal of GLBT Family Studies*, 6(3), 326-340.
- Payne K & van den Akker O (2016) Final Report: Infertility Network UK Survey on the Impact of Fertility Problems.
- Peel E & Cain R (2012) 'Silent' Miscarriage and Deafening Heteronormativity: A British Experiential and Critical Feminist Account. In *Understanding Reproductive Loss: perspectives on life, death and fertility*. (Earle, S, Komaromy, K., & Layne, L. eds) Ashgate, Farnham (UK): . pp. 79-92
- Peters K, Jackson D & Rudge T (2007), Failures of Reproduction: Problematizing 'success' in assisted reproductive technology. *Nursing Inquiry* **14**(2), 125 - 131
- Peters K, Jackson D & Rudge T (2008) Research on couples: are feminist approaches useful', *Journal of Advanced Nursing*, **62**(3), 373 - 380.
- Raphael-Leff J (1991) *Psychological processes of childbearing*, Chapman-Hall, London
- Shaw RL & Giles DC (2009) Motherhood on ice? A media framing analysis of older mothers in the UK news. *Psychology & Health* **24**(2), 221-236