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Cross-border-assisted reproduction: a qualitative account of UK travellers' experiences

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ABSTRACT Surveys on patients' experiences of cross-border fertility treatment have reported a range of positive and challenging features. However, the number of such studies is limited, and there is no detailed qualitative account of the experiences of UK patients who travel overseas for fertility treatment. The present study used a cross-sectional, qualitative design and in-depth interviews. Fifty-one participants (41 women and 10 men, representing 41 treatment 'cases') participated in semi-structured interviews. The experiences reported were broadly positive with a large proportion of participants (39 cases, 95%) citing a favourable overall experience with only two cases (5%) reporting a more negative experience. Thematic analysis revealed 6 major categories and 20 sub-categories, which described the positive and challenging aspects of cross-border fertility travel. The positive aspects were represented by the categories: 'access', 'control' and 'care and respect'. The more challenging aspects were categorized as 'logistics and coordination of care', 'uncertainty' and 'cultural dissonance'. The study confirms findings from others that despite some challenges, there is a relatively high level of patient satisfaction with cross-border treatment with participants able to extend the boundaries of their fertility-seeking trajectories and in some cases, regain a sense of control over their treatment.

INTRODUCTION Surveys of cross-border reproductive care suggest that this is a growing global phenomenon, driven by a range of social, political and economic forces (Nygren, Adamson, Zegers-Hochschild, & De Mouzon, 2010; Pennings et al., 2009; Rozee Gomez & de La Rochebrochard, 2013; Shenfield et al., 2010). There has been a great deal of commentary on this topic, and a small but growing body of academic literature on why and how patients navigate such journeys. This reveals a wide range of reasons why people travel outside their country of residence, indicating that cross-border fertility travel is not a homogenous phenomenon but takes different forms in different contexts (G€urtin & Inhorn, 2011; Hudson et al., 2011). The small number of studies which have explored patient experiences of cross-border treatment has noted a range of positive and challenging features. Challenging features include: making travel arrangements (Speier, 2011); accessing blood tests and scans in the home country (Blyth, 2010; Lunt et al., 2014); communicating with overseas clinic staff (Infertility Network UK, 2008); and the (sometimes unexpectedly higher) cost of treatment abroad (Infertility Network UK, 2008; Shenfield et al., 2010; Whittaker & Speier, 2010). Despite these challenges, studies generally report a relatively high level of patient satisfaction with cross-border treatment (Bergmann, 2011a; Blyth, 2010; Lunt et al., 2014; Pennings et al., 2009; Van Hoof, Provoost, & Pennings, 2013). Positive factors include the availability of donors (Bergmann, 2007, 2011a, 2011b; Blyth, 2010; Culley et al., 2011; Hudson & Culley, 2011; Infertility Network UK, 2008), shorter waiting times (Blyth, 2010; Infertility Network UK, 2008), being involved in decision-making (Van Hoof et al., 2013) and the ability to have treatment in a culturally and linguistically familiar country (Inhorn, 2009; Inhorn & Shrivastav, 2010; Whittaker, 2009; Whittaker & Speier, 2010). However, there is no detailed account of the experiences of UK patients who travel overseas for fertility treatment. This paper describes the experience of people travelling from the UK, where there is formal access to a wide range of treatments (NICE, 2013), a high degree of regulation (HFE Act, 1990, 2008) and limited public funding (Johnson, 2011): features of a context, which may appear to negate the need for cross-border reproduction. It builds on earlier papers from the 'TRANSREP' study, which explored the socio-demographic characteristics of UK fertility travellers,

the countries they visited and their pregnancy outcomes (Culley et al., 2011), their motivations for travel (Hudson & Culley, 2011) and the specific experiences of male travellers (Hudson & Culley, 2013). In this paper, we report participants' experiences of the logistics and coordination of care and, specifically, the assessments they made of the care they received overseas.

