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'What are you going to do, confiscate their passports?' Professional perspectives on crossborder reproductive travel,

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Abstract

Objective: This article reports findings from a UK-based study which explored the phenomenon of overseas travel for fertility treatment. The first phase of this project aimed to explore how infertility clinicians and others professionally involved in fertility treatment understand the nature and consequences of crossborder reproductive travel. Background: There are indications that, for a variety of reasons, people from the UK are increasingly travelling across national borders to access assisted reproductive technologies. While research with patients is growing, little is known about how 'fertility tourism' is perceived by health professionals and others with a close association with infertility patients. Methods: Using an interpretivist approach, this exploratory research included focussed discussions with 20 people professionally knowledgeable about patients who had either been abroad or were considering having treatment outside the UK. Semi-structured interviews were recorded, transcribed verbatim and subjected to a thematic analysis. Results: Three conceptual categories are developed from the data: 'the autonomous patient'; 'cross-border travel as risk', and 'professional responsibilities in harm minimisation'. Professionals construct nuanced, complex and sometimes contradictory narratives of the 'fertility traveller', as vulnerable and knowledgeable; as engaged in risky behaviour and in its active minimisation. Conclusions: There is little support for the suggestion that states should seek to prevent cross-border treatment. Rather, an argument is made for less direct strategies to safeguard patient interests. Further research is required to assess the impact of professional views and actions on patient choices and patient experiences of treatment, before, during and after travelling abroad.

Keywords: fertility tourism; IVF; cross-border reproductive care; medical tourism; infertility

Background

Growing demand for fertility treatment, technological developments in assisted conception and a strong commercial imperative have created a large and highly lucrative industry in reproduction in many countries, extending the 'fertility-industrial complex' (Spar, 2006) to the global context (Dickenson, 2008). Cross-border reproductive travel can thus be seen as part of a broader trend of medical tourism (Crone, 2008; Lunt & Carerra, 2010) which parallels the emerging trend of a consumer culture in healthcare in late modernity (Lury, 1996), fuelled by the availability of cheap air travel (Mladovsy, 2006) and the growth of the Internet as a source of information and communication between travellers and as an opportunity for clinics and drug companies to advertise and compete for trade (Blyth, 2010; Culley & Hudson, 2010; Ikemoto, 2009; Smith, Behrmann, Martin, & Williams-Jones, 2010).

There are few robust statistics on the numbers of people involved in cross-border reproductive travel (Nygren, Adamson, Zegers-Hochschild, de Mouzon, & International Committee Monitoring Assisted Reproductive Technologies, 2010; Shenfield et al., 2010; Hudson et al., 2011, Qualitative research on peoples' experience of treatment outside their own countries is small but growing (Bergmann, 2011; Blyth, 2010; Culley et al., 2011a; Gurten, 2011; Hudson & Culley, 2011; Inhorn, 2009; Inhorn, 2011; Pennings et al., 2009; Shenfield et al., 2010; Speier, 2011; Whittaker, 2011; Whittaker & Speier, 2010; Zanini, 2011). However, little research explores professional perspectives on cross-border travel. Hughes and DeJean (2010) surveyed clinics in Canada and the US, and reported physician concerns about the quality of care for fertility travellers where the receiving country does not employ the same standards of treatment and guidelines for practice. Similar concerns are also voiced by Collins and Cook (2010), who stress the potential failure of continuity of care of those treated outside their home country and the absence of legal protection in the case of malpractice. Clinicians in the UK have expressed concern that cross-border reproductive care appears to result in more multiple pregnancies (McKelvey, David, Shenfield, & Jauniaux, 2009), although data on this are very limited.

