

POSTER ABSTRACT

Trans-disciplinary learnings from lived experience: person-centred integrated infertility care.

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Introduction: Infertility is a stigmatising condition with profound psychosocial impacts. It is estimated it affects 48.5 million couples globally (Mascarenhas et al., 2012) and in the UK, one in seven couples have problems conceiving (NHS, 2020). Rates of infertility are increasing in both genders (Sun et al, 2019).

Aims: To explore the lived experience of patients with infertility to identify opportunities for improvements in care and education of healthcare professionals (HCPs), and to investigate the potential of nutrition and lifestyle medicine as an adjunct to care.

Methods: Critical reflections on a trans-disciplinary portfolio of seven publications about infertility authored or co-authored by a researcher with personal experience of infertility. These were published from 2015, and include peer-reviewed research articles, a case report, a textbook, a performance, creative artefacts including poems and a story. All embed patient voice as a fundamental element. The overall methodological framework adopted reflects a multi-lens interpretive, phenomenological, heuristic inquiry informed by a relativist ontology. Synthesis connectivity has been used to analyse the works, this approach is recommended by both Grant (2011) and Smith (2015).

Findings: Three research questions and findings were identified.

1. How to improve care / outcomes?

Explored in publications 1, 2, 3, 4, 6, 7. Findings were optimal nutritional status and weight management supports fertility in both men and women, so nutrition care should be an integral part of care. Additionally, understanding the lived experience of infertility better facilitates effective care/counselling and improves patient experience.

2. How lived experience of infertility can shape clinical education/research?

Explored in publications 2, 3, 4, 4a, 4b, 4c, 5, 6, 7. Findings were that co-creation of educational resources with people experiencing infertility, narratives of lived experience and interdisciplinary approaches have the potential to improve HCP & medical education; however, this needs to be aligned with involvement and engagement within research and curricula design.

3. The role of gluten (a protein in grains) in infertility?

Considered in publications 1,2,3,4,6,7. Gluten can negatively affect fertility in people diagnosed with coeliac disease, but fertility can also be affected in women with non-coeliac gluten

sensitivity and more education is needed as professional awareness of the fertility implications of both coeliac disease and gluten sensitivity is low.

Conclusions: Person-centred integrated infertility care needs to take account of the psychosocial impacts associated with infertility, include psycho-therapeutic support and also nutritional and lifestyle medicine. Where there is unexplained infertility or recurrent miscarriage, the potential role of gluten should be considered. Lived experience of infertility can be used as tool in HCP and medical education and socially to lessen stigmatisation and improve communication about infertility. Involvement needs to be aligned across the entirety of healthcare delivery, from clinical settings, through to both education and research (a 3-dimensional model called PRISM has been developed to triangulate involvement).