METHODS The TRANSREP study employed a cross-sectional, qualitative design and used in-depth interviews with individuals and couples who had been, or were planning to go, overseas for fertility treatment. The interviews, carried out between May 2009 and June 2010, were semistructured and lasted between one and two hours, to allow participants to express in detail their reasons for considering or undertaking treatment abroad, as well as their experiences of this process and perspectives on the care they received. Ethical approval for the study was obtained from De Montfort University Human Research Ethics Committee (Ref. No. 459). Resultant interview data were analyzed thematically, assisted by the computer software package Nvivo (Silverman, 2001). The thematic structure presented in this paper was achieved by selecting from the Nvivo dataset all codes that featured a positive or challenging¹ account of the treatment and care experience. These codes were then refined using principles of interpretive thematic analysis (Braun & Clarke, 2006). In some cases, this involved the merging of existing codes, for example 'accessing drugs', 'scanning' and 'tests' were refined and merged to create the new sub-category 'accessing scans, test and drugs from a distance'.

RESULTS Fifty-one participants (41 women and 10 men, representing 41 treatment 'cases'²) took part in qualitative interviews. Participants were recruited through online patient forums (44%); support group newsletters and mailings (22%); media coverage about the project (17%); word of mouth (7%); overseas clinics (7%); and UK clinics (2%). The socio-demographic profile of participants has been reported previously (Culley et al., 2011). The majority of participants had been abroad for treatment at the time of the interview (83%, 34 out of 41 cases). In the remaining seven cases, firm plans to travel had been made at the time of participation in the study, including for most, booked flights and initial consultations. For this reason, these seven cases are included in this paper. Twenty-six of the cases had at least one positive outcome (i.e. a live birth n=22 or pregnancy confirmed by ultrasound scan n=10³ which included 26 singletons and 6 twin pregnancies (total pregnancies, n=32). Participants were travelling to a total of 18 countries, not only within Europe (Spain and Czech Republic were the most popular destinations) but also to USA, Barbados, India and South Africa, and had diverse and complex motivations (Culley et al., 2011). A need for treatment using a donor was an important factor for the majority (71%; Culley et al., 2011). However, a significant minority (29%) of participants did not require such a procedure and had a range of other reasons for travelling outside the UK, including the cost of treatment. In total, 6 major categories and 20 sub-

¹ We use the term 'challenging' here to refer to experiences described by participants that were in some way difficult or complex. We avoid the term 'negative' because overall the majority of participants described the experience of seeking cross-border reproduction as a positive rather than negative one, albeit with challenging aspects.

² A 'case' is defined as either an individual or a couple seeking treatment together, even where only one partner took part in the study.

³ In a small number of cases (n=4) there had been both a live birth (at least one) and there was also a current pregnancy.

categories, which describe the positive and challenging aspects of cross-border fertility travel, were derived from the qualitative interview data. The positive aspects are constituted by the categories: 'access', 'control', 'care and respect'. The more challenging aspects are categorized as 'logistics and coordination of care', 'uncertainty' and 'cultural dissonance'. Each of these six categories comprises a number of sub-categories (Table 1).

Table 1. Positive and challenging aspects of cross-border treatment

Positive Aspects	<p>Access</p> <p>Control</p> <p>Care and respect</p>	<p>Short waiting times Availability of donors Quick test results Low costs</p> <p>Involvement in decision making Receiving individualized care Choice of donors Choosing numbers of embryos</p> <p>Getting a timely response Having a dedicated coordinator Regular contact with clinician Staff positivity</p>
Challenging Aspects	<p>Logistics and coordination of care</p> <p>Uncertainty</p> <p>Cultural Dissonance</p>	<p>Accessing UK records Accessing scans, tests and drugs from a distance Travel and accommodation difficulties</p> <p>Future implications of decisions Trustworthiness and safety in overseas clinics</p> <p>Lack of shared language Unfamiliar drugs and medical systems Unfamiliar cultures and places</p>

Positive aspects of cross-border treatment Experiences were broadly positive with a large proportion of participants (39 cases, 95%) citing a favourable experience overall. This was often contrasted (where relevant) with the way participants felt that they had been treated in the UK, with common complaints relating to: long waiting times for and between appointments; a lack of contact with the consultant leading their care; feeling they were treated 'like a number' or that they were 'on a conveyor belt'; a lack of new options following treatment failure; and high costs. For these reasons, 'access', 'control' and 'care and respect' were the features of cross-border treatment with which participants were most satisfied.