Most media commentary on cross-border fertility treatment constructs cross-border reproductive travel as at best a significant social problem if not a deviant act (Culley & Hudson, 2010). The 'fertility tourist' is typically characterised as a middle-aged career woman, selfishly seeking treatment in dubious 'foreign' clinics, returning pregnant with triplets and draining the NHS of scarce resources. Some critics, especially those fundamentally opposed to assisted conception or some forms of it, also seek to stress the harmful impact of fertility travel on patients, offspring and gamete providers. Those who insist on the primacy of genetic links in parenthood and the importance of a child having knowledge of their genetic parentage, for example, raise concerns about the practice of using anonymous donors (which is common in many countries receiving cross-border patients), whereby the child will not have the possibility of knowing this part of their personal 'history' or building a relationship with genetic parents and siblings (Ciocci et al, 2006). Those who stress the physical risks of IVF to women in particular, are concerned at the possibilities of almost unlimited treatment available to desperate consumers in a global market, fuelled by and re-inscribing the motherhood mandate (Mulay & Gibson, 2006). The physical risks to egg providers, and the opportunities for the exploitation of surrogates in less-developed societies and economically disadvantaged groups generally, have also given rise to calls to halt or regulate the global reproduction market (Gupta, 2006; Ikemoto, 2009; Klein, 2008). In the UK, the regulatory body for fertility treatments, the Human Fertilisation and Embryology Authority (HFEA) and patient groups, such as Infertility Network UK, have offered advice to patients considering overseas treatment and professional bodies in the field of reproduction (e.g. the European Society for Human Reproduction and Embryology (ESHRE) have called for a more active stance to protect patients (Shenfield, Pennings, de Mouzon, Ferraretti, & Goossens, 2011)). However, there has been no published qualitative study of professional perspectives of crossborder fertility treatment. In this article we present data on how infertility professionals in the UK (clinicians, counsellors, nurses), support group representatives and legal and regulatory advisors understand the nature and consequences of crossborder reproductive travel. We present key themes from focused discussions with 20 people with professional interests in crossborder fertility travel, carried out as part of a broader investigation of UK fertility travellers. We draw on concepts of healthcare consumerism, choice and 'risk' (Lupton, 1999), and debates about the global governance of reproductive decision-making to discuss the complex and often ambiguous way in which these professionals perceive this phenomenon.

Methods

The 'Transrep' study, funded by the Economic and Social Research Council (Grant: RES-000-22-3390), was designed to explore the motivations and experiences of UK residents who travel abroad for fertility treatment (Culley et al., 2011b). While media coverage and bioethical and feminist commentary has positioned cross-border treatment as inherently problematic, the research team made no assumptions that people travelling abroad for fertility treatment should be identified as necessarily 'problematic'. Rather, we designed an exploratory study to seek to understand this under-researched area from the perspective of those engaged in the phenomenon as users or potential users, service

providers and other interested parties. At the time the study was carried out, the issue of cross-border treatment had been discussed in the UK media and had attracted the attention of patient support groups and the regulatory body (HFEA), but there had been no qualitative research with those involved. Few UK clinics had a direct formal partnership with overseas clinics due to uncertainties surrounding the legal implications of 'shared care' of patients with clinics in different jurisdictions. Some clinicians in the UK were prepared to assist those travelling abroad with an initial infertility 'workup', offering scans and blood tests and sometimes provided post-treatment tests and drugs. A small number of UK clinics organised foreign trips where professionals accompanied patients to receive egg donation treatment and played an active part in their care abroad. As part of a broader interview study, to ascertain professional perspectives of cross-border travel we conducted 14 individual interviews and 1 group interview (n = 6) with a purposive sample of people working in this field who were professionally knowledgeable about patients who had either been abroad or were considering having treatment outside their own country. The participants included five infertility clinicians, seven nurses and coordinators, three specialist infertility counsellors, three patient support group/voluntary sector representatives and two legal and regulatory advisors. The first phase of the study included a systematic review of the literature on cross-border care (Hudson et al., 2011).