Access Despite the need for international travel, participants gave a number of reasons why overseas treatment was a more easily accessible option than treatment in the UK. Principally, these were shorter waiting times, availability of donors, quicker test results, and in some cases, low costs:

It happened very quickly, no messing about, no waiting, it was all very straightforward actually.
(female, IVF with donor eggs, Spain)

We haven't got money to just keep throwing away at this, so price was a factor I have to say. It is cheaper than this country but it just made it more affordable for us to go over there and do all of this.
(female, IVF donor eggs and donor sperm, South Africa)

For those deciding to travel overseas, these advantages were crucial since it was acknowledged that infertility treatment in any context can be physically and emotionally demanding and therefore finding ways to make the process less difficult was welcomed.

Control Many participants (n=32 of 41 cases, 78%) had already experienced treatment trajectories (sometimes lengthy) in the UK before embarking on treatment abroad. They were therefore, relatively well versed in treatment protocols by the time of their overseas treatment. This allowed participants the possibility of some negotiation and control over their treatment, which was one of the positive aspects of treatment abroad. This had several dimensions. Participants described being more involved in decision-making about treatment; receiving individualized care; having a choice of donor and in a small number of cases, having a choice about the number of embryos to transfer. Feeling that they were able to ask questions and negotiate their treatment was a positive experience for many. More than half of the sample, especially those with longer, unsuccessful treatment histories, and those trying to conceive using their own gametes, described this process as allowing them to feel more in control of their care pathway than they had experienced previously:

I think we were well informed, it was more transparent, [we had] more control. Any questions that we had were answered quickly, fully, without being patronising, and we felt that they weren't being answered according to an NHS textbook, which is how we felt [in the UK]. (female, IVF own gametes, Barbados)

Care and respect One of the main benefits of going overseas was the quality of care participants thought they received. Almost all (39 cases, 95%) reported broad satisfaction with the way they had been treated in the clinic and when corresponding with staff. The category of care and respect includes a number of dimensions and was central to the sense that they had received good quality treatment. It included the following four aspects: getting timely responses to questions, often by email (most participants highly valued this approach to communication); having a dedicated person coordinating their care (in some cases this was a translator or patient coordinator); regular contact with the clinician leading the care, and finally, a feeling that the staff carrying out the treatment wanted it to succeed. Feeling cared for was an important part of the emotional well-being of participants alongside a perception that the clinicians had their best interests at heart, both of which were fundamental to a feeling they had been treated well.

Challenges of cross-border treatment Although experiences were broadly positive, treatment abroad did not always run smoothly and participants highlighted a number of concerns. In two cases (5%), participants felt that overall they had a more negative than positive experience of cross-border treatment. In both cases, this was related to the lack of familiarity with their surroundings: in one case, this was exacerbated by differences in language, and in the other the female participant felt she had been treated abruptly by busy staff on the day of embryo transfer. In both of these cases treatment had been successful and had resulted in a pregnancy. For the rest of those interviewed, the experience was generally positive but occasionally gave rise to issues related to the following themes: logistics and coordination of care; uncertainty; and cultural dissonance.

Logistics and coordination of care This theme describes the complexity of facilitating care between national contexts. Needing to provide UK records to overseas providers, negotiating scans, tests and drugs required for the cycle from the UK, and making travel and accommodation arrangements characterized this theme. In two-fifths of all cases, participants described having to provide their UK

medical records or treatment details to the overseas clinic. For a small number, this was automatically facilitated via the process of shared care they were accessing. The remainder of participants described needing to request the information from UK clinicians. Whilst on the whole, participants were able to request and receive this information (nothing in UK law prevents people from accessing their medical records); in a small number of cases, this was problematic as UK-based clinicians were slow or reluctant to share information:

He [the overseas consultant] asked me for my protocol from the previous [UK] clinic, which it took me a long time to get from them. They wanted to charge me for it, it was just ridiculous, the English clinic, getting my information from them. In the end I threatened them and said 'I'm entitled to this information, I don't want my full file, just give me a synopsis', so they gave me that and then I sent it to him. (female, ICSI with own gametes, Czech Republic)

Another major complexity for those managing their own fertility treatment cycles was accessing scans, blood tests and drugs whilst in the UK. Solutions to this problem included: using private (non-NHS) General Practitioners and scanning facilities; having prescriptions raised and dispensed by UK-based clinics where they were former patients; using international pharmacies; and deciding to stay longer in the treating country. These were carried out with varying degrees of ease and success, but led more than a third of participants to feel that they were 'outside of the system'. In some instances, this was described as being made to feel that they were engaging in 'shady' or 'dodgy' practice, in many cases by UK health care professionals who were described as unsympathetic to their plight. Needing to source drugs on the internet and to carry drugs and needles through airport security also heightened feelings of unease. Specific to the experience of treatment-seeking abroad were the travel and cost implications. In two thirds of all cases, the added pressure of arranging travel at the last minute and the additional cost this incurred were reported as challenging. This was especially the case for those having donor egg treatment, since donor and recipient cycles often needed to be closely coordinated.

Uncertainty Participants described a sense of uncertainty around certain aspects of seeking treatment abroad and these concerns fell into two main groups: uncertainty about the trustworthiness and safety of the clinics and anxiety about the future implications of their treatment decisions, especially in relation to the wellbeing of any children that had been, or might be, born as a result. Uncertainty as described by our participants was defined as feelings of doubt or ambiguity about their decisions and the actions of others, both in the short- and long-term. In a third of all cases, participants described feeling unsure about whether or not the information they were given by clinic staff was accurate. This related to information about success rates and that provided about donors. The need to trust individual clinicians and clinic staff was of particular significance in an unfamiliar context and a number of participants reported 'checking' information given by overseas clinics with UK health care professionals, as well as with other patients travelling to these destinations:

The doctor in this country, because I did actually discuss it with one of the consultants in [the UK],... even she suggested that she felt that those [success] rates were likely to be true. ...She was also very positive about the Spanish clinics, which is why we chose a Spanish clinic the first time. (female, IVF donor eggs, Spain and Czech Republic)

For a small number of participants who were using donor gametes, anxieties were expressed about the information they were given about the donor, and in countries where donors were anonymous, whether the information was correct. Two-thirds of participants described feeling anxious or uncertain about the implications of their treatment for their actual or anticipated children. All of these participants were seeking or had sought treatment using donor gametes. In many of these cases, these concerns were difficult to disentangle from the perceived implications of using an often anonymous donor, regardless of where treatment had taken place. However concerns were often exacerbated by treatment having taken place abroad. For example: the use of a donor of 'Spanish' appearance; not having information about a donor to give to a resulting child; and being worried about how to explain their decision-making, for example, in relation to the choice of country to which they had travelled:

We had to think about what we are going to tell the children, and how much detail do we give them about the whole thing. So we felt that at least if we could tell them that they're both from the same, you know, we'd been to the same country for the treatments, it might be something that would make it easier for them. (male, IVF donor eggs, Spain and Greece)

Cultural dissonance Lack of familiarity with a country, the local language and its medical system were described as some of the more challenging features of cross-border treatment. Despite the fact that language was not reported as a major barrier to choosing to go abroad, a quarter of participants recounted an issue with communication during treatment due to different languages spoken by staff and patients. In half of these instances, there had been difficulties in face-to-face communication, including a small number of participants who were disconcerted by staff talking amongst themselves in a language other than English during consultations or procedures (such as at embryo transfer). In the other half, there were difficulties in understanding or interpreting written instructions or information from the clinic in letters and emails. Lack of a shared language often heightened the feeling of having treatment in an unfamiliar or culturally 'strange' place. Almost a quarter of participants described the impact that cultural differences between the UK and their country of choice had on their experience. This appeared to be particularly acute in countries like Russia or Ukraine but was also experienced by people travelling to Spain; a country which, as well as having plentiful donors, was often chosen because of its cultural and physical closeness to the UK:

It was incredibly nice in [Spain] but everything feels foreign I suppose and it emphasizes the strangeness of everything. (female, IVF with donor eggs, Spain)

It was a bit more daunting. There's the language and Cyrillic script and then it was a totally unknown culture and there are dodgy dealings going on in [Ukraine]. I mean it is gangster land in a way. (female, ICSI with donor eggs, Spain and Ukraine)

In addition to the lack of cultural familiarity, uncertainty about medical systems in the chosen destination was also reported as unsettling.