Participants were invited to discuss their perceptions of cross-border reproductive travel and their views on the potential responsibilities of regulators (such as the HFEA), professional bodies (such as the British Fertility Society and ESHRE) and other agencies towards cross-border treatment. Interviews were recorded, transcribed verbatim and subjected to a thematic analysis. This involved initial reading of transcripts for emergent categories, which were subsequently developed into a framework of codes, elaborated into analytic themes and re-applied to the transcripts systematically (Silverman, 2001). Coding was carried out by two members of the team to improve validity. Analysis generated six broad themes (patient motivations; patient choice; implications and risks; the role of providers and regulators; public and media perceptions; commercialisation). In this article we develop three conceptual categories from these themes drawing on the literature on choice and risk: the autonomous patient; cross-border travel as 'risk', and professional responsibilities in harm minimisation. We conclude with suggestions for further studies in this under-researched field.

Results

The autonomous patient: exercising choice

A strong theme from these data was that of patient choice and autonomy and the fertility patient's 'right to choose'. All participants considered that treatment abroad was a legitimate 'choice' for patients, especially in the context of limited public funding in the UK. This was expressed by patient support group representatives in the following way:

We feel there is no need to be hypocritical about this, it's just another choice that the patient is being offered. (Support group representative)

I have got no problem with private treatment. I have got no problem with going abroad for treatment. It's where people don't have a choice, having that choice taken away – that makes me angry. (Support group representative)

Here we see the significance of a neoliberal, pro-choice agenda in consuming (private) health care, where citizens become consumers and choices become individualised (Bauman, 2001). This consumerist discourse is one that in the UK context has recently become significant in relation to publicly funded (NHS) as well as private healthcare and has been discussed as an important part of patient willingness to travel overseas for healthcare more generally (Exworthy & Peckham, 2006). In our participants' accounts, patients are discursively constructed as free agents, able to make choices to exercise their individual 'rights'. This was, however, constructed in the context of the inability of UK services to meet the needs of patients, particularly around the provision of donated oocytes, and where

treatment in nearby countries such as Spain or the Czech Republic is available within a short timescale (Culley et al., 2011a).

We are looking here at the average wait for an egg donor in the UK is two years. So, when they can go abroad and be treated in a matter of days or weeks, from their point of view there is no real decision. They are looking at it from their point of view, which is absolutely right. (Nurse)

Most participants considered that while people should have the choice of overseas treatment, this 'choice' was imbued with potential risks, which patients had to negotiate and manage, and few would choose to travel abroad for treatment if the treatment they needed was available in the UK.

Cross-border reproductive travel as risk

The autonomous patient is described as existing at the nexus of a range of 'risks' from which they require protection. Travelling abroad for fertility treatment was clearly seen by many participants as representing a complex web of challenges that emanated primarily from patients' inherent vulnerability combined with the perceived potential for exploitation in 'foreign', less well-regulated jurisdictions.

If there was more advice and support available for them in the UK they wouldn't resort to surfing the internet and ending up in Vladivostok with some extraordinarily dodgy unregulated clinic. In a more supportive and informed environment they might make more rational choices. (Clinician)

While some participants recognised that the quality of care and standards of safety 'abroad' were not invariably lower than in the UK, several nevertheless suggested that patients were not always well-informed or were prone to being misled in their desperation to achieve a much-wanted pregnancy.

I think couples are open to exploitation if they are not careful. (Nurse)

These patients are very vulnerable. (Support group representative)

It makes me want to cry at the potential for exploitation of desperate people. (Counsellor)

For many social commentators the modern era has become characterised by 'risk' (Beck, 1992), a concept which has come to stand for feelings of fear, anxiety and uncertainty (Lupton, 1999; O'Malley, 2004). A lack of trust in traditional institutions such as the state and science, it is argued, means that there is increasing openness about how people should live and a corresponding decrease in reliance on 'expert' systems. This implies that individuals are required to become increasingly 'risk-conscious' and adept at negotiating a range of potential dilemmas and anxieties.

These risks are often identified as stemming from the development of new scientific (and medical) technologies, which public groups are themselves required to become experts in negotiating. The presence of this discourse is interesting as it reflects a trend for the media discourse of reproductive travel as 'risky' to be re-inscribed into respondents' accounts. Of course, it is also possible that 'experts' are themselves intimately involved in producing this 'risk object', as they are often called upon to comment in media accounts, in the absence of research based evidence. This discourse also contributes to the notion 'British is best', reflecting ideals about UK regulation of fertility treatment often valorised as being superior to that in other countries.