Discussion This study demonstrates that despite certain challenges, there is a relatively high level of patient satisfaction with cross-border fertility treatment, confirming data from the UK, Canada, Germany and Belgium (Bergmann, 2011b; Blyth, 2010; Lunt et al., 2014; Pennings et al., 2009; Van Hoof et al 2013). Most had undertaken extensive research and received treatment in the UK prior to seeking treatment overseas (Blyth, 2010; Van Hoof et al., 2013) and were thus in a position to

compare their experiences of overseas clinics with those in the UK. Favourable comparisons of the overseas experiences with those they had received in the UK were common in these accounts. Almost all participants who had been abroad at the time of the study reported general satisfaction with the way they had been treated in overseas clinics, irrespective of clinical outcome. Our participants reported that on the whole they felt involved in decision-making about their treatment in line with recent findings from research with Dutch patients who were seeking treatment in Belgium (Van Hoof et al., 2013). Participants also felt that communication with clinics was better than in the UK, often with direct and readily available access to the clinician leading their care. Many of these factors have been identified as key components of 'patient-centred fertility care' generally (Dancet et al., 2010; Dancet et al., 2011; Redshaw, Hockley, & Davidson, 2007; Schmidt et al., 2003). A systematic review of patients' perspectives of fertility care concluded that fertility patients 'want to be treated like human beings with a need for: medical skills, respect, coordination, accessibility, information, comfort, support, partner involvement and a good attitude of and relationship with fertility clinic staff' (Dancet et al., 2010, p. 467). Most studies of patient experience suggest that infertility patients desire information, continuity of care, individualized care and staff who are friendly and supportive (Dancet et al., 2012; Greil, Slauson-Blevins, & McQuillan, 2010; Redshaw et al., 2007; Schmidt et al., 2003). For some, the option of having more than one embryo transferred was mentioned as a positive aspect of treatment abroad, contrary to social and political initiatives in the UK to encourage patients to undergo elective single embryo transfer as a mechanism to reduce multiple births (HFEA, 2010). However, in contrast to findings from an earlier UK study relating to multiple births, (McKelvey, David, Shenfield, & Jauniaux, 2009) most people did not desire, or indeed have, more than three embryos transferred, (Culley et al., 2011) but several felt that they certainly did not want to be restricted to a single embryo transfer; an initiative recently introduced in the UK. As with previous studies, increased chances of success were perceived as an important consideration when considering single versus double embryo transfer (van Peperstraten et al., 2008). Importantly, it was the feeling that they were involved in decision-making, and that treatment was tailored to them, which was of significance in assessments of care. A lack of control over the experience has been identified as a major issue for fertility patients more generally (Greil, 2002). People experiencing infertility often deal with wider challenges to their identity and social roles, and are often considered as vulnerable. However, as Greil has argued, people seeking treatment do not on the whole simply respond passively to medical definitions of them, but often act strategically to push treatment in the direction they wish it to go (Greil, 2002). They are not uncritical consumers, but problem solvers, operating creatively within a system they do not control. This description would characterize many participants in our study. The rise of medical tourism has been linked to a growth in consumerism in health care (Carerra & Lunt, 2010) and within this discourse of 'patient choice' fertility travellers seek out what they desire. Participants therefore valued highly the opportunity of more shared decision-making about treatment options. The speed and ease with which participants could access overseas treatment was another welcome advantage of cross-border treatment over treatment carried out 'at home'. Shorter waiting times in overseas clinics have been reported in other studies as a positive reason to seek treatment abroad (Blyth, 2010; Infertility Network UK, 2008; Lunt et al., 2014). The greater availability of gamete donors in other countries, especially egg donors, was also mentioned as a benefit which facilitated timely access to treatment, with participants citing the lengthy waits in the UK for a suitable donor, a feature described elsewhere (Bergmann, 2007, 2011a, 2011b; Blyth, 2010; Infertility Network UK, 2008). The few published accounts of experiences in other contexts demonstrate that cross-border fertility travel can be