In our data, there appeared to be an interesting tension between the discourse of 'choice' in which patients are represented as active, autonomous agents in a neoliberal late-modern state, exercising their right to consume private healthcare and the control it entails, and the discourse of risk, which seems to flow from the enforced movement of what are seen as a group of highly vulnerable people. Our respondents placed a great deal of emphasis on the need for users of overseas clinics to become adept managers of risk to protect themselves and their (potential) families. Becoming 'informed' and

making 'informed choices' was therefore viewed as a highly salient process for patients to engage in. This was particularly evident in the interviews with support group representatives and counsellors.

And as long as they go in to it with their eyes open and fully aware of the implications then who are we to judge. (Support group representative)

The most important thing is the patient and informed choice. (Counsellor)

A small number of participants discussed the risks for those other than the person undertaking overseas travel for treatment, several mentioning concern for the welfare of donors in overseas countries and one nurse described the need for 'harm minimisation' for donors to ensure provision of monitoring, support and health protection.

We know so very little about the long-term implications of being stimulated by drugs and I certainly worry very much about places which stimulate women to produce very large amounts of eggs. (Support group representative)

The welfare of offspring in cross-border reproductive treatment was an issue raised by counsellors in particular, by some patient support group representatives, and by legal advisors, although this was less evident in the clinician interviews. Concerned participants stressed the lack of information about gamete providers and other genetic 'relatives' for future children when people accessed treatment in countries permitting donor anonymity. Offspring conceived following oocyte donation in popular destination countries for UK patients, such as Spain and the Czech Republic (Culley et al., 2011a), have no opportunity to learn the identity of their donor, and relatively little information about donors is provided to patients, unlike the situation in the UK – at least since 2005 (Her Majesty's Stationery Office, 2004). This issue has been raised as problematic by some commentators, especially those writing from a counselling or social work perspective (Blyth & Auffrey, 2008; Blyth & Farrand, 2005; Ciocci et al., 2006).

Professional responsibilities – international regulation and harm minimisation

While to some extent participants placed the emphasis for risk management on the individual, several saw a role for other agents in this process. As Foucault's analysis of governmentality suggests, while there is an important and growing role for individuals to regulate themselves in late modernity, there is still the potential for more coercive or directive state strategies (Lupton, 1999) and we see this in the practice of more or less restrictive regulation of fertility treatment in different nation states. As we have seen, this is a major 'enabling factor' for cross-border reproductive travel (Blyth & Farrand, 2005; Pennings, 2002; Pennings, 2004; Storrow, 2005). While international harmonisation of the law on assisted conception and its regulation would, therefore, remove one of the main drivers of cross-border travel, most participants took the view that, regardless of its desirability, there was little chance of any international harmonisation of regulation materialising:

I think practically, regulating anything internationally is going to be a nightmare. I don't know where you'd start or who you'd involve in that, both here in the UK and abroad. I don't think you are going to get all the countries of the world to agree to have a consistent policy on these very sensitive issues, things like sex selection and donor conception and surrogacy. (Clinician)

Furthermore, all participants were of the view that even if restrictions on forms of overseas treatment not legal in the UK were introduced, such laws would be quite impossible to 'police'.

Who can prove where a child is conceived? ... we have got the free movement of people, cheap travel ... what are you going to do, confiscate their passports? (Clinician)

In the absence of formal international regulation of standards and procedures, many participants reflected that professionals had a key role to play in 'educating' people about possible risks and to ensure that patients were aware of the issues that they need to consider when having treatment abroad;

awareness of the possibilities of differences in safety procedures; and appreciation of the potential legal implications of treatment outside the UK.

I think the only realistic responsibility is to try and keep people safe. (Counsellor)

I think we have a responsibility to educate people to the risks of what they are doing, which is what we do with smoking and things like that but we still allow people to choose. (Nurse)

I think that people have the right to choose. I would be unhappy if some of my customers say, well I want to go to a unit that I might not know or that would exploit couples and that would be my concern. If they don't validate their results or they exploit financially the couples, then that is what I worry about. (Nurse)

Clinicians also stressed the importance of professional judgements of standards and safety issues. Several had links with foreign clinics and were involved in either preparing and following-up patients going abroad for treatment, or recommending particular clinics to patients. In all cases, the clinicians stressed the importance of UK clinics 'checking out' the overseas clinics carefully, visiting them and ensuring that standards and forms of treatment were congruent with UK practice, thus reducing the risks to patients.

Yes, so we hopped over there and basically sussed out that the clinic was kosher and said we wanted them to run by British rules. We didn't want them putting back 5 embryos and things like that. (Clinician)

Discussion

The professional ('insider') discourse discussed here does not represent cross-border reproductive travel as inherently 'wrong', and to some degree it contests the dominant media representations of 'fertility tourism'. These commonly highlight the most extreme cases and generally report events in a negative way (Culley & Hudson, 2010; Jones & Keith, 2006) and have many of the hallmarks of a classic moral panic (Cohen, 2002). There has always been something of a moral panic about new reproductive technologies, but in many societies, 'ordinary' IVF has now become normalised as a legitimate form of reproduction. 'Fertility tourists', however, are constructed as deviant users of this technology, subverting the 'natural' processes of reproduction (as in the case of post-menopausal childbearing) and 'normal' family forms (as in the case of non-heterosexual couples, or single women). The moral agents of the media readily represent the voices of moral entrepreneurs to highlight the most sensationalist examples of older mothers, multiple pregnancies and 'baby shoppers'. Those who cross borders for treatment are frequently portrayed as illegitimately challenging nature (or 'playing God') in wanting to 'design' their babies by selecting their sex or seeking out particular physical or intellectual attributes.

In contrast, professional perspectives draw on an insider status and a sympathetic approach to the needs, anxieties and expressed interests of fertility patients. Professionals clearly have a concern for the suffering of the infertile, although their accounts are not immune to the wider public and moral panic aspects of the media presentation of this phenomenon as seen in references to 'risky' overseas scenarios. However, they are constructing more nuanced, complex, sometimes contradictory counternarratives of the 'fertility traveller', as vulnerable and knowledgeable; as engaged in risky behaviour and in its active minimisation. In presenting reproductive travel as 'risky' they also simultaneously articulated the position that the UK is by comparison superior and risk-free, and is therefore an ethically unproblematic context in which to 'shop' for treatment. Although we did not explicitly ask about the quality of UK-based treatment, none of our interviewees offered the view that poor practice can exist everywhere, although it seems likely that such a statement would not be denied. Instead, they discursively constructed the idea of a risk-laden 'abroad' with the comparatively risk-free UK. Professionals are engaged in both re/presenting media accounts and also in contributing to their construction, as they are often called upon to comment in press accounts. The perspectives of the

professionals in these interviews resonate with the position expressed by many scholarly commentators, who stress the potential dangers of cross-border reproductive travel: concerns about the control of quality and safety standards in 'foreign' places; the need to protect patients against potential incompetence, negligence and recklessness on the part of some practitioners; an alleged absence of counselling and psychological support in some clinics; inadequate information about possible health risks to patients, donors and offspring. It is important to make the point that these views are expressed in the absence of strong evidence to confirm or refute them. Subsequent research has shown that many patients travelling for fertility treatment outside the UK (mostly to European destinations) felt that they had received a better quality of care than in the UK, and that the rate of multiple pregnancies was no higher than that following UK treatment (Culley et al., 2011a). The professionals also emphasise the importance of good public and patient information to assist people to evaluate the potential risks and benefits of overseas treatment and the claims made about success rates in countries with less-official monitoring of standards, safety or reporting of outcomes. This was a major recommendation of the research from which this article is drawn, which was produced by delegates at a stakeholder workshop which included members of the professional groups represented in this data (Culley et al., 2011b).