logistically, emotionally and financially challenging and this was also a feature of our data (Inhorn, 2012; Lunt et al., 2014). Most participants in the present study reported feeling comfortable with overseas travel, but nevertheless suggested that coordinating care at a distance complicated matters. One of the main issues related to the need to coordinate aspects of care with UK providers. Participants reported difficulties with UK clinics providing medical records or test results to overseas providers and finding UK practitioners who were willing to carry out scans or to dispense drug prescriptions. Similar experiences were also reported in a survey of Canadian and Australian support group members, (Blyth, 2010) where participants cited this as a major disadvantage of cross-border treatment. This is also consistent with the situation whereby UK residents were less likely than German, French and Swiss patients to be receiving the help of a clinician in their home country (Shenfield et al., 2010). Few participants in our study were engaged in 'shared care' arrangements between a UK and overseas clinic (Culley et al., 2011), and as a result became 'contractors' of their own treatment programmes (Greil, 2002). Whilst this afforded a level of control, it added to the complexity of the process; a problem exacerbated for those booking travel at the last minute to coincide with specific parts of their treatment cycle (Speier, 2011). Participants described cross-border treatment as often characterized by uncertainty. Studies of the infertility treatment experience generally highlight this as a process typified by doubt and anxiety (Dancet et al., 2010; Franklin, 1997; Thompson, 2005; Throsby, 2004). The uncertainty associated with cross-border treatment had a particular set of inflections due to its transnational dimension. The need to place trust in foreign medical systems and practitioners was highlighted by some as causing apprehension, particularly in relation to information about success rates, treatment protocols and donors. Despite considerable criticism of some of the restrictions they felt the HFEA (Human Fertilisation and Embryology Authority) placed on patients and clinicians, several participants nevertheless valued the existence of a body overseeing the safety of treatment in the UK. Some expressed feelings of uncertainty about how children might be viewed by others and what they could or should disclose to children or potential children about their conception. Some of these dilemmas are common to all those opting for third party assisted conception, (Blake, Casey, Readings, Javda, & Golombok, 2010; Mac Dougall, Becker, Scheib, & Nachtigall, 2007; Nachtigall, Tschann, Quiroga, Pitcher, & Becker, 1997) though the use of anonymous gamete providers from a different country clearly gives rise to additional sources of concern. Research that has explored the phenomenon of 'return reproductive travel' whereby patients living away from their countries of origin return 'home' for treatment, has described this as motivated by a desire for treatment in a culturally and linguistically familiar environment (Inhorn, 2011, 2012). Others have reported the significance of place when deciding on cross-border treatment (Whittaker & Speier, 2010). In the present study, the choice of country was also an important consideration, but some participants underestimated the impact of an unfamiliar culture, language and medical and administrative system on their experience. These travellers subsequently highlighted this as a disadvantage of overseas treatment. This cultural dissonance was heightened in countries like Russia and Ukraine, where participants felt much less acquainted with local customs and languages than those who travelled to western European countries or the US and South Africa. Whilst the majority of participants reported good communication with staff, many of whom spoke good English, a minority described an occasion on which they had not understood written or spoken information or had felt unable to complain.

Limitations The sample population, whilst diverse in terms of destinations and motivations for treatments, was relatively homogenous in relation to social class and ethnicity and only included a

small number of male participants; a persistent limitation in research on infertility (Culley, Hudson, & Lohan, 2013). Satisfaction with care (as measured by questionnaires) appears to be influenced by treatment outcome, whereby patients with a positive result are more likely to have a positive perspective on care than those with a negative result. Given the high success rates of treatment in this sample, this could account for the more positive views described. However, those of higher social class or educational status are less likely to have a positive perspective on care, which may provide a counter balance within this sample, and demonstrates that the relationship between treatment outcome and experience of care is not straightforward. Given that the majority of UK travellers are not travelling in order to circumvent restrictive legislation in their home country, these accounts are unlikely to be representative of all cross-border fertility patients.

Future directions for research and practice Participants in this study confirmed the view that fertility patients wish to receive care that places them and their needs at the centre. Many participants felt that this was not the case with care provided in the UK; a feeling that featured in their decisions to travel overseas. This finding needs closer consideration by practitioners and policy makers, such as the HFEA in the UK. Arguably, fertility treatment intervenes in one of life's most intimate spheres and wherever it is conducted, care, respect and patient involvement are principles that should consistently be held in high regard. The longer-term implications of having created a family via cross-border treatment, particularly for those using donor gametes, emerged as a more challenging issue for a proportion of participants, and is worthy of further research.

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