Within this discursive account 'fertility tourists' are certainly defined as at risk and multi-centred strategies of governmentality are proposed (Rose, 1999). Medical travel more generally highlights the challenges to global governance (Whittaker, 2010). There are no internationally accepted standards for fertility treatment, beyond guidelines of professional bodies, and patients would benefit from an independent international system of benchmarking for fertility clinics (Culley et al. 2011b). Exploring the example of cross-border reproductive travel could illuminate the possibilities and limitations of the power of the nation state in a world of 'flexible citizenship' (Martin, 2009; Storrow, 2005). Crossborder fertility travel raises a host of legal issues, most of which remain largely unexplored (Crockin, 2011; Storrow, 2011). Direct coercive state regulatory strategies are suggested by some commentators, and indeed this has been attempted in the case of Turkey (Gurten, 2011). Our participants placed more emphasis on less-direct strategies that rely on individual voluntary compliance by both patients and physicians to reduce the risks seen as inherent in crossing borders for treatment. They were opposed to any suggestion that states should seek to contain or prevent crossborder treatment. Their views were broadly in line with the argument of Pennings (2002, 2004), that while the negative aspects of 'reproductive tourism' need to be minimised, and as international moral consensus about the harmfulness of treatments is unclear (Van Hoof & Pennings, 2011), there should be no attempt by the state to curtail free movement of patients to other jurisdictions. These views are also echoed in the accounts of cross-border travellers themselves (Culley et al., 2011a). In the UK the HFEA has stated that it has no remit to interfere with the decisions of patients to travel overseas for treatment (HFEA, 2010).

There is no apparent contravention of good medical practice should doctors in the UK assist patients to undertake cross-border treatment, although many would argue that there is an ethical responsibility to provide a full discussion of the risks involved (Forman, 2011). All of our participants were concerned to safeguard patient interests and a minority stressed the importance of developing professional codes of conduct. ESHRE has recently approved a document called 'Good Practice Guidance to Cross-border Reproductive Care' (Shenfield et al., 2011) for fertility clinics and physicians treating foreign patients, which is designed to safeguard the interests of both patients and donors. Counsellors and patient representatives in particular discussed the importance of counselling for patients considering treatment abroad. An ethical framework for psychosocial counselling of intending travellers and those who have undergone such treatment has now been proposed (Blyth et al., 2011). Other commentators suggest a system of international accreditation of infertility clinics to ensure minimum safety standards (Culley et al., 2011a; Pennings, 2006), although the feasibility of developing and implementing such a system at the present time is questionable.

Conclusion

Our understanding of the motivations for and experiences of cross-border fertility travel and its consequences for patients, families, donors, surrogates, healthcare systems and economies is limited but growing. Very little is known, however, about how this phenomenon is understood by health professionals and others professionally involved in the process, or what professionals consider to be the implications of cross-border treatment for their clinical practice. There would appear to be growing international brokering in gametes and increasing links between UK and overseas clinics, largely driven by the donor shortage in the UK, and further research is needed into how professionals negotiate and patients navigate this form of transnational reproduction. Travelling abroad for treatment also impacts on the work of general practitioners, secondary care fertility clinicians, gynaecologists and obstetricians, nurses, midwives, counsellors and those supporting people who have given birth to children conceived abroad, many of whom (in the UK context at least) will have used the gametes of anonymous overseas providers. Therefore, it is important for social research to both understand and inform this engagement with a growing phenomenon and consider the potentially significant implications for healthcare systems in the home country.

While this article outlines some preliminary data, the small scale of this study gives rise to several limitations. It is necessary to carry out a larger study exploring more extensively and in more depth, differences and similarities in the perceptions of different professional stakeholders. It is also important to assess the impact of professional views and actions on patient choices and patient experiences of treatment, before, during and after travelling abroad. The views of professionals receiving patients from abroad are also largely absent from the literature (see De Sutter, 2011, for an exception) and the role of international professional brokers in the growing global phenomenon of transnational reproduction merits urgent investigation.